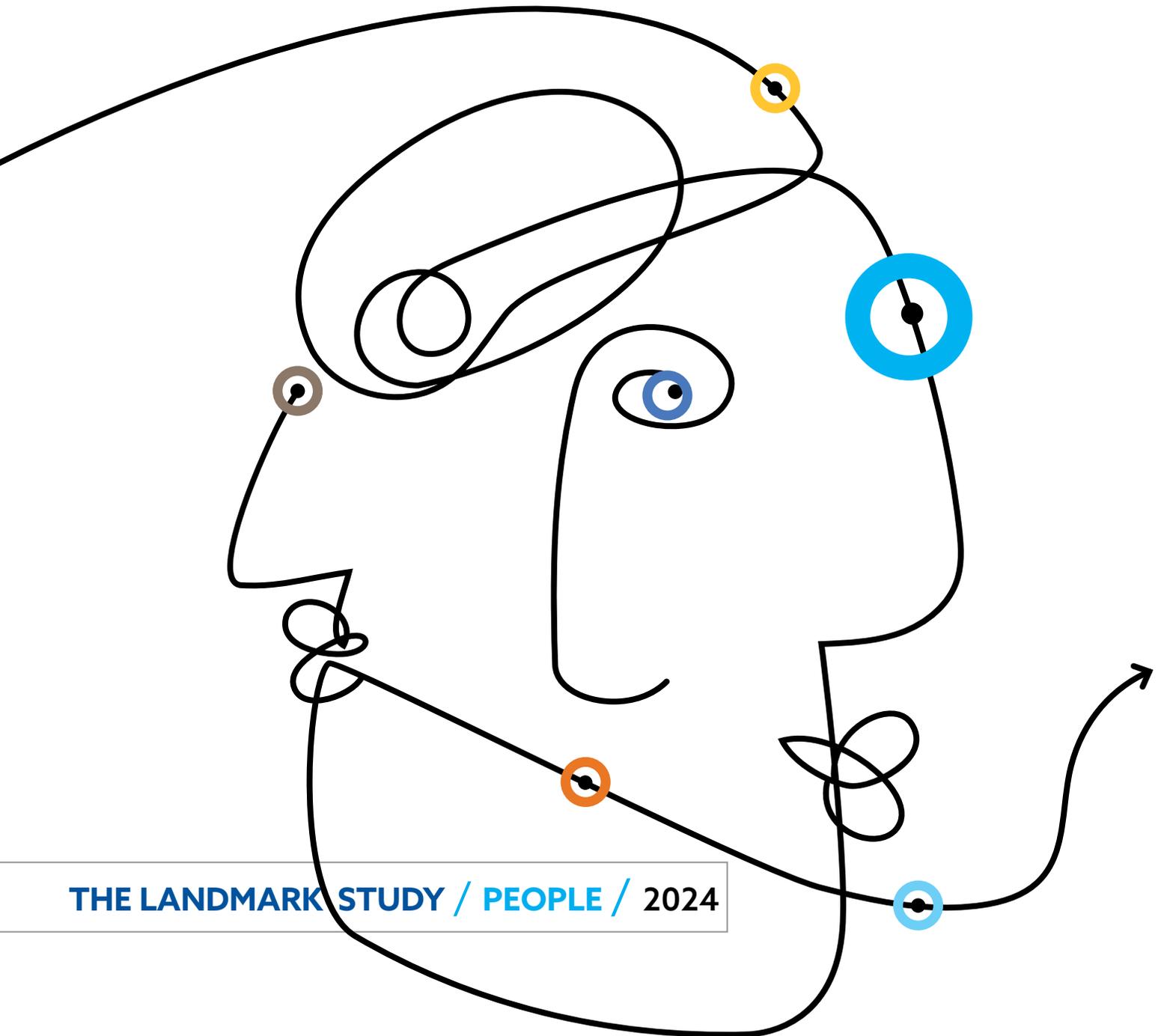


REPORT

2

THE MANY FACES OF DEMENTIA IN CANADA



THE LANDMARK STUDY / PEOPLE / 2024

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 causes and cures.

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EXECUTIVE SUMMARY

In Canada, more than 650,000 people have dementia. They live with Alzheimer's dementia, vascular dementia, young onset dementia, or one of many other combinations or types, as there are over 50 different diseases or conditions that can cause dementia. Their family and friends are also deeply affected by the challenges presented by cognitive decline, memory loss, loss of independence, changes in mood and behaviour, and the many other changes that can occur with dementia.

As the population in Canada ages, we will continue to see increases in the number of people affected by dementia. We have made progress in the last decade in trying to better address this condition and now have a national dementia strategy, but much more work needs to be done.

With this report, we at the Alzheimer Society of Canada aim to achieve the following five points:

1. **Increase awareness of the diversity of who develops dementia in Canada.** We will challenge and expand public knowledge and understanding of the diversity found among people living with dementia in Canada.
2. **Improve knowledge.** Dementia is a complex condition that impacts a wide range of people. This report aims to identify the many characteristics of individuals who are projected to develop dementia over the next 30 years.
3. **Advocate for better dementia care.** Everyone who develops dementia has different and evolving personal resources and health care needs. Services and supports must be tailored to the unique needs and diverse experiences within the population—optimal care is our goal.
4. **Create action.** Inspire individuals, organizations, and all levels of governments to work collaboratively toward inclusion, equity and diversity in dementia research and support—leading to better care for all.
5. **Push for change.** We can devote more dollars to research; fight stigma, discrimination and stereotypes; and create and adapt policies to improve dementia care. Working toward these changes will ensure that we find equitable solutions to the dementia challenges we face.

Data from the Landmark Study

The Many Faces of Dementia in Canada is the second in a series of three reports that will share the results of the Landmark Study. The Landmark Study is a microsimulation study developed by the Alzheimer Society of Canada to better understand dementia in the Canadian population over the next 30 years. This includes investigations into Indigenous people in Canada, ethnic origins, sex (gender data was not available to be included in the model), and age (young onset dementia) as key individual characteristics related to dementia.

The study's results come from a microsimulation model produced by the Canadian Centre for Economic Analysis (CANCEA). A microsimulation model is similar to the way simulation video games work. Rather than setting up a character or a city in a game and looking at how interactions and events occur over simulated time, our model uses "agents" that act as a statistical representation of persons living in Canada. Each agent is associated with several demographic characteristics, including age, sex and ethnicity, which match those of the Canadian population.

The model can simulate the agents and their interactions over time as they age and pass through various states, such as a dementia diagnosis, hospitalization and death. This allows the model to provide estimates and forecasts of the rates of dementia in Canada and related impacts over time.

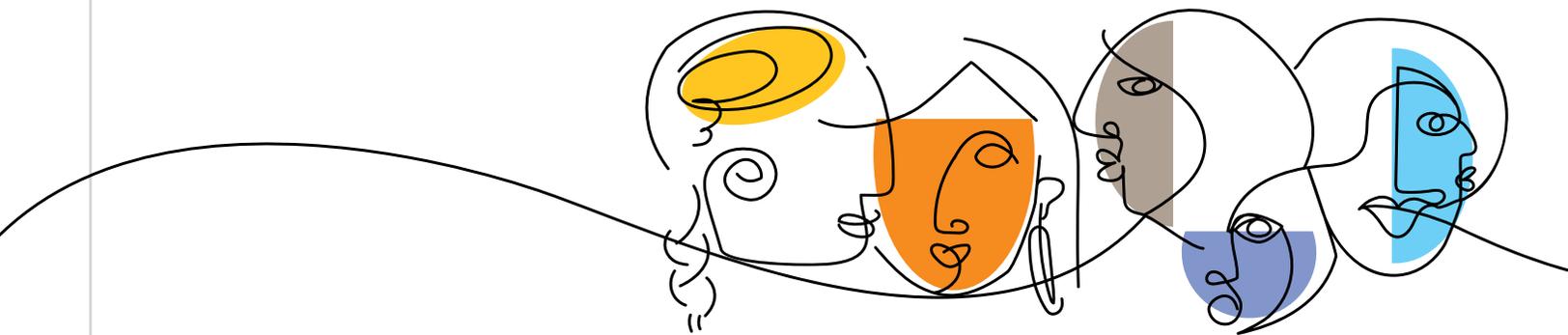
In the first report from the Landmark Study, available at alzheimer.ca/landmarkstudy, we covered the following topics:

- current trends of dementia numbers in Canada
- number of care partners and hours of care provided
- potential for dementia risk reduction efforts to shift trends downwards
- differences in expected dementia numbers across regions of Canada
- recommendations for finding the best path forward for dementia in Canada

In this second report, we will build on the insights of the first report by focusing in on some of the groups of people who will likely develop dementia in Canada over the next three decades based on the Landmark Study microsimulation model:

- **Chapter 1:** The Many Faces of Dementia in Canada
- **Chapter 2:** Dementia and Indigenous Peoples
- **Chapter 3:** Ethnic and Racial Diversity of People Affected by Dementia
- **Chapter 4:** Sex and Gender Differences in Dementia
- **Chapter 5:** Young Onset Dementia: Distinct Challenges
- **Chapter 6:** Promoting Inclusion for All People Living with Dementia

Our third and final report from the Landmark Study will continue to use the simulation model to examine the economic impact of dementia in Canada.



Ethnic and racial diversity of people affected by dementia

Dementia and Indigenous people

There are many diverse communities of First Nations, Inuit, and Métis in Canada. Many have their own cultural perspectives and knowledges on health and aging.

Research has established that health disparities faced by Indigenous Peoples are rooted in colonization and ongoing social inequities. These factors may also increase the risk of developing dementia for Indigenous people. Stress from racism can affect brain health. Indigenous people also face structural barriers to dementia diagnosis and treatment.

The study estimates that in 2020 there were 10,800 people of Indigenous ancestry living with dementia in Canada. By 2050, we can expect this number to increase by 273% to 40,300. (This is a higher increase than for the overall population, which would have a 187% dementia increase by 2050.)

There is a clear need to take further action. Some steps include recognizing Indigenous Peoples' right to health, supporting Indigenous leadership, and pursuing cultural safety and humility in health care and research. More support is needed for Indigenous-led dementia research and care resources.

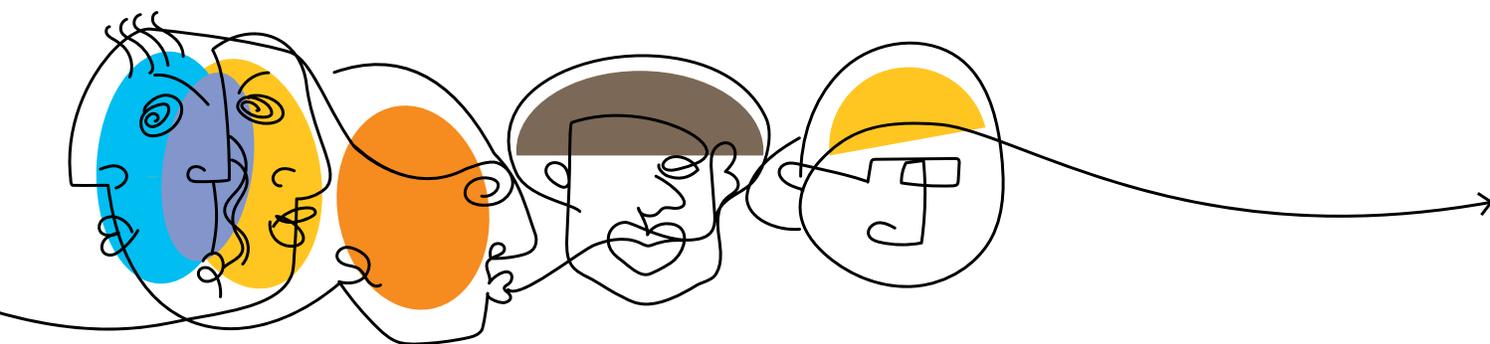
In the 2016 Canadian census, over 250 different ethnic origins were recorded.

Given changes in immigration over recent decades, the ethnocultural demographics of older adults here are shifting. Age increases dementia risk, so these demographic changes are being seen in the population living with dementia, as well as projections around it.

The Landmark Study results indicate that **by 2050, one out of every four people who develop dementia in Canada will be of Asian origin.** That is a **785% increase from 2020.**

Over the same timespan (2020 to 2050), **people of African descent in Canada are predicted to experience a 507% increase in dementia numbers in Canada. And people of Latin/Central/South American descent will experience a 434% increase in dementia numbers.**

Research shows that racism can affect brain health. In Canada, there is a lack of dementia research that focuses on the experiences of racialized communities. More support for this type of research is needed, as is support for anti-racist, culturally safe policies, programs and services.



Sex and gender differences in dementia

Both sex and gender can shape a person's dementia experience. There are sex and gender differences in the number of people affected by dementia; risk factors for developing dementia; how symptoms are expressed; care needs and caregiving.

Both biological and social factors play a strong role in dementia risk. Both sex and gender are vital to consider in dementia outcomes and care.

In high-income countries, females experience dementia at a much higher rate than males. The number of females who will develop dementia is projected to exceed males by almost a two-to-one ratio. In the past, this has mainly been attributed to the fact that females live longer on average, but research is now uncovering more to this story.

In 2020, **an estimated 61.8% of persons living with dementia in Canada were female. By 2050, our study projects that over 1 million women will be living with dementia in Canada.**

More research is needed, especially on dementia experiences of people who are intersex, non-binary and gender-diverse.

Young onset dementia: distinct and diverse challenges

Most dementia care is organized for people in their 70s and 80s. But **there is a growing group of people developing dementia in their 40s, 50s and early 60s—or even earlier.** We call this young onset dementia.

Young onset dementia is not new. Two of the first patients who helped Dr. Alois Alzheimer to identify the condition we now know as Alzheimer's disease were patients who developed symptoms in their 50s.

By 2050, our study estimates that there could be over 40,000 people under the age of 65 living with dementia in Canada. In 2020, our estimate was 28,000.

When dementia symptoms develop in younger adults, they present an overlapping range of unique challenges, including: a large variety of potential symptoms and causes, both of which can lead to delayed diagnoses; lack of awareness among many health-care workers about the existence of young onset dementia; and practical challenges of obtaining proper workplace accommodations for disability, particularly for issues that take years to diagnose.

Promoting inclusion for all people living with dementia

Diversity in dementia doesn't stop at Indigeneity, ethnocultural diversity, sex, and age. Other key things that can impact dementia experience and vary structural barriers around risk reduction, diagnosis and care include: sexual orientation; intellectual and developmental disabilities; being incarcerated; being underhoused; experiencing a substance use disorder; and more.

While cures for most dementias have not yet been found, there are actions to create positive outcomes for people living with dementia and their care partners.

In the final report section, we highlight the opportunities for optimizing health-care systems and supports for the wide range of people who experience dementia now and in future.

This includes implementing or further implementing many strong recommendations already made in the federal government's National Dementia Strategy, as well as building on those recommendations.

We are all unique, but our shared characteristics and differences are vital to know when planning dementia health supports.

ACKNOWLEDGEMENTS

Land acknowledgement

We would like to begin by acknowledging the Indigenous Peoples of all of the lands that we are on today; we acknowledge the importance of the lands which we each call home.

Dementia-dedicated organizations are located in facilities on the original lands of First Nations and Inuit, and on the homeland of the Métis Nation.

The Alzheimer Society respects that First Nations treaties were made on these territories, acknowledges harms and mistakes, and we dedicate ourselves to collaborate in partnership with First Nations, Inuit and Métis in the spirit of reconciliation.

We do this to reaffirm our commitment and responsibility in improving relationships between nations and improve our own understanding of local Indigenous people and their cultures.

Landmark report acknowledgements

The Landmark Study is based on a project conducted by the Canadian Centre for Economic Analysis (CANCEA) on behalf of the Alzheimer Society of Canada. This project was made possible by contributions from our generous donors.

This Landmark Study report was developed and executed by the Research and Knowledge Transfer and Exchange team at the Alzheimer Society of Canada and was led by Dr. Joshua J. Armstrong. We would like to thank everyone involved for their time and dedication given to this project. We would also like to thank the Board of Directors for their support which enabled us to perform this study.

The Alzheimer Society of Canada would like to express a special thank you to its Advisory Group of people living with dementia and care partners, subject matter experts, story providers, citizen reviewers, sensitivity readers, and community organizations who have graciously provided their thoughts and guidance for the report.

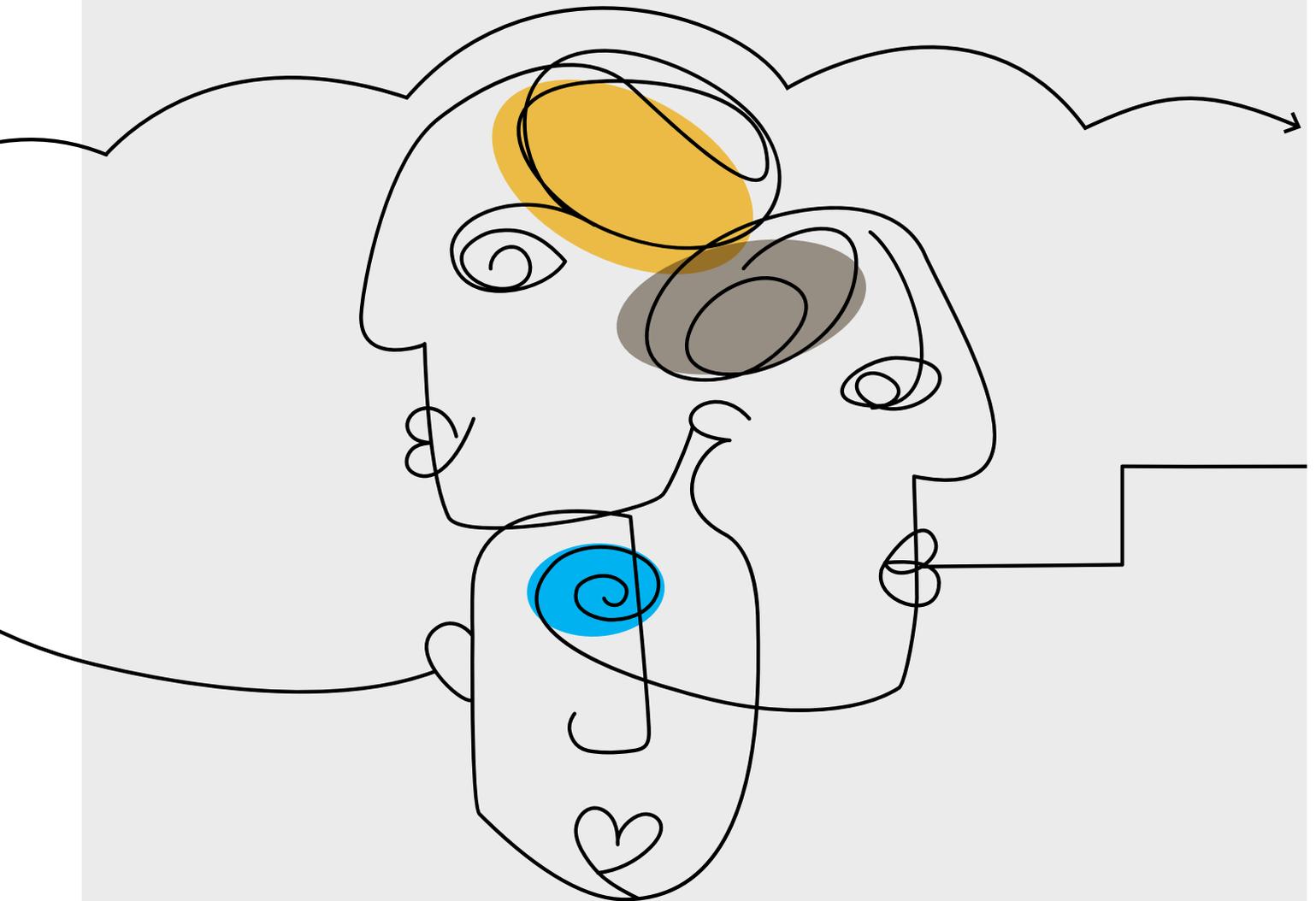
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THE MANY FACES OF DEMENTIA IN CANADA

It's vital to look from wider population trends to diverse experiences of dementia.



Dementia is a public health challenge affecting hundreds of thousands of people in Canada and millions of people worldwide. While dementia is a growing public health concern, research has shown that there are substantial differences in risk of development, prevalence, clinical presentation, and health outcomes across various communities in Canada. This includes variation across ethnicity and race, sex and gender, and age.

Understanding these differences is an essential step in providing optimal care and support for those who are affected by dementia. By learning the unique needs and experiences of different communities, we can work together toward improving quality of life for people living with dementia and their care partners.

To address this challenge in Canada, a national dementia strategy was developed in 2019 to guide actions by all levels of government, non-government organizations, communities, families and individuals to address dementia in Canada. The vision of the strategy is: “A Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood, and effectively treated” (Public Health Agency of Canada, 2019).

What is dementia?

Dementia is a term that describes a set of symptoms caused by what is most often a progressive loss of brain function and structure over time.

Symptoms of dementia can include (but are not limited to) memory loss, language difficulties, impaired judgment, changes in mood or behaviour, decreased ability to perform daily activities, disorientation, and problems with abstract thinking. Some forms of dementia can affect other areas of functioning, including vision and movement.

Dementia is not a single specific condition; it is an umbrella term that covers more than 50 different diseases or conditions that can cause the symptoms of dementia. Some of the more common types of dementia are outlined in [Box 1](#). We now know that people living with dementia often have features of more than one type.

* A note on word choice: care partners, caregivers, carers, family, friends, kin and community

In Canada, people use many different words to describe their relationship to a person who is living with dementia. There is no one “correct” way to designate yourself. For conciseness, we have chosen to mainly use the term “care partner” in the research analysis parts of this report. In individual stories in this report—and beyond—we also respect and honour however people self-identify. No matter what term is used, we recognize the important role care partners, caregivers, carers, family, friends, kin and community play in the dementia space in Canada.

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 can involve changes in personality, behaviour, and/or language comprehension or expression. Other changes, including problems with movement, can occur later as the condition progresses.
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 diagnosed Parkinson's disease.
5	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, but also can be caused by brain injuries, heavy alcohol use, and environmental toxins, among other factors.
6	MIXED DEMENTIA	Mixed dementia occurs when people have symptoms of at least two different types of dementia. The older someone is, the more likely it is that multiple disease processes in their brain are leading to their symptoms.

* A note on word choice: "Alzheimer's disease" and "Alzheimer's dementia"

The term "Alzheimer's disease" refers to an illness that causes changes to brain structure years before any problems with thinking, memory, mood, communication and/or behaviour emerge.

The term "Alzheimer's dementia" refers to a later stage of that same disease; during this stage, problems with thinking, memory, mood, behaviour and/or communication are evident.

Risk of developing dementia

While there still is an incomplete understanding of the mechanisms that lead to dementia, researchers have identified several risk factors that can increase a person's chances of developing dementia. These factors affect different people across their life course and are commonly divided into two categories: non-modifiable risk factors and modifiable risk factors.



Dementia risk factors that can't be changed: age, sex at birth, and genetics

Non-modifiable risk factors may increase your chance of developing dementia and they cannot be changed.

Advancing age is the strongest known risk factor for dementia, but 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. 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 people has been diagnosed with dementia.

With the size of our older population increasing quickly, population aging plays a strong role in the projected number of people in Canada living with dementia over the next 30 years. This is a period when both the entirety of Gen X (born between 1965 and 1980) and a portion of Millennials (born between 1981 and 1996) will reach the age of 65 or older. It's also a period when the rest of Millennials and the entirety of Gen Z will reach middle age and have increased chances of taking on caregiving roles.

Sex at birth is also considered a risk factor for dementia, as research has shown that females are more likely to develop the condition compared to males. The reasons for this are not yet fully understood and may include differences in longevity, sex hormones, lifestyles, and genetics. We will examine this topic in more depth in [Chapter 4](#).

The third non-modifiable risk factor for dementia is genetics. The role of genes in the development of all dementias is not yet fully understood. Some genes have been found to be directly related to the development of Alzheimer's dementia (i.e., PS1, PS2, and APP). Other genes have been associated with increased risk of developing dementia (e.g., Apolipoprotein E ε4 or APOE ε4). Overall, there are at least 75 genes that are associated with an increased risk of developing Alzheimer's dementia (Bellenguez et al., 2022). Other forms of dementia also have some well-known genetic risk factors, such as Huntington disease and some subvarieties of frontotemporal dementia, among others.

* A note on word choice: gender, sex and sex at birth

In 2021, Statistics Canada (2021a, 2021b) approved updated language around sex and gender. "Sex at birth" is the term that "refers to sex assigned at birth." The term "gender" is "a multi-dimensional concept that is influenced by several additional factors, including cultural and behavioural norms, and self-identity." More on the impacts of both of these on dementia risk and experience in Chapter 4.

Dementia risk factors that can potentially be changed: hearing aids, physical activity, social activity, and more

Modifiable risk factors—or risk factors that can be changed—include a range of lifestyle or behavioural factors (such as physical exercise, social activities, using hearing aids if needed), as well as heart health, mental exercise or activities, and protecting your brain from injuries. These and other activities can help reduce the risk of developing dementia.

Here is a list of key dementia risk factors that can potentially be changed, as published in a large Lancet review by Livingston and colleagues in 2020:

- less education (meaning less than both primary and secondary education)
- hypertension
- obesity
- traumatic brain injury
- depression
- physical inactivity
- diabetes
- high alcohol intake
- hearing loss
- smoking
- social isolation
- air pollution

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.



Context affects whether someone can actually change their dementia risk factors

There is a growing interest in the social determinants of dementia—and for good reason.

Social determinants of health are the non-medical, social and economic factors that influence the risk of dementia across the population. These factors occur within the living and working conditions that people experience every day. Depending on where one falls within these factors, the influence on dementia risk can either be negative or positive.

For example, there are known negative risks for neurologic complications associated with living in poverty (Maalouf et al., 2021). In contrast, those who are wealthy or live in well-off regions tend to have better health outcomes (Hofbauer & Rodriguez, 2021).

In other words, modifiable risk factors are not always modifiable by individuals. Individuals live within a context—those of social determinants of health. And this context can shape the determinants for dementia for better or for worse.

For dementia, risk factors are only truly modifiable or changeable if social determinants are adequately addressed and the proper supports are provided. Refer to [Box 2](#) for a summary of select risk factors for dementia. More details on how some of these can create barriers to risk reduction are included in Chapters 2, 3 and 4.

Box 2. Select risk factors and social determinants of health for dementia

RISK FACTORS THAT CANNOT BE CHANGED

- ✗ Age
- ✗ Sex
- ✗ Genetic

RISK FACTORS THAT CAN BE CHANGED OR MODIFIED

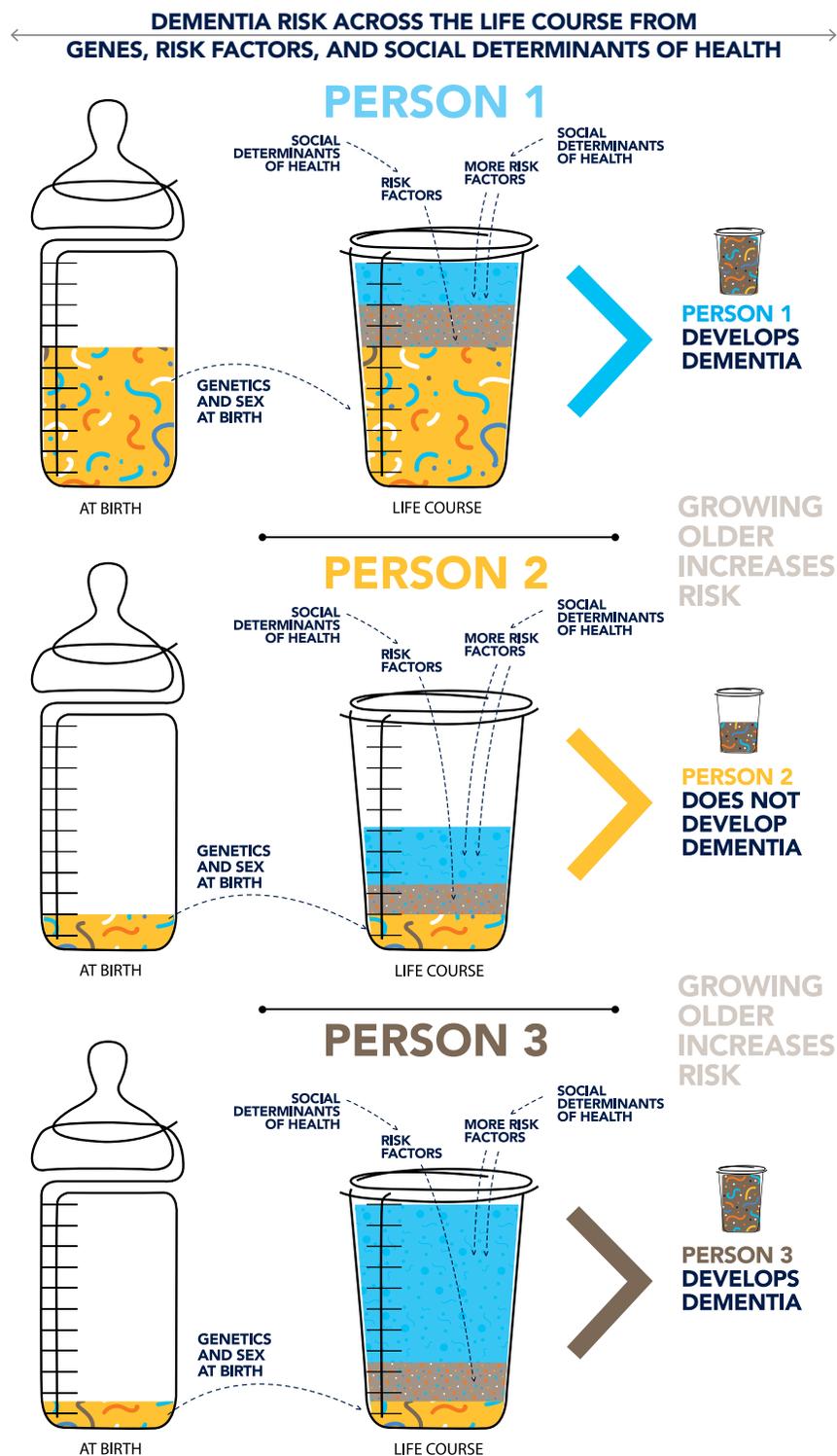
Potentially modifiable risk factors for dementia

- + Low education
- + Hypertension
- + High alcohol intake
- + Obesity
- + Hearing loss
- + Traumatic brain injury
- + Smoking
- + Depression
- + Social isolation
- + Physical inactivity
- + Air pollution
- + Diabetes

Social determinants of health affecting degree of or access to potential risk factor change

- + Income and social status
- + Employment and working conditions
- + Education and literacy
- + Early childhood development
- + Physical environments and housing
- + Social supports
- + Access to health services
- + Biology and genetics
- + Gender
- + Culture
- + Race, racism and racialization
- + Disability and ableism

Figure 1. Cup analogy illustrating dementia risk across the life course from genes, risk factors, and social determinants of health



Note: Risk for developing dementia can come from many sources. In this simplified cup analogy, three individuals start out with varying levels of risk based on their genetics and their sex at birth. Across the life course, each individual will experience exposures to different risk factors leading to the onset of dementia in some individuals but not others. Furthermore, the social determinants of health can also influence people’s exposure to dementia risk factors, influencing brain health outcomes later in life.

Life beyond a dementia diagnosis

As worldwide and national advocacy by people living with dementia has demonstrated (Dementia Alliance International, 2023; Gregorio and Purveen, 2020; Marple, 2022; Thelker, 2020; Wighton, 2021), life with dementia is much different from the way it is depicted in movies or in the media. People who develop dementia can live from three to more than twenty years after their diagnosis, with a wide range of symptoms. Not one of these personal stories ends with a diagnosis. Life continues, and people can spend years living relatively well with the condition, working or participating in their community, learning to live on their terms, and having a life intentionally full of purpose and joy.



The Landmark Study: from population trends to diverse experiences of dementia

In September 2022, the Alzheimer Society of Canada released the first report from the Landmark Study entitled *Navigating the Path Forward for Dementia in Canada*. The report contains projections for the number of people living with dementia and the number of dementia care partners over the next 30 years in Canada. It also demonstrates the potential power of dementia risk reduction for the population in Canada.

The first report revealed that with current trends, we can expect more than 6 million people to develop dementia over the next three decades (2020–2050). This means that without the discovery and implementation of effective approaches for risk reduction and treatment, the stories of millions of people in Canada may conclude with years dealing with memory loss; difficulties with attention, problem solving and language; loss of independence; and changes in mood and behaviour.



Data from the Landmark Study

The Landmark Study is a microsimulation study developed by the Alzheimer Society of Canada to better understand dementia in the Canadian population over the next 30 years. This includes investigations into sex and gender, young onset dementia, and ethnocultural identity as key characteristics.

The study's results come from a microsimulation model produced by the Canadian Centre for Economic Analysis (CANCEA). A microsimulation model is similar to the way simulation video games like *The Sims* or *SimCity* work. Rather than setting up a character or 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 people living in Canada. Each agent is associated with several demographic characteristics, including age, sex and ethnicity, which match those of the population in Canada.

The model can then simulate the agents and their interactions over time as they age and pass through various states, such as a dementia diagnosis, hospitalization and death. This allows the model to provide estimates and forecasts of the rates of dementia in Canada and related impacts over time.

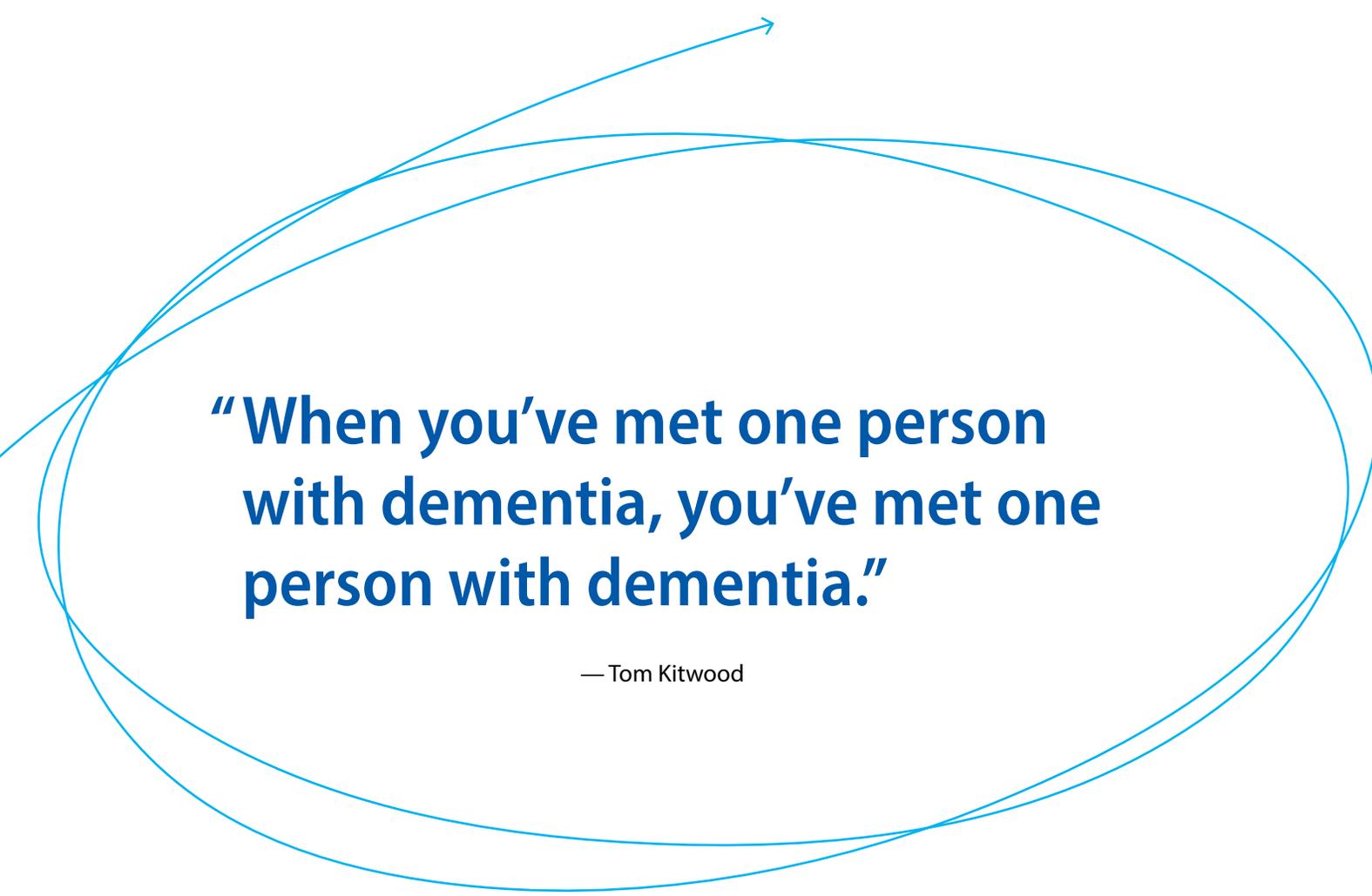
Limitations

The Landmark Study model is not without limitations. The data used to produce the projections was limited by both the data available in the 2016 census and the academic literature used to inform dementia risk. No projections were developed for the Yukon, Northwest Territories or Nunavut.

The model also doesn't produce any findings related to gender; only findings related to sex were developed because gender data wasn't collected in the 2016 census (it was first introduced in 2021). Large groupings were used for ethnic origins, which doesn't allow for more disaggregated estimations for the diverse population within Canada. Also, data from the census may not accurately capture the number of Indigenous people living in Canada.

It is also important to note that our projections of dementia are based on many current trends, but do not factor in any of the impacts of the COVID-19 pandemic. Analyses accounting for the impact of COVID-19 can only be done once the evidence has been fully developed. This takes time with chronic conditions like dementia that have long preclinical phases.

Therefore, it is likely that the COVID-19 pandemic (and in fact, future pandemics) will factor into the changing faces of dementia in Canada in the coming decades—and into the inequities producing these differences.



**“When you’ve met one person
with dementia, you’ve met one
person with dementia.”**

— Tom Kitwood

The many faces of dementia in Canada

This second report from the Landmark Study takes a closer look at the many faces of dementia in Canada and highlights the diversity that is found within those who are at risk for developing dementia. With the rapidly increasing size of the dementia population, now more than ever it is important to get a better understanding of the diversity that is found in dementia.

Because each person has a unique identity and history that affects their dementia experience, we share personal stories of people living with dementia and their care partners. Whereas the first report focused on current trends across the population, we want to put faces to these numbers so that together we can begin to understand the impact of rising dementia numbers at the individual, family and community level.

To ground the statistics from the Landmark Study with the experiences of people living with dementia, this report will highlight some of the many differences across groups who experience dementia in Canada:

- **Increasing numbers of Indigenous people are developing dementia.** Risk is increased due to the growing number of older Indigenous people and the impacts of social determinants of health—including the impact of colonization.
- **Variation exists in dementia risk and dementia care across racialized communities in Canada.** With changing immigration patterns, the ethnic profile of older people in the country is shifting. This changing population profile is directly reflected in the ethnic origins of those who are projected to develop dementia over the next 30 years.
- **There are differences in dementia when it comes to sex and gender.** Approximately two out of three people with dementia in Canada are female. Understanding differences in sex and gender is essential if we want to accurately address dementia risk, dementia care, and overall experiences across the population.
- **Distinct challenges exist for young onset dementia.** Some people in their 40s and 50s—or even their 20s and 30s—can develop dementia. Dementia in younger adults poses specific challenges to the individual and their families, and in their care and support needs.

These characteristics, as well as other distinctions across people and their social circumstances, can profoundly affect the ways dementia is experienced by individuals and their care partners. This second report examines dementia in each of these groups, followed by Landmark Study model projections for these populations leading up to 2050. The report will conclude with a series of recommendations for these communities affected by dementia.

We propose that the best way forward is to study these distinctions, generate evidence, listen to recommendations from people living with dementia and their care partners, and collectively advocate for systemic change.

FACES OF DEMENTIA RUBINA'S STORY

Rubina lives with Alzheimer's disease. She lives with her family in Milton, Ontario. Here, she shares some insights on her experiences.



"BEFORE the diagnosis, I noticed a decline in my memory for over two years. I was forgetting items of my daily routine. I was concerned and fearful; my father and two paternal uncles had had Alzheimer's disease.

I noticed a decline in my short-term memory, word-finding abilities, object use and simple calculations. I was forgetting what task I was doing. I was forgetting plans for the day. I had difficulty remembering recipes and what I ate two hours before. I could not recall names, events, and appointments. I was forgetting details of conversations and asking repetitive questions. I felt lost while driving.

Photo: Courtesy of Rubina Qureshi and family, and Faces of Dementia/Hamilton Council on Aging.

I discussed this condition with my family physician. He referred me to the Toronto Memory Program. After the initial assessment, brain MRI and other diagnostic tests, the doctor confirmed that I had young onset Alzheimer's disease. Initially, it was difficult to accept the diagnosis. I feared the next phases of the condition; I saw my father and uncle during their last stages of the disease. I was sad and in denial.

Slowly, I accepted the diagnosis and made a promise to myself to stay positive, do whatever possible to delay the progression of the disease, and help in the research program of finding a cure for Alzheimer's disease. I am involved with social programs to help others and myself during this journey.

I have been participating in a drug clinical study program. It may or may not help me, but it will bring research closer to finding a cure for Alzheimer's disease. I pray and hope that later Alzheimer's patients can take medication to avoid, delay and cure the disease.

I am comfortable with cooking and doing housekeeping tasks. When I feel lost or frustrated, I get help from my husband. I ask him to guide me to complete the task but to not take over. I love sewing, walking, and spending time with family and friends. Occasionally, I do not know what to do, but I am still going on, and I figure it out.

Until my brain is not working, I am going to do whatever I can. It's a disease, and I must figure things out and have to go on—not stop anything.

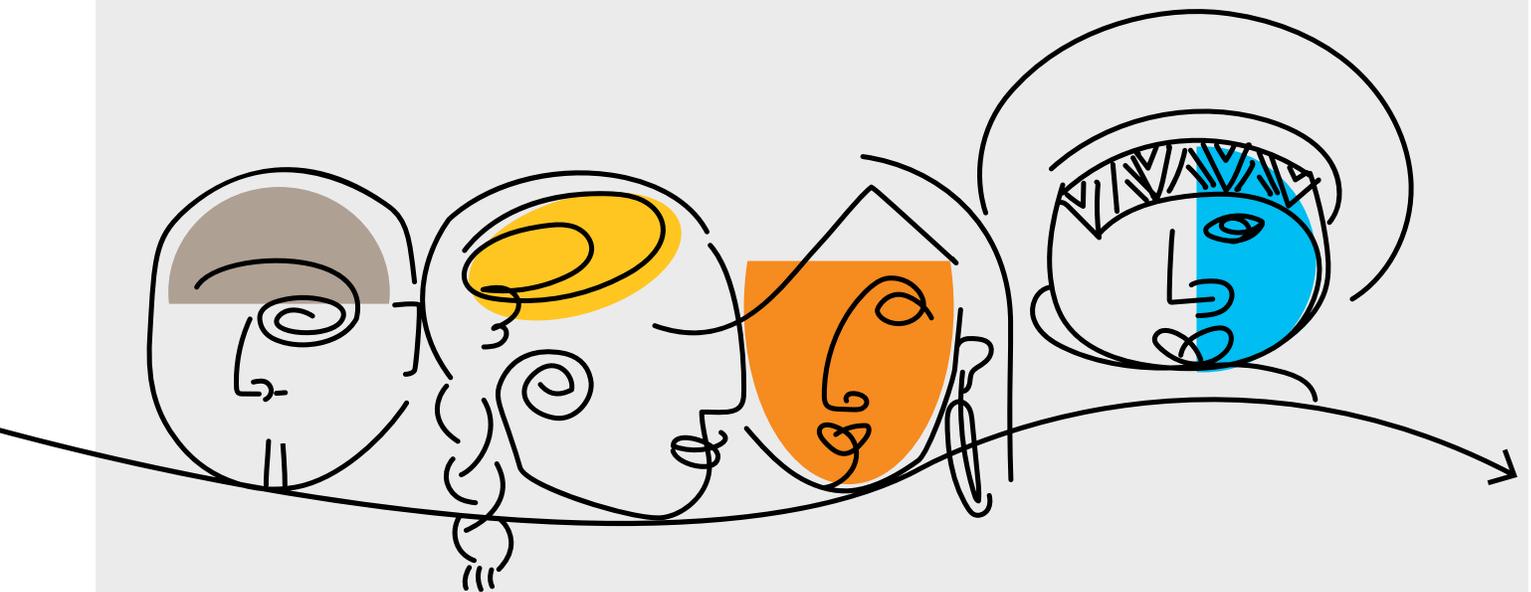
Don't stop your life! If you stop, you're not going to gain anything."

Adapted and expanded with participation and permission, following Rubina's video and story-sharing in the Hamilton Council on Aging's Faces of Dementia project (2022).

"Slowly, I accepted the diagnosis and made a promise to myself to stay positive, do whatever possible to delay the progression of the disease, and help in the research program of finding a cure for Alzheimer's disease."

DEMENTIA AND INDIGENOUS PEOPLES

There are increased risks of dementia from population aging and social determinants of health—including colonization.



Dementia is a growing public health issue for Indigenous people in Canada. Canada's first national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire*, identified that Indigenous Peoples are a population at higher risk of developing dementia (Public Health Agency of Canada, 2019). In addition to research indicating higher rates of dementia among Indigenous populations compared to the general public, Indigenous people also face challenges accessing health-care services and receiving supports, and they are impacted by many social determinants of dementia. This chapter outlines some of the issues related to dementia in Indigenous populations and concludes with some estimates for dementia in Indigenous people in Canada.

In the 2016 Canadian Census of Population, 2.1 million people, making up 6.2% of the population, reported Indigenous ancestry (single or multiple response). Roughly 1.5 million First Nations people, approximately 600,000 Métis, and 79,125 Inuit responded to that 2016 census. Across hundreds of communities in Canada, there are many Nations speaking more than 70 languages. Along with the general Canadian population, the Indigenous population of Canada is aging. In 2006, less than 5% of the Indigenous population was over the age of 65. By 2016, this rose to 7.3% and could double by the year 2036 (Statistics Canada, 2019).

With an aging population comes increases in risks for dementia across Indigenous communities. Despite the historical presence of Indigenous Peoples in Canada, little is known about how dementia impacts these diverse populations. Research conducted in Alberta in 2013 found that rates of dementia were 34% higher in First Nations populations compared to non-First Nations populations (Jacklin et al., 2013). Less is known about how dementia impacts Métis and Inuit populations.

Research also suggests that these rates are rising more quickly than the general Canadian population. The same Albertan study found that First Nations men experienced increased risk of dementia in comparison to women. This contrasts to what is typically found in the general population but is consistent with what has been found in Indigenous Peoples of Australia (Smith et al., 2008).

These trends mirror those in Indigenous populations worldwide. In 2015, conducting the first systematic review on this matter, international researchers found that dementia among Indigenous populations appears to develop more frequently than it does for non-Indigenous populations (Warren et al., 2015).

One American study (Mayeda et al., 2016) examined dementia incidence across six racial and ethnic groups over a 14-year time span. They found that age-adjusted dementia incidence rates were highest among both American Indians and Alaskan Natives, as well as in African Americans. The findings of this study revealed differences in dementia risk between racial and ethnic groups and spotlighted the need to reduce disparities in dementia diagnosis, prevention and support, as well as the need to address the health impacts of colonization—topics we will expand upon later in this chapter.

There are currently no known national estimates looking at dementia prevalence in Indigenous people across Canada. For more details on estimates from this study, refer to the Landmark Study results portion of this chapter, starting on page 37.

Colonization is a root factor of dementia risk and other health problems in Indigenous populations

“These higher rates [of dementia] are rooted in colonial disruption and collective trauma that affect diverse Indigenous nations worldwide,” Haudenosaunee researcher Dr. Jennifer D. Walker and Blackfoot researcher Dr. Lynden (Lindsay) Crowshoe and colleagues explain in an essay in the World Alzheimer Report 2021.

They also emphasize a finding from prior research around diabetes and Indigenous health—namely, that “colonisation is the predominant cause of health inequity for Indigenous People” (Crowshoe, 2019). Diabetes in later life is well established as one of the major risk factors for dementia globally. In a 2020 Lancet study by Livingston et al., onset of diabetes over the age of 65 increased dementia risk by an average of 50%. This is significant for Indigenous populations affected by later onset diabetes. In a 2018 paper, Crowshoe reported that Indigenous people living in Canada are among the highest-risk populations for diabetes and related complications such as dementia. This study emphasizes that the increased risk for diabetes is due, in no small part, to the legacy of colonization. He points out that this legacy:

- “Maintains socio-economic disadvantage that limits healthy choices (diet, physical activity, adherence to medication, etc.), increases levels of stress, and decreases capacity for self-care and healthy behaviour change;
- Perpetuates a toxic social environment for the individual, family, and community with pervasive and accumulated psychosocial adversities throughout the life course;
- Stirs experiences of shame and stigma with a diagnosis of diabetes.”

Another dementia risk factor listed by the Lancet in 2020 includes less education in early life (60% higher risk for dementia). Consider this in tandem with the last residential “school” in Canada closing only in 1996 and that residential “schools” were colonial sites of assimilation and cultural genocide. Current research also suggests that formal educational institutions and structures continue racist attitudes and systemic barriers for Indigenous students in Canada (Fowler, 2020; Fowler & McDermott, 2020; Talaga, 2017; Directions Evidence and Policy Research Group, 2016).

Depression in later life is another risk factor for dementia listed in the Lancet study (90% higher risk of dementia) which places Indigenous people at higher risk. A 2015 paper by the National Collaborating Centre for Indigenous Health notes that “colonization and forced assimilation” have produced “increased risk and loss of protective factors for depression” (Bellamy et al., 2015).

These examples demonstrate just a few ways that colonization has increased the risk of dementia and other health conditions for Indigenous people.

Risk factors for dementia in Indigenous populations are also strongly impacted by social determinants of health

Notwithstanding the vast diversity of Indigenous people in Canada, many similarities exist with regards to the determinants of their health. A recent qualitative evidence synthesis found that dementia is often considered a natural part of the circle of life by Indigenous people across communities in British Columbia, Saskatchewan, Ontario, and in the US (Jacklin & Walker, 2020).

The risk of dementia for Indigenous people may also be elevated due to higher rates of potentially modifiable risk factors for dementia, which are, in this case, heavily influenced by socio-economic context and other factors (Walker et al., 2020). Such risk factors include conditions such as diabetes, lower levels of education, head injury, cardiovascular disease, alcohol use, childhood trauma, midlife hypertension, obesity, physical inactivity and smoking.

Due to the many impacts of colonialism, Indigenous populations in Canada are subject to higher dementia risks associated with social determinants of health—the conditions in which people are born, grow, live, work, and age (World Health Organization, n.d.) and over which individuals have little control. These non-medical factors play a strong role in influencing health outcomes and include income, education, employment, food security, housing and social exclusion.

Box 3. Social determinants of health in Canada

<ul style="list-style-type: none">+ Income and income distribution+ Education+ Unemployment and job security+ Employment and working conditions+ Early child development+ Food insecurity	<ul style="list-style-type: none">+ Housing+ Social exclusion+ Social safety net+ Health services+ Geography+ Disability	<ul style="list-style-type: none">+ Indigenous ancestry+ Gender+ Immigration+ Race+ Globalization
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Source: Raphael et al., 2020

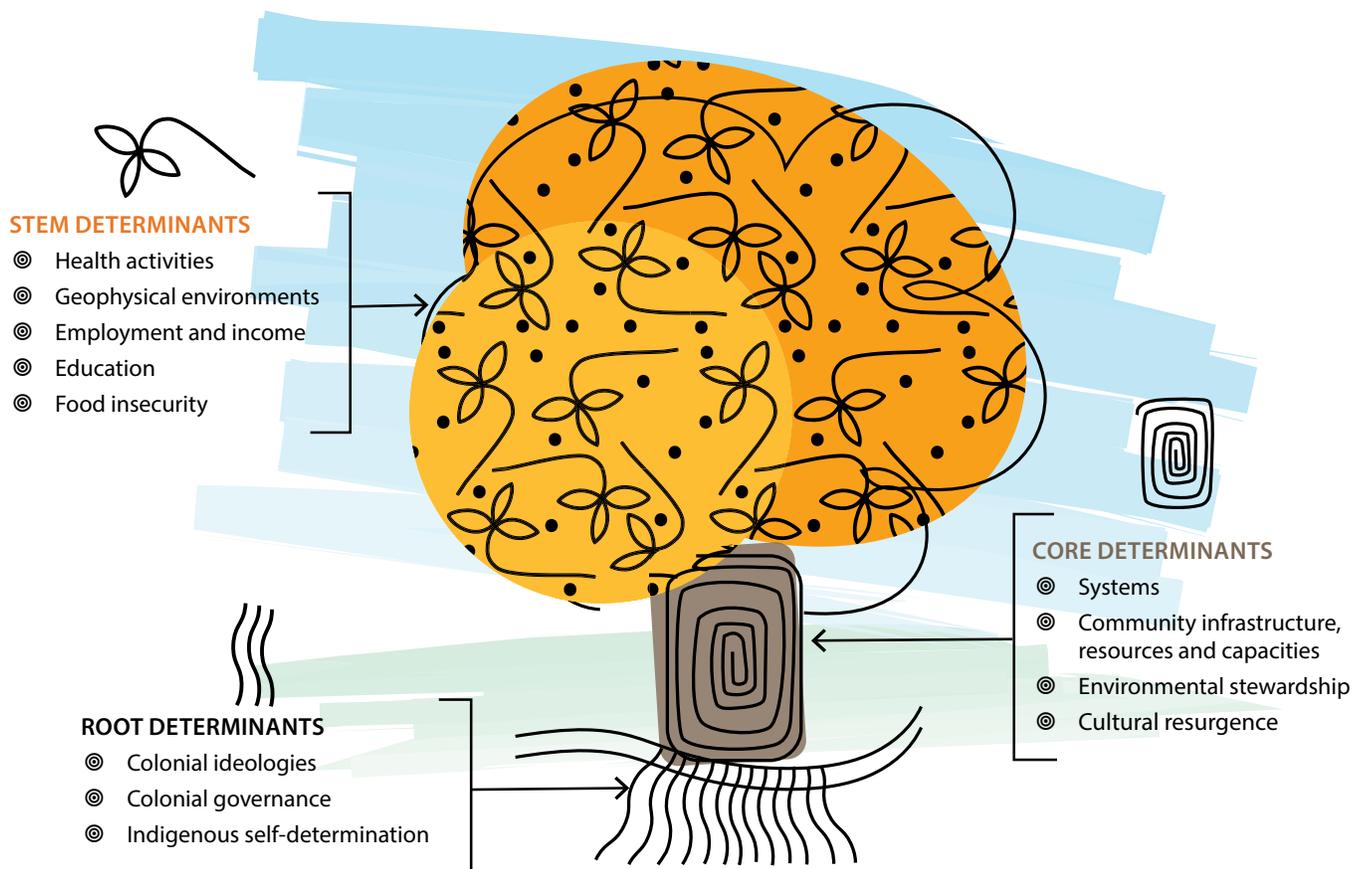
A social determinants of Indigenous health model to consider: root, core and stem determinants

When it comes to the social determinants of health, the Indigenous determinants of health model developed by Loppie and Wien (2022) clarifies the interconnections between health and social factors, something that is currently lacking in traditional biomedical frameworks.

This model separates the social determinants of Indigenous health into three categories:

- **Root determinants:** colonial ideologies; colonial governance; Indigenous self-determination
- **Core determinants:** systems; community infrastructure; resources, and capacities; environmental stewardship; cultural resurgence
- **Stem determinants:** health activities; geophysical environments; employment and income; education; food insecurity

Figure 2. Social determinants of Indigenous Peoples' health: one model



Source: Adapted with permission from *Understanding Indigenous Health Inequalities through a Social Determinants Model* (2022) by C. Loppie and F. Wien, published by the National Collaborating Centre for Indigenous Health.

This model depicts the influence that the various levels have on each other, and how the core and root determinants directly influence health activities, education, income, and other stem determinants.

Loppie and Wien use the model of a tree to show these connections: “Like the roots of a tree, structural determinants are deeply embedded ideological and political foundations, which shape all other determinants. The integrity of these foundations also determines health equity and thus the wellness of entire societies.”

“As a powerful root determinant of health, the colonization of what is now known as Canada cannot be overstated,” they continue. “The imposition of foreign cultures, governance structures, and ideologies profoundly reshaped the lives of Indigenous Peoples. It is important to note that colonization is not a singular, historical event, but a persistent and complex constellation of intersecting environments, systems, and processes intended to entrench social, political, and economic determinants that benefit White settler societies, often to the detriment of Indigenous lands, waters, cultures, communities, families, and individuals” (Loppie & Wien, 2022).

We agree that this model is vital for understanding that systemic factors such as poverty, racism, and colonialism can influence brain health and dementia outcomes in Indigenous populations. However, this model should also be adapted to enhance our understanding of the complex web of associations between individual and social factors that exist for the health of all people.

This framework also shows how modifiable risk factors might not always be modifiable for individuals. Individuals live within certain circumstances, and these circumstances can shape the determinants for dementia for better or for worse. For dementia, risk factors are only truly modifiable if social determinants are adequately addressed and the proper supports are provided.



How stress can affect brain health

When examining social determinants of health and dementia, the stress resulting from factors such as racism, inadequate housing, poverty, residential schools and colonialism cannot be ignored.

A 2019 study outlines how stress relates to cognitive outcomes through physiological mechanisms, particularly for racialized and marginalized groups. African American scholar Dr. Sarah Forrester and colleagues developed the Framework of Minority Stress to explain how social conditions directly impact stress levels in Black persons in the United States. These elevated stress levels in turn adversely affect physiological regulation (the body’s ability to maintain itself) and lead to negative impacts directly on the brain.

This stress response to social determinants (noted above) creates problems that accumulate over a lifetime, resulting in higher risk for age-related neurodegenerative diseases, including cognitive impairment or dementia.

More recently, emerging scholars are investigating if this same framework might be helpful to apply to Indigenous people and their dementia risk. Cliff Whetung, a member of Curve Lake First Nation and a PhD candidate at New York University, is currently applying this framework to Indigenous older adults and has found that everyday discrimination was associated with worse cognitive outcomes (2022).

Developing a more thorough understanding of social conditions, stress and brain health can lead to enhanced dementia risk reduction strategies across Indigenous communities and other marginalized populations affected by racism in Canada. Despite the higher dementia risk that Indigenous people face, research also shows that there are also many barriers to accessing diagnosis and care.



Studies show that racism is a barrier to health care for Indigenous people; this affects dementia care access, too

The World Health Organization, the Government of Canada, the College of Family Physicians of Canada, the Medical Council of Canada, and the Canadian Medical Association have all recognized that anti-Indigenous racism exists in health care systems, and that this creates barriers to health care access for Indigenous people. These recognitions are bolstered by decades of studies on anti-Indigenous racism and discrimination in health care (see, for example: Addressing Racism Review Team, 2020; Adelson, 2005; Allan & Smylie, 2015; Boyer, 2017; Browne et al. 2011; King et al., 2009; Matthews, 2017; McLane et al., 2022; Phillips-Beck et al., 2020; Pilarinos et al., 2023; Reading & Wien, 2009; Wylie & McConkey, 2018).

Despite some data indicating higher rates of dementia in Indigenous people, underdiagnosis and misdiagnosis are major concerns due to structural barriers and health-care systems that are under-resourced and ill-equipped for the needs of Indigenous populations (Walker et al., 2021). In addition, findings from Indigenous-engaged dementia research projects raise concerns that standard Western biomedical assessments do not accurately detect dementia in Indigenous populations (Walker et al., 2021).

In 2023, some dementia testing options were developed that are more culturally appropriate, such as the Canadian Indigenous Cognitive Assessment which is freely available at i-caare.ca.

The toolkit for this resource, and its testing, has been used mainly among Anishinaabe groups. Much more is still needed for other First Nations, Inuit and Métis—including removal of other barriers. “Additional healthcare resources for Indigenous populations will facilitate improved access to diagnosis, but it is equally critical that systemic barriers arising from racism and discrimination be addressed” (Walker et al., 2021).

Those who are unfamiliar with the issue may think that this problem of health-care access is most pronounced in rural areas. However, living in an urban area does not guarantee health-care access for Indigenous people.

“For urban Indigenous populations, although there may be a greater availability of formalised health-care services, systemic racism rooted in health-care systems create a significant barrier to accessing health care, therefore preventing or delaying a diagnosis of dementia” (Walker et al., 2021). They cite a Canadian Journal of Public Health article from 2020 that found prevalence of discrimination by health-care providers for Indigenous people was almost 30% in downtown Toronto (Kitching et al., 2020).

Walker and colleagues further discuss the impact of these experiences: “Fears of experiencing racism or discrimination in health-care service settings can prevent individuals from seeking medical help for symptoms of dementia. Indigenous families may avoid accessing health-care due to a lack of trust in colonial institutions, and a lack of culturally-relevant, or culturally-appropriate care.”

More recently, a 2023 study led by Métis researcher Dr. Pamela Roach reinforced that such fears are accurate. This study’s cross-sectional survey of Albertan physicians identified that about 10% to 25% reported explicit anti-Indigenous bias and that overall, physicians had moderate implicit anti-Indigenous bias (Roach et al., 2023).



Future research on dementia in Indigenous communities must be Indigenous-centred and Indigenous-led

Reliable epidemiological data on dementia in Indigenous populations is limited. This lack of data, coupled with the few findings that have found higher and increasing rates of dementia, indicates that improvements are quickly needed. Indigenous-led monitoring of dementia patterns and rates is necessary to fully determine the trends in dementia among the many Indigenous communities in Canada.

Without sufficient and up-to-date data, it is difficult for health systems and communities to plan for this emerging public health challenge.

The national dementia strategy (Public Health Agency of Canada, 2019) highlights that Indigenous individuals have distinct needs and experiences when it comes to dementia in their communities. The many communities of First Nations, Inuit and Métis have their own languages, dialects, cultures and histories. This multiplicity extends to perspectives on health, aging, and dementia. Indigenous-led research that honours and centres the many diverse voices in Indigenous communities can ensure that historical, cultural and socio-economic experiences are featured when considering dementia in these communities.

Approaches to dementia risk reduction also need to honour diverse knowledges and understandings of how the risk factors for dementia may be affecting outcomes across Indigenous populations.

Indigenous participants in research studies frequently report distinctive views of the causes and symptoms of dementia and issues around caregiving by both the family and the community (Jacklin & Walker, 2020). This suggests that dementia is an area that could benefit from developing resources to support culturally safe care so that services and supports are appropriate, effective and well-matched to the perspectives of the people directly affected by dementia.



Barriers to support also include income, care navigation and more

Indigenous people in Canada face a range of barriers to good health care—and by extension, good dementia care—that include poverty, cultural and linguistic differences, racism and a lack of cultural safety in health care, a mistrust of health-care providers, stigma associated with dementia, and geographical distance from communities to care centres (Beatty and Berdahl, 2011; Cameron et al., 2014; Chakanyuka et al., 2022; Finkelstein et al., 2012; Goodman et al. 2017; Halseth, 2018; Jacklin et al., 2015; Kitching et al., 2020; National Collaborating Centre for Indigenous Health, 2019; Petrasek McDonald et al., 2018).

Delayed dementia diagnosis and misdiagnosis can occur in more remote Indigenous communities due to a lack of awareness and knowledge about dementia, the need to navigate a multi-jurisdictional health-care system, lack of geriatric care specialists, the use of culturally inappropriate diagnostic tools, and the need to travel to urban centres to access specialized care services (Halseth, 2018). Dementia may also present differently in this population, with research indicating there may be a younger age of onset and higher incidence among males (Ody et al., 2022; Jacklin et al., 2013).

Lack of access to supportive care services such as home care, personal support workers, and respite care can result in greater challenges for Indigenous care partners. This is further exacerbated by the lack of long-term care options for Indigenous people within reserve communities.

These challenges in dementia care for Indigenous populations have the potential to lead to a range of issues including poorer quality of life and health outcomes for people living with dementia and their care partners, families, and communities. For context, see Beatty and Berdahl (2011), Jacklin et al. (2015), Loppie and Wien (2022), Racine et al. (2022), Smith et al. (2011), and Webkamigad et al. (2020), among others.



More culturally safe dementia resources are needed

Across all health systems in Canada, culturally appropriate and culturally safe care has become recognized as important in addressing the health inequities and barriers that exist for Indigenous people. In the dementia sphere, teams consisting of Indigenous and non-Indigenous researchers have developed resources for Indigenous persons living with dementia; their care partners, families and communities; and their health-care providers.

The need for culturally safe health-care services is especially true in some urban areas

In a recent study in the Calgary/Treaty 7 area, participants clearly voiced a need “for urban health-care services to implement Indigenous knowledge of healing including the inclusion of Elders and holistic services” and “incorporating traditional Knowledge Keepers into health-care services in a culturally appropriate manner” that promote “multiple ways of knowing” (Ody et al., 2022).

Dana, a Métis woman with more than 10 years’ experience of dementia in the family, told the study authors that she would like to see a safe space within urban health care “for victims of residential schools or [runaways] or that are Indigenous people to have—like a safe space for them to be able to talk.”

Other suggestions from participants in the study included creating spaces in health-care centres for smudging or sweat lodges creating culturally safe [early onset dementia] diagnostic tools by collaborating with Indigenous communities; and having centralized health-care services and systems that are Indigenous-specific and Indigenous-led.

The need for culturally safe health-care resources has been expressed in other contexts as well. In the Native Women’s Association of Canada *A Sacred Journey* (2022), Doris Tourangeau shares these reflections on her brother Joe’s dementia: “He has become another person in front of my eyes. ... But more recently, I notice he can speak our language fluently, which is Cree. Often, he shares his fears of being alone and yet, refuses any help, especially any White aid coming into his home. It’s a mission thing we never forget, I guess.”

Doris adds, “We live in an urban setting, and I do not want to place my brother in an old folk’s home. The resources are limited. Especially if you are First Nations person living in the city. We left our communities to better our lives, but, as we age, we find more barriers.”



A map toward breaking the cycle caused by colonialism in health care

To address Indigenous-specific racism and discrimination found in British Columbia’s health-care system, the provincial government commissioned an independent review into this topic in June 2020. The resulting report, released in November 2020, was called *In Plain Sight: Addressing Indigenous-Specific Racism and Discrimination in B.C. Health Care*.

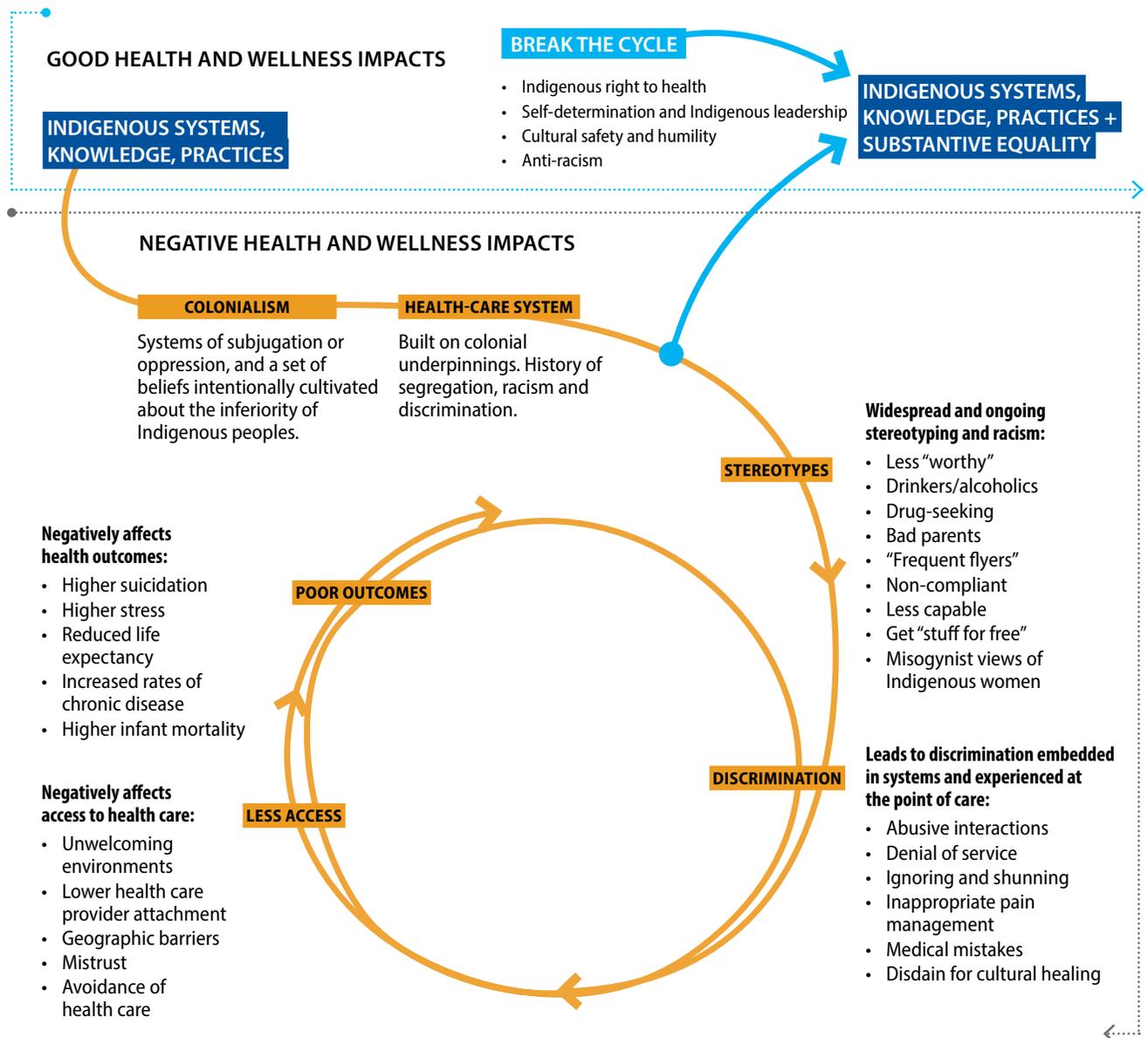
Through consultations with almost 9,000 people, including 2,780 Indigenous people and 5,440 health-care workers, the investigation found evidence of widespread systemic racism against Indigenous people in the health-care system. Of the Indigenous people interviewed, 84% shared personal experiences with racism, which discouraged them from seeking health care.

This widespread and ongoing racism leads to discrimination, less access, and poor health outcomes. These poor outcomes reinforce stereotypes, creating a cycle of inequity.

The report emphasizes the need to break this cycle: “Addressing Indigenous-specific racism as identified in this report requires attacking the roots of the problem and addressing the underlying causes of racism ... This includes upholding the Indigenous right to health, supporting self-determination and Indigenous leadership, designing systems that have cultural safety and humility embedded within them, and practicing anti-racism.”

The graphic below further maps this problem of Indigenous-specific racism in health care and suggests ways to break the cycle.

Figure 3. Visualizing Indigenous-specific discrimination in health care, and ways to intervene



Source: Adapted with permission from *In Plain Sight: Addressing Indigenous-Specific Racism and Discrimination in B.C. Health Care* (2020)

Some Indigenous-led resources about dementia

The Native Women's Association of Canada (NWAC) has been building capacity and developing tailored, culturally safe and trauma-informed resources and supports for Indigenous caregivers and Indigenous people living with dementia. Examples include a toolkit (2022a) to address dementia-related stigma and a photobook, *A Sacred Journey: The Long Goodbye* (2022b), to raise awareness; both were supported by funding from the Public Health Agency of Canada through the Dementia Strategic Fund.

The Indigenous Cognition and Aging Awareness Research Exchange (I-CAARE) has developed culturally appropriate resources for those living with dementia (e.g., fact sheets on signs/symptoms, dementia prevention and care) and health-care professionals (e.g., Indigenous perspectives on dementia, training modules and practice tools). These resources can be accessed at i-caare.ca.

I-CAARE has adapted the Kimberley Indigenous Cognitive Assessment (KICA) tool to create the Canadian Indigenous Cognitive Assessment (CICA) for use by Canadian health-care providers to diagnose dementia in Indigenous contexts in Canada (Jacklin et al., 2020; Walker & O'Connell et al., 2021). The CICA is an outcome of the Canadian Consortium on Neurodegeneration in Aging (CCNA) Phase I and was led by Dr. Kristen Jacklin. This work has been taken on by CCNA Team 18: Issues in Dementia Care for Indigenous Populations under the direction of Dr. Jennifer Walker.

Another website with resources to support healthy aging and dementia care for Indigenous communities is anishinaabekdementiacare.ca. This project was produced by a collaboration between Health Sciences North Research Institute (HSNRI), N'Mninoeyaa Aboriginal Health Access Centre, and Noojmowin Teg Aboriginal Health Access Centre. There are a wide range of supportive resources available on the website.

These are just a sample of the Indigenous-led and co-led initiatives in dementia and dementia caregiving now ongoing in Canada.

“Across the globe, Indigenous Peoples as well as people of African descent, Roma and other ethnic minorities experience stigma, racism and racial discrimination. This situation often increases their exposure and vulnerability to risk factors and reduces their access to quality health services. The result is that these populations often experience poorer health outcomes.”

— World Health Organization

NEW FINDINGS FROM OUR LANDMARK STUDY

It is important to note that these numbers from the Landmark Study are based on Statistics Canada population estimates from the 2016 Census of Population. Studies have indicated that the Canadian Census may not always accurately capture the number of Indigenous people living in cities across Canada due to issues with under coverage (not being able to count every individual within the population; McConkey et al., 2022). Therefore, these estimates for Indigenous populations should be considered conservative based on the best data we have available, with much more Indigenous-led work needed to improve the accuracy of estimates of Indigenous populations across Canada.

In 2020, it was estimated by the Landmark Study that there were 10,800 people of Indigenous ancestry living with dementia in Canada (refer to Table 1). By 2050, we can expect this number to increase by 273%. This percentage increase is significantly higher than the increase expected for the general population (187%). This is driven both by the aging of the Indigenous population and by higher rates of potentially modifiable risk factors.

Table 1. Estimates for the number of Indigenous people living with dementia in 2020 and projections for 2050

YEAR	FEMALE	MALE	TOTAL
2020	6,400	4,400	10,800
2050	25,800	14,500	40,300
% INCREASE BY 2050	303%	230%	273%

The increase in the number of Indigenous people living with dementia is projected to steadily increase over the three decades as examined in the model. The projected number of Indigenous individuals living with dementia (prevalence) from 2020 to 2050 is found in [Figure 4](#), and the estimated number of new cases in this population each year is illustrated in [Figure 5](#).

Figure 4. Projections for the total number of Indigenous people living with dementia, 2020 to 2050

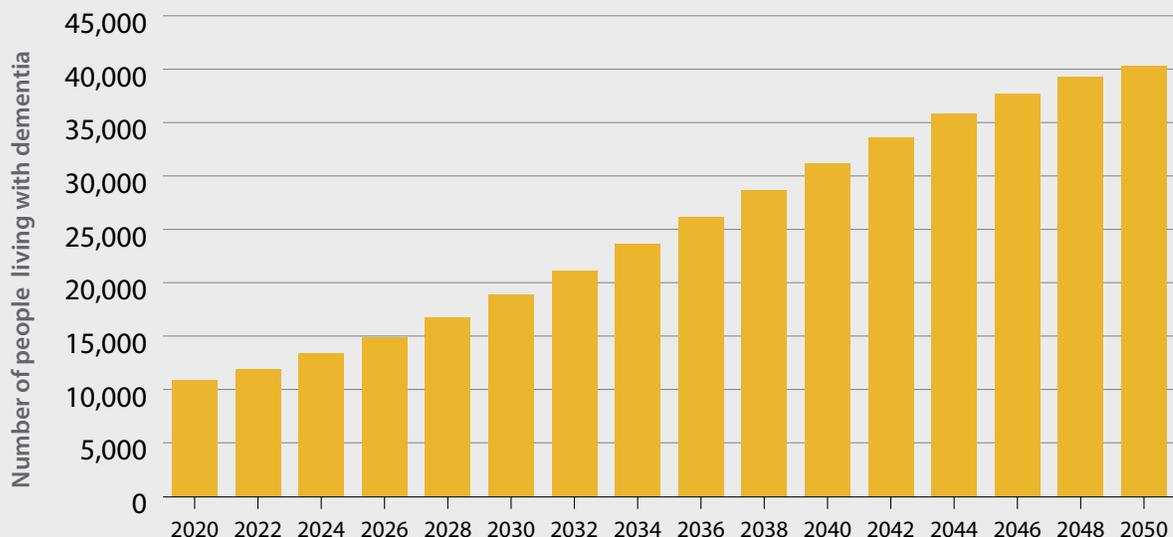
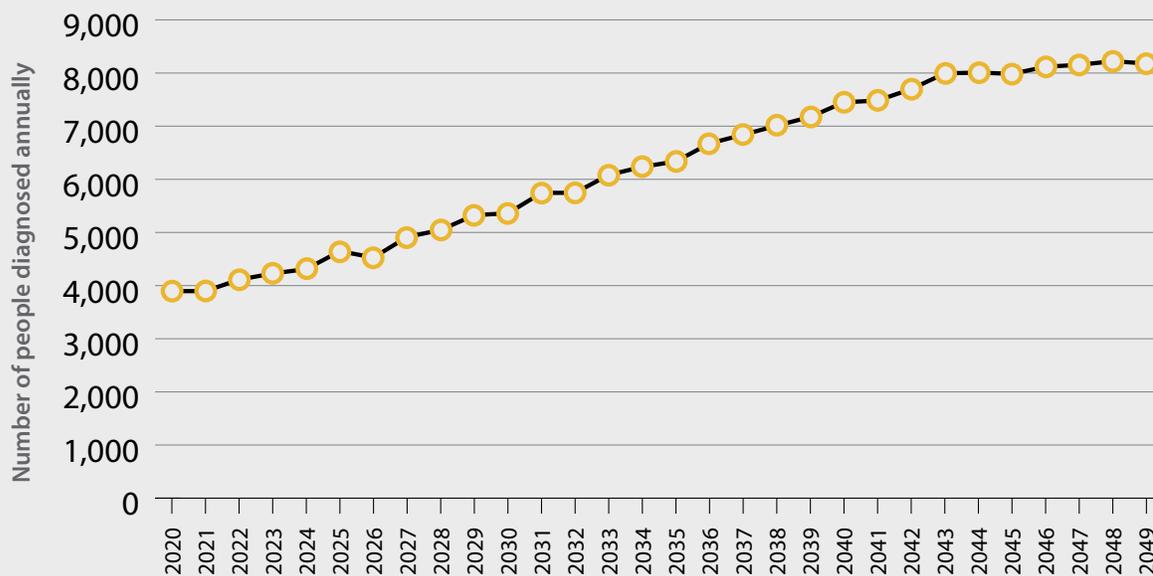
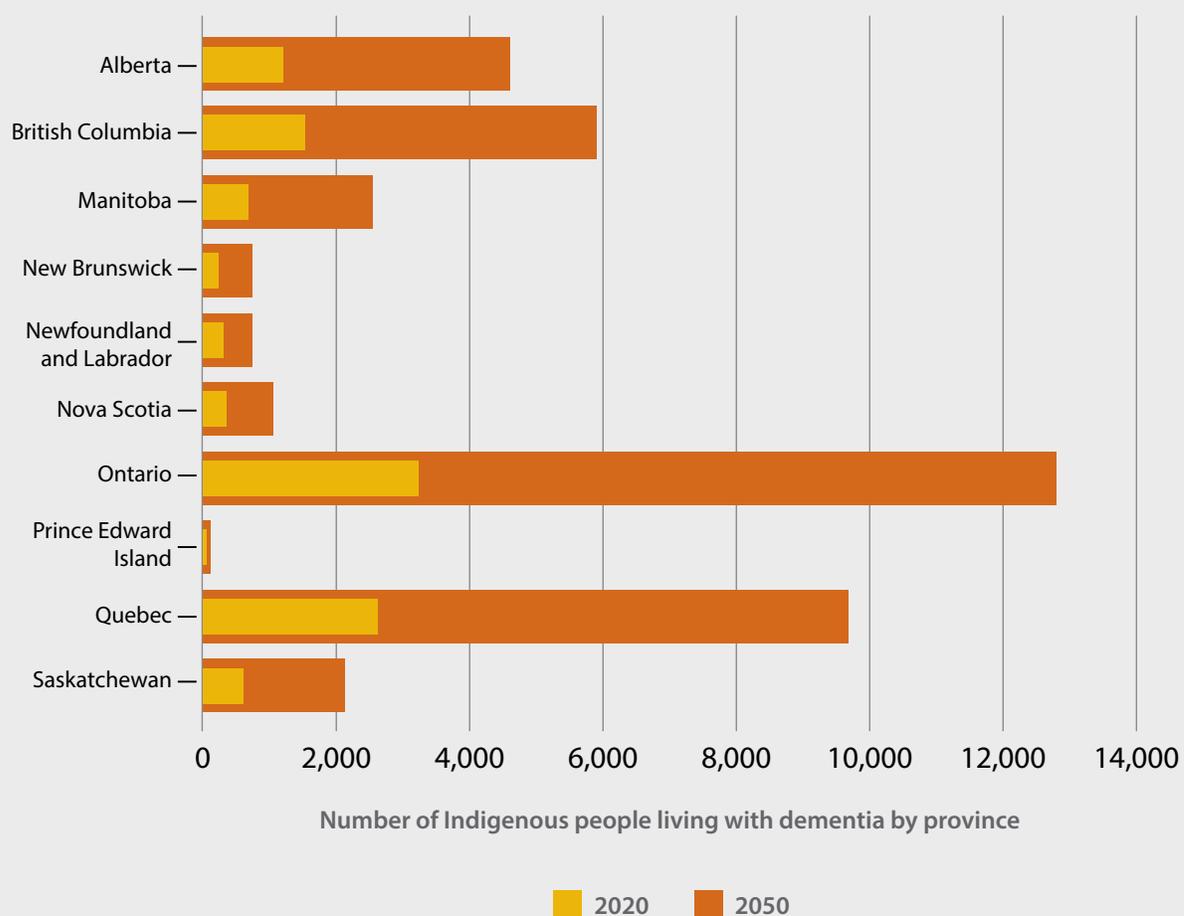


Figure 5. Projections for the annual number of Indigenous people with newly developed dementia, 2020 to 2049



There are also many differences across the Canadian provinces (refer to Figure 6). Ontario and Quebec, followed by British Columbia and Alberta, will see the largest increases in dementia among Indigenous people over the next three decades.

Figure 6. Number of Indigenous people living with dementia in 2020 and 2050, by province



Due to a lack of data, there are no projections for Yukon, Northwest Territories or Nunavut. Overall, these findings provide conservative estimates for the number of Indigenous people who may experience dementia in the next 30 years. This growing public health challenge requires responses from our public health and health systems that are culturally safe and address the underlying determinants of dementia among Indigenous Peoples in Canada.

FACES OF DEMENTIA PIITA'S STORY

Piita, an Inuk and a residential school survivor, describes how he helped bring Inuit culture and food to a southern facility caring for Inuit Elders with dementia.



"IN my particular period of time, we never had dementia among Inuit. We never had people with Alzheimer's. Basically, this was because we died too young, and we had different diet of country food.

Today we have people, particularly in the last 10 years or so, who have dementia—Inuit from the Arctic and Inuit from Nunavut. Because these people cannot be looked after in their own communities—and because we have no facilities in our own communities—they often have to come here, to West Embassy in Ottawa. West Embassy is a place where they look after people with Alzheimer's and dementia.

Photos: Courtesy of Piita Irniq and Livingmyculture.ca/
Canadian Virtual Hospice (left) and Nunavut News (right).

A lot of the people who are at West Embassy are Elders. Some are older than I am. Some are in their 80s and they don't speak a word of English.

So a few years ago, a colleague and I decided that we would like to help the organization make some changes and provide more Inuit cultural awareness.

It was hard in the beginning to make this change, because it's a Southern organization without much knowledge about Inuit, Inuit history and Inuit culture. This organization didn't know about things like Inuit country food, or how to create culturally appropriate Inuit rooms, or why Inuit smile a lot. They didn't necessarily understand why Inuit are very friendly people, and why Inuit may have different attitudes about life.

So a colleague and I talked to the management, and they accepted all of our recommendations. Our recommendations included a translator for Inuit Elders; bringing in country food like caribou meat, Arctic char, seal meat from Nunavut; and establishing a better relationship with the Government of Nunavut.

We also recommended and got visitations, which hadn't been possible before—now Inuit can visit their relatives. We also got a good-sized room where we can gather and talk in Inuktitut with Inuit Elders. The staff tend to call them "patients" or "Inuit residents," but we prefer to call them Inuit Elders because that's what they are.

When you eat your country food, it's very sustaining. I knew an Inuk would need that food, and that's what I really fought for them to have.

For the culturally appropriate room, a manager and I went to an Inuit art shop in Ottawa on Sparks Street and we bought Inuit drums so that Elders could hear Inuit drum dancing. We bought Inuit dolls so they could see their own artwork. We bought some carvings so they could see their own Inuit carvings from home. We bought some Inuit prints from Cape Dorset so they could heal more being in that place.

We also bought some pictures with walruses, polar bears, seals, belugas and muskox, as well as pictures of an igloo and a tent. We want to make the Inuit Elders feel more at home as much as possible.

It took about two and a half years of working together to get these things that we pushed for. Now, I believe that those things help a lot."

Adapted from a video at Livingmyculture.ca with the permission of Canadian Virtual Hospice and Piita Irniq.

"This organization didn't know about things like Inuit country food, or how to create culturally appropriate Inuit rooms... Our recommendations included a translator for Inuit elders, bringing in country food... [and] Inuit art."

FACES OF DEMENTIA

BECKIE'S STORY

Here, artist and Elder Beckie Labilliois, Mi'kmaq from Ugpi'Ganjig First Nation, talks about her mother's life, legacy and experiences of dementia.



"MY mother was once an icon all over Canada, the United States, and even overseas. She fought for her heritage, culture, beliefs, and for her way of life. She was a strong Inu Epit. She grew up to be the first from her reserve of Eel River Bar to graduate with high honours.

She was the first female Chief elected in the province of New Brunswick. She was a strong advocate for having the Mi'kmaq language taught in schools to ensure that the children of Eel River Bar would know who they are. She hoped to reconnect the severed ties caused by residential schools and to heal their effects on the reserve.

Photos: Courtesy of Beckie Labillois and family (left) and Vanessa Blanch/CBC Licensing (right).

“We need to educate ourselves on dementia to know the signs and symptoms, so that we can put resources in place before any abuse can happen to our respected Elders.”

I recall having to identify people for my mom as she presented with signs of early dementia. We always giggled and laughed that we just were getting older and forgetting people, places, and things. We as Inu people are familiar with the little people playing tricks or being tricksters and hiding things on us until we forget about it. We call these people the Booglatamootj.

I learned to compensate for mom early on by identifying people, places and things to what they were connected to, to help jog her memory. It was my great honour to get to know the circle of people that she was surrounded by in her years of dedication to the Union of New Brunswick Indians, and the various boards and associations with which she was involved. The powwows, gatherings, and conferences were the time to meet, greet, trade, and reflect upon ideas, while also reminding us that whatever we learn is not ours to keep for ourselves, but rather to be passed on. That is the circle of life.

Her presence and wisdom were sought after at various gatherings and meetings. It was after these gatherings that she would ask me who certain people were, and we would giggle. She would talk to everyone as if she knew them; everyone's voice mattered in her eyes. She was a great listener. She gifted me with the listening ear.

Many times, we would have to jog her memory and then she would recall who that person was and the connection. We would just giggle and say, “we are not lost, we are just taking a different way to get there.” The best one was when she would say, “well we are here, better late than never.”

I recall many times waking up early to travel to meetings all over North America. We were well known as the road runners. I had my youngest daughter Jenna travel with us most of the time.

My mom needed someone to take her because she never had a licence or a vehicle, so all the siblings, nieces, nephews, and even the Chief would drive her to meetings. She was always busy with her crafts, and she would sell them at every event, trying to keep the Apitjipeg crafts alive. This was her connection to her cycle of life.

Our family and our whole community had a chance to learn from her hands-on approach, so we can pass it on to the next generation. It is with great pride to be able to acknowledge our ancestors of the past, present and future.

We are all connected in this circle of life. We come to a journey of birth, adolescence, adulthood, and elderhood. We need to educate ourselves on dementia to know the signs and symptoms, so that we can put resources in place before any abuse can happen to our respected Elders.”

Adapted from the Native Women's Association of Canada's *A Sacred Journey* with the permission of Native Women's Association of Canada and Beckie Labillois.

FACES OF DEMENTIA

JANA'S STORY

Jana Schulz is a social worker and is the past women's regional representative of Region 4, Métis Nation British Columbia. She is also past president of the Rocky Mountain Métis Association. Here, she talks about her dad, who is Métis and who is living with Alzheimer's disease.



"MY dad is Métis and was born in Edmonton, but he spent the majority of his childhood and youth in Yellowknife. Eventually he went to Hinton, and that's where he met my mom, who is of European descent. My dad worked there at the pulp mill. And from there they moved to Cranbrook.

Around 2015, might have even been 2014, my dad and my husband were building a fence. And my dad was a drafting engineer. But he could not figure out the right horizontal and vertical measurements. Basically, he was putting the gate on backwards.

After noticing some things such as the fence, I spoke to his doctor and requested a check-up. But the doctor concluded, "It's normal aging. There's some decline, but you know, nothing to worry about." I thought, "No, there's something else going on." My mom started documenting things, which we also brought to the doctor, and my dad got a new doctor, then was diagnosed with Alzheimer's disease in 2016.

My dad was really never into his culture, but has become more so in recent years, during his Alzheimer's. I'll never forget the first time he said to a health-care provider, "I am Métis." I remember, it just hit me in the heart. Going from not ever talking about it to, more recently, sharing stories. It brings pride.

Photos: Courtesy of Jana Schulz and family.

“We may not see change in care in my dad’s lifetime. If I can make it so that Métis generations after me can have better care, I’ll have made the ancestors proud.”

The cost of caregiving is huge, though. I lost approximately \$50,000 in annual income and went below the poverty line by having to switch from a full-time job to a part-time (remote) job. My dad’s disease progressed faster than the health-care system could keep up, and I wanted to better support my mom so that she could support my dad and reduce her risk of burnout. My mom would indicate that she needed respite, so I would go pick him up. I’d take him to nature. In nature, just walking, it would really calm him.

And with the Métis side of things [in dementia care], I started doing research on it myself. Because all I could find was First Nations–based, a First Nations lens brought into it. How can we provide a Métis lens into care? For that, we need the research.

Now Dad’s in long-term care. I know the care aides work so hard there. And in thinking about how to change long-term care, or home care, or community care, there’s still lots that can be done. Like, place a Métis sash somewhere, even if it’s in a picture frame. Think about food. Make it less institutionalized [as a space].

The Métis perspective is about building relationships. In long-term care intake, let’s talk about how I feel I need to be a part of his care plan—because I’m not just a caregiver, I’m kin. And a cousin or auntie or sister or community member should be able to visit too. And Elders. But the westernized [colonial, nuclear] family model used in so many care spaces really blocks any type of traditional healing that way.

I’ve been pretty bold in talking about this at Dad’s long-term care home, and it has been a game changer. I went and led two trainings—a lot of staff came, and I talked about an Indigenous perspective, and then put that Métis lens on it. We also talked about intergenerational trauma.

I’ve made clear I want to be part of my dad’s care. If my dad’s awake at 2 o’clock in the morning and disrupting the whole pod, why not call me and say, “Hey, can you come on down?” They laugh because every time I’m there, he falls asleep. I don’t know why it calms, but it works.

Speaking out and advocating has helped. Before, I was burnt out, and I was angry. I was mad at the system; I was ready to quit my job. Now, my voice matters. I knew it did before, but now the right people are listening. At the same time, when I’m asked to share, I always say, “Am I a token? Or do you actually want my input?”

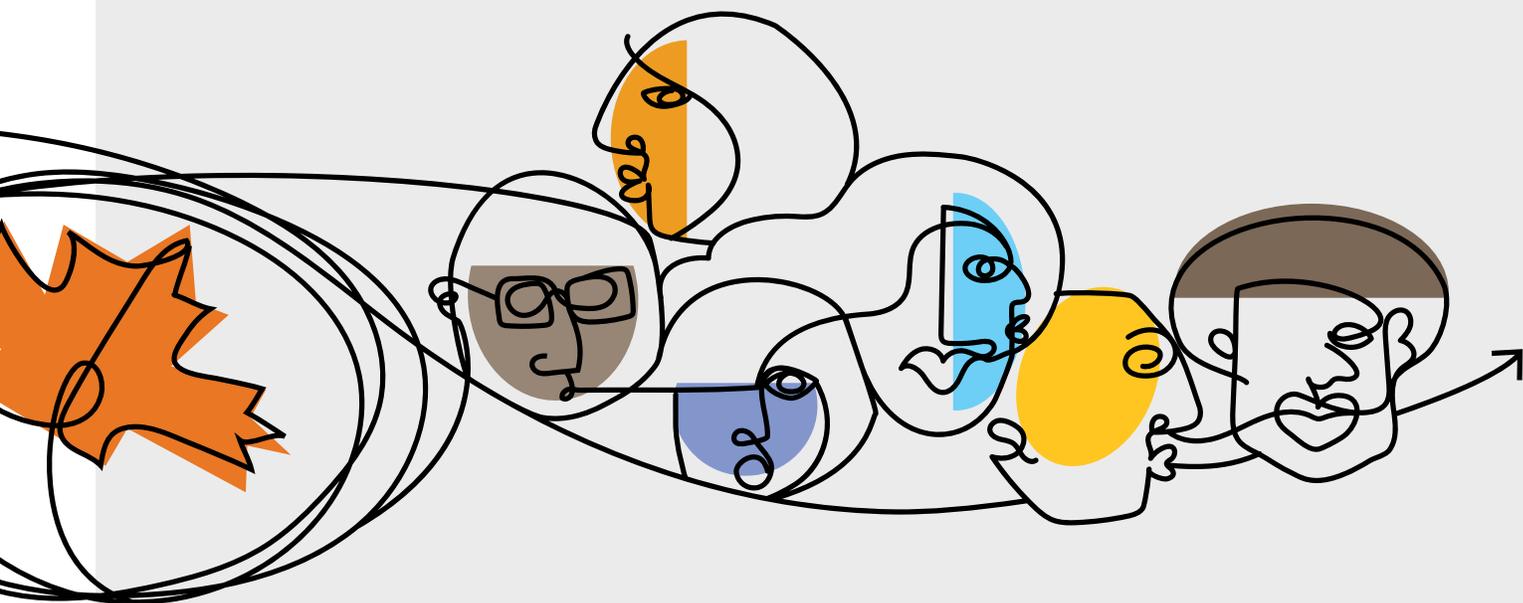
I do wish we had more discussion around dementia stigma in my community—a place I could talk about my fears from a culturally specific lens and use traditional medicines. Again, there are some great resources out there, but they are very First Nations–focused, like using the Medicine Wheel; we in my community don’t necessarily follow the Medicine Wheel.

My mom always called me a rabble rouser. And I am. I think change happens in uncomfortable conversations. But I’m not expecting change overnight. We may not see change in care in my dad’s lifetime. If I can make it so that Métis generations after me can have better care, I’ll have made the ancestors proud.

Even though the dementia journey is challenging, and it’s hurtful and it hurts the heart and the spirit, I believe we’re all put in a path for a reason. My dad is paving the path for Métis after him. And that, to me, fills me with so much love and gratitude because it’s leaving a legacy.”

ETHNIC AND RACIAL DIVERSITY OF PEOPLE AFFECTED BY DEMENTIA

Variation exists in dementia risk and dementia care across different ethnocultural and ethno-racial communities in Canada.



Canada is considered one of the most multicultural countries in the world. In the 2016 Canadian census, over 250 different ethnic origins were recorded as part of the Canadian demographic landscape. This diversity is now widely considered a fundamental Canadian value and is largely the result of several waves of immigration over the past 50 years.

An aging multicultural population

Prior to 1970, newcomers to Canada arrived mainly from European countries or the United States. However, because of significant changes to Canadian immigration policies, the major places from which people migrated changed in the 1970s. These changing immigration patterns, shifting away from European countries toward countries from Asia, Africa, and the Middle East, have resulted in a Canadian population that is more ethnically, racially, linguistically and culturally diverse.

With an aging population in Canada, we are now witnessing a rapidly growing number of older adults from a wide range of ethnic and racial backgrounds. With age as the strongest risk factor for dementia, this diversity in older Canadians is also reflected within the population of people living with dementia in Canada.

Over the next 30 years, we can expect even further changes to the ethnic and racial makeup of people living with dementia in Canada. Consequently, care services for people living with dementia need to be designed to meet the diverse needs of these populations. Canada's national dementia strategy emphasizes the need for increased understanding and expanded data on health-related issues in ethnic and cultural minority communities in order to assist efforts in dementia risk reduction.

This chapter will highlight some of the experiences of individuals living with dementia across different ethnic and racial groups in Canada. This is a complex, deep area of work that deserves a dedicated, fulsome review. Our report will only cover the initial framework relevant to the estimations and projections from the Landmark Study model with a deeper review planned for the future.

Key definitions for this chapter

Prior to discussing the impact of dementia across different ethnic and racialized communities, it is important to first consider some helpful definitions for this chapter.

Box 4. Key definitions: ethnic origin, race, culture, and racialization

Ethnic origin: Ethnic origin refers to the ethnic or cultural origins of a person's ancestors. An ancestor is usually more distant than a grandparent (Statistics Canada, 2017). This includes shared language, religion or traditions. Ethnic origin does not have to have a genetic component but can, especially if this includes common ancestry.

Race: Race is a social construct. This means that society forms ideas of race based on geographic, historical, political, economic, social and cultural factors, as well as physical traits, even though none of these can legitimately be used to classify groups of people (Bhopal, 2004).

Culture: Culture refers to the shared knowledge, values and beliefs of a group of people that is built and shared over generations (Samovar & Porter, 2003).

Racialization: This is the process in which groups are designated by society as being part of a particular "race" and on that basis they are treated differently. Some people and institutions use the terms "racialized person" or "racialized group" rather than "racial minority," "visible minority" or "person of colour" in order to explicitly recognize that race is a social construct (Ontario Human Rights Commission, 2023).

While some of these terms are at times used interchangeably, they can have distinctive meanings and consequences when speaking to health status and access to health services for different populations in a society. The concepts of ethnicity, race and culture in public health and health care are central to addressing health inequities, yet they are often overlooked and not measured well by health systems and researchers.

For the Landmark Study projections, we used ethnic origin groupings based on 2016 Canadian census data. We recognize that these groups are extremely broad and do not fully capture the complexity of ethnic origin and dementia risk in Canada. However, the analyses can provide some initial broad insights into what dementia differences we can expect across ethnicity and race in Canada over the next 30 years.

Significant gaps in dementia risk exist across ethnic and racial groups

There have been many international studies on how frequently dementia occurs in racialized populations. Studies from the United States and the United Kingdom have consistently reported on racial and ethnic differences in dementia within these populations. However, in Canada, data on these differences is currently lacking.

A 2016 American study by Mayeda and colleagues looked at new dementia cases that developed in a large, diverse cohort of older adults in northern California. They found that rates of dementia onset varied widely (over 60%) between six racial and ethnic groups. Of the six groups, they found the highest rates of dementia were among African Americans and Native Americans. The lowest rates were among Asian American populations, with intermediate rates for Latin American, White, and Pacific Islander populations.

In a similar UK-based study, researchers found significant differences in dementia risk across three groups (Pham et al., 2018). This study looked at primary care electronic health records over an eight-year period and examined diagnosis rates by Black, White and Asian groups. They found similar findings, with risk being lowest among Asian people and highest among Black people in their study population.

Relying on internationally published reports like the two outlined above, a recent systematic review pulled together further evidence examining differences based on ethnicity and race in the risk of developing dementia (Shiekh et al., 2020). After compiling data from 19 studies taken from various locations around the world, the research team found that subjects in the Black group had the highest incidence rates (new cases) of dementia, those in the Asian group had the lowest incidence rates, and subjects in the Latin group was found to have similar incidence rates as the White group. While this study confirmed that there are clearly differences in risk of developing dementia, the authors suggested that a better understanding of the causes for these differences is urgently needed.

In Canada, we need to both develop our understanding of the extent of these differences and aim to identify the factors that drive these differences. While there have not been a lot of Canadian studies on this topic, there is emerging evidence that strongly suggests that Black populations in Canada have a higher occurrence of dementia compared to other populations, while at the same time experiencing gaps in culturally responsive care and adequate supports (Iroanyah et al., 2021).

Why do differences in dementia rates exist across ethnic and racial groups?

The reasons for these differences are complex. We highlight some of the key drivers, including differences in dementia risk factors, social determinants of health, and the stress resulting from social conditions experienced by distinct groups within the Canadian population. However, this is a critical area of research that needs to be further explored for a diverse aging population.

Potential disparities in rates of dementia risk factors

One explanation for variations in dementia risk may come from differences in modifiable risk factors across race and ethnicity. Modifiable risk factors for dementia are factors related to dementia risk that can be changed (e.g., hypertension, obesity, smoking, depression, physical inactivity, diabetes). One study by Lee and colleagues (2022) took a closer look at racial and ethnic differences across 12 well-established modifiable risk factors for dementia. They found that risk factors such as diabetes, physical inactivity, obesity, and exposure to air pollution were higher in Latin American and Black individuals. These researchers' analyses concluded that the proportion of potentially preventable dementia cases was highest among both Black and Latin American groups.

Unfortunately, many people may not be able to address these modifiable factors due to their personal situation and resources. These risk factors are only truly modifiable if the proper supports are provided by our communities, public health agencies and other governmental organizations.

Social determinants of health negatively affecting brain health

Racial and ethnic differences in dementia may also be linked to how different populations experience social determinants of health (refer to [Box 3](#)).

Experiencing racism is a social determinant of health associated with poorer physical and mental health, as well as faster cognitive decline with aging. As a form of psychosocial stress, the experience of racism over time has been found to cause structural changes in brain physiology and accelerate brain aging and memory declines. For instance, a study from Boston University found that African American women who were exposed to or experienced racism had increased risk for lower cognitive function (Coogan et al., 2020).

The Forrester Framework of Minority Stress, created by African American scholar Dr. Sarah Forrester and colleagues in 2019 (discussed in [Chapter 2, page 29](#), or refer to Forrester et al., 2019) also helps explain how people in Canada from different racial and ethnic groups might be at higher risk for developing dementia. The theory is that increased risk for dementia occurs due to social conditions that chronically activate a physiological stress response. Social factors such as racism, lower levels of education, and lower socio-economic status directly impact stress levels and contribute to physiological dysfunction—which can negatively impact the brain and heighten the risk of dementia.

Unlike acute health issues (e.g., infection, physical trauma), the factors that produce most dementias are multiple and complex. To effectively address dementia risk across all people in Canada, we will need to think about dementia not just as an individual biologically-driven condition but as a social one, by also thinking more closely about the underlying causes and core determinants of brain health.

Differences in biomarkers connected to dementia risk

In addition to differences in people's lives and environments, there are also differences that have been found in the biomarkers linked to dementia and dementia risk across ethnic and racial groups. Biomarkers (short for "biological markers") are any aspects of biology that can be measured accurately and help indicate the medical state of the body.

One of the key biomarkers for dementia risk is the Apolipoprotein epsilon 4 gene (APOE- ϵ 4). APOE- ϵ 4 has been linked with the risk of late onset Alzheimer's dementia (Farrer et al., 1997). There are three alleles (types) of the APOE gene (ϵ 2, ϵ 3, or ϵ 4) and each individual has two of these genes (one from each parent). This leads to six possible combinations of the gene (ϵ 2/ ϵ 2, ϵ 2/ ϵ 3, ϵ 2/ ϵ 4, ϵ 3/ ϵ 3, ϵ 3/ ϵ 4 and ϵ 4/ ϵ 4). People carrying the ϵ 4 type have a higher risk of developing Alzheimer's dementia, whereas people carrying the ϵ 2 type have a lower risk. Black populations have a higher rate of ϵ 4 compared to White populations, who in turn have higher rates of ϵ 4 compared to Asian and Latin American populations (Alzheimer's Association, 2021).

Most of what we understand about APOE and developing dementia has been mainly studied in European ancestry populations (Weiss et al., 2021). Studies that have looked at Alzheimer's dementia risk related to APOE in Black populations have varying results. More research is needed to better understand how APOE status influences Alzheimer's risk across different ethnic and racial groups.

Research has also found differences across ethnic and racial groups across other blood biomarkers, neuropathological changes in Alzheimer's disease (changes in the brain that include amyloid plaques and neurofibrillary tangles), brain volume changes, and functional connectivity (Roselli et al., 2022). As more research is conducted in this area, it will help develop better disease modifying drugs and therapies for all people living with dementia.

People from racialized communities may receive poorer quality of dementia care

Despite how diverse older adults in Canada are, we still understand little about dementia care experiences across different ethnic and racialized communities. Sang A. Lee's and colleagues (2022) have shown that there are ethnic and racial disparities in dementia diagnosis and screening. There are many potential reasons. While language can be a barrier, as may be lack of awareness and education on dementia in communities, a similar lack of education among health-care professionals as well as dementia diagnostic assessments that do not account for cultural and language differences can all lead to diagnostic errors.

Racialized health-care users can also experience racism when receiving health-care resulting in experiences that may include professional misconduct, negligent communication, parallel structure, discrimination, and unequal access to services (Mahabir et al., 2021).

Different cultural views and stigma about dementia can also prevent individuals and families from seeking a diagnosis, as well as make it difficult to accept a diagnosis or ask for help with dementia care. Dr. Naaheed Mukadam and colleagues (2010) conducted a systematic review to better understand why people from minority ethnic groups present to specialist care once their dementia has progressed more toward the moderate or severe stages of dementia. They found that barriers for accessing specialist help for dementia included:

- “not conceptualising dementia as an illness;
- believing dementia was a normal consequence of aging;
- thinking dementia had spiritual, psychological, physical health or social causes;
- feeling that caring for the person with dementia was a personal or family responsibility;
- experiences of shame and stigma within the community;
- believing there was nothing that could be done to help; and
- negative experiences of healthcare services” (Mukadam et al., 2010).

These are just some of the barriers that members of racialized communities may face in accessing dementia care. A focus on higher risk and equitable care is outlined as a focus of activities in Canada's national dementia strategy (Public Health Agency of Canada, 2019). This has led to growing federal efforts on higher-risk population groups and equitable care, including support for a range of projects related to dementia guidance across underserved ethnic and cultural communities.

Not enough research to understand differences in the experiences of care partners across ethnic and racial groups

Not much research has been done about the experiences and outcomes of care partners across ethnic and racial groups. The limited research has found differences between Black, White, Latin American and Asian care partners in levels of stressors, resources, psychological outcomes, and caregiver self-care (Pinquart & Sörensen, 2005; Waligora et al., 2019). Expanding work in this area would help inform and expand the range of services that are provided for these essential providers of care.



Diversity is missing in dementia research overall

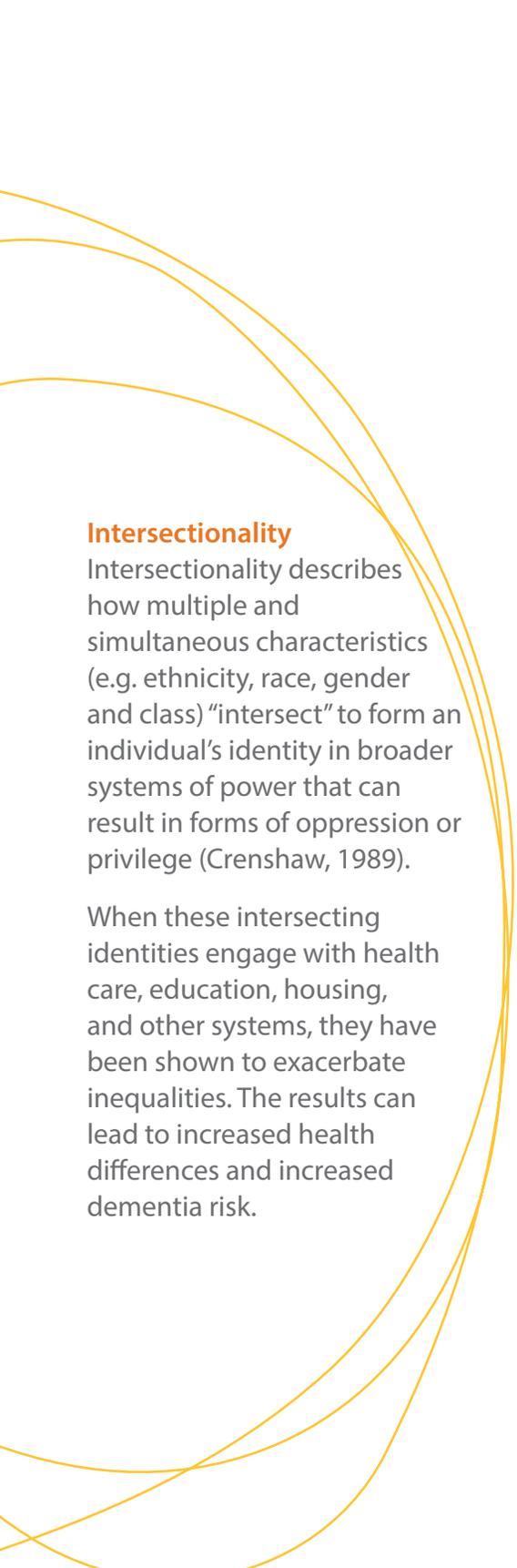
There is generally limited research and data focused on the dementia experiences and care needs of racialized communities. This lack of knowledge has significant implications for the development of policies, programs, supports and services that can meet those needs.

It is essential that the field of Canadian research expands to better understand the unique experiences of all people living with dementia in this country.

Federal research granting agencies have recently sought ways to address systemic racism in their funding models and to increase representation of racialized applicants who have been found to be excluded in previous funding cycles. There is evidence to show that research in ethnic and racialized communities conducted by researchers from those same communities ensures broader representations of thought and results in better uptake among information because of co-design and early engagement.

There has also been a lack of inclusion of participants from racialized groups in research studies on dementia. Barriers to participation include a lack of trust, geographical barriers, and research recruitment protocols that don't consider the needs, experiences and best practices for recruitment of racial and ethnic minority populations (Shaw et al., 2022). Research has shown that community-led research and community representation of research leads can increase engagement, quality of research, data collection and implementation.

Although there has been some research in Canada on dementia experiences of some minority ethnic groups, there has been a relative absence of research around prevalence and incidence rates for these groups. Furthermore, the data and research that is available is limited in scope and sample sizes. Canada has yet to establish systematic infrastructure for collecting race-based data on groups living with dementia, though several jurisdictions have taken it upon themselves to fill in those gaps (e.g., the Anti-Racism Data Act by the BC provincial government, the Fair Care Project by the Nova Scotia Department of Health and Wellness, and more recently, Shared Health in Manitoba).



Intersectionality

Intersectionality describes how multiple and simultaneous characteristics (e.g. ethnicity, race, gender and class) “intersect” to form an individual’s identity in broader systems of power that can result in forms of oppression or privilege (Crenshaw, 1989).

When these intersecting identities engage with health care, education, housing, and other systems, they have been shown to exacerbate inequalities. The results can lead to increased health differences and increased dementia risk.

The growing need for intersectionality in dementia care and research

Person-centred approaches to dementia care and research cannot be considered in isolation from broader social systems and environments in which people live with dementia. An intersectional approach to dementia and dementia care can help us to consider how multiple social identities (e.g., race, gender, class) overlap to shape health outcomes, including dementia.

To fully support people living with dementia and their care partners, it is important to consider the totality of their experiences. By taking a holistic approach, policies, programs, supports and services may account for the many influential aspects of dementia experience (Dilworth-Anderson et al., 2020). These considerations are vital to ensure that people’s unique experiences are captured and reflected when developing truly inclusive dementia care.

Furthermore, intersectionality can tell us how intersecting identities shape and influence access to care and health service utilization, as well as the extent to which these services are equipped to respond to the complex care needs of individuals. For example, this type of approach will give us specific insight into how dementia impacts Black women of lower socio-economic status versus Black men, White women and White men of lower socio-economic status, and the extent to which services are equipped to address the needs of each group.

The population of people living with dementia in Canada is becoming more diverse. Now is the time to enhance our understanding of diversity to ensure that future dementia care will be both culturally safe and appropriate in meeting the needs of all individuals living with dementia in Canada.

NEW FINDINGS FROM OUR LANDMARK STUDY

The Landmark Study is based on findings from a simulation model that combined data from the 2016 Statistics Canada census and findings from the literature to estimate the impact of dementia in Canada over the next 30 years.

The results portrayed in this section use estimates on self-reported broad ethnic origin categories used by Statistics Canada. Ethnic origin refers to the ethnic or cultural origins of the person's ancestors. The Landmark Study model is simplified to assume only one ethnic origin of individuals, when in reality many Canadians often report more than one ethnic origin of their ancestors.

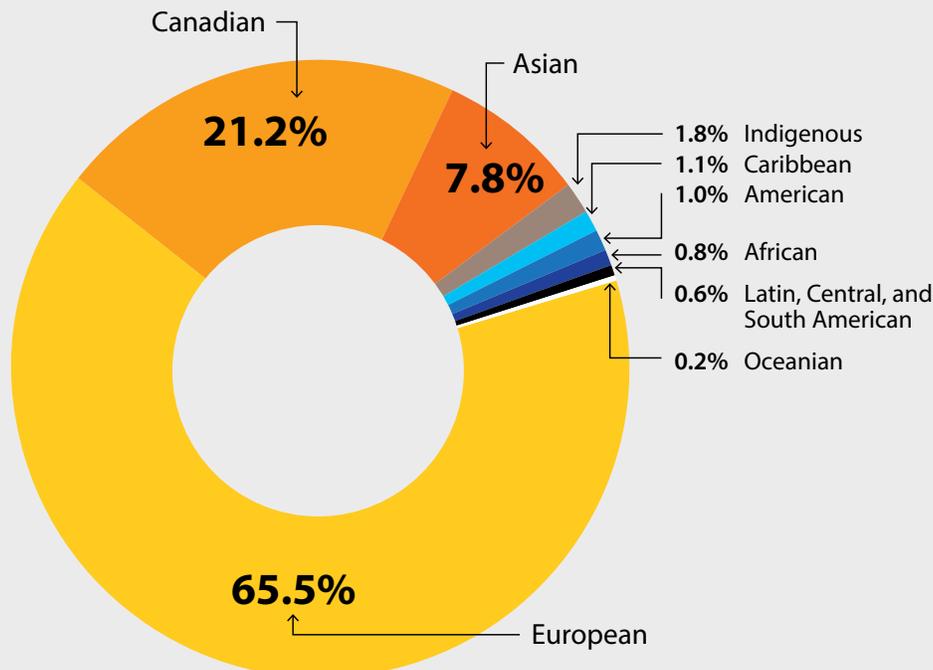
It is also important to clarify that "Canadian" is one category that was commonly self-reported in the 2016 Canadian census and reflects an individual's thoughts on their ancestral background and ethnic origin.

By 2050, one in every four persons who develops dementia will be of Asian origin

Using the data from the Landmark Study model, we were able to begin to understand the self-reported ethnic origins of people living with dementia in Canada.

The estimated proportions of ethnic origins for people living with dementia in Canada in 2020 are illustrated in Figure 7. Almost two thirds of the individuals living with dementia are of European ancestry, with the remaining one third made up of individuals reporting Canadian; Asian; Indigenous; African; Caribbean; Latin, Central, and South American; and American origins. By 2050, this population profile is projected to drastically change.

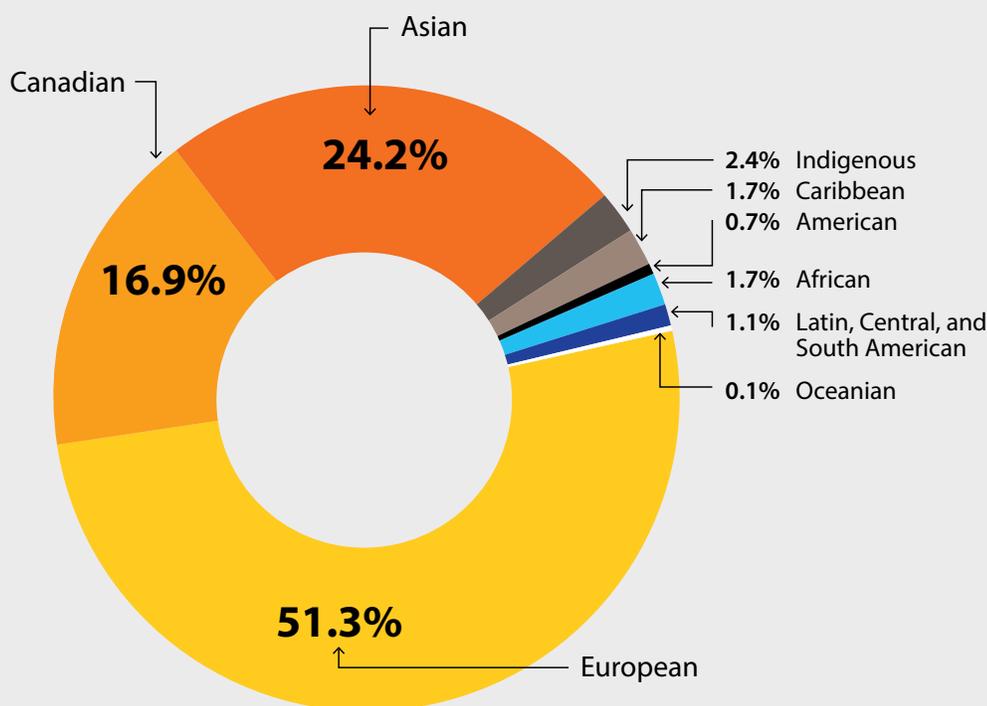
Figure 7. Ethnic origins of people living with dementia in 2020 according to the Landmark Study model, using 2016 Canadian census categories



By 2050, the projected proportion of people of Asian ancestry who are living with dementia is projected to increase substantially from 8% in 2020 to 24% in 2050 (refer to Figure 8 below). In other words, by 2050 one out of every four persons who develops dementia in Canada will be of Asian ancestry. Asian Canadians are a diverse population whose ethnic origins include Chinese, Indian, Filipino, Vietnamese, Lebanese, Pakistani, Iranian, Korean, Sri Lankan, Japanese, and more. Similarly, all groups within these analyses are made up of diverse groups of people.

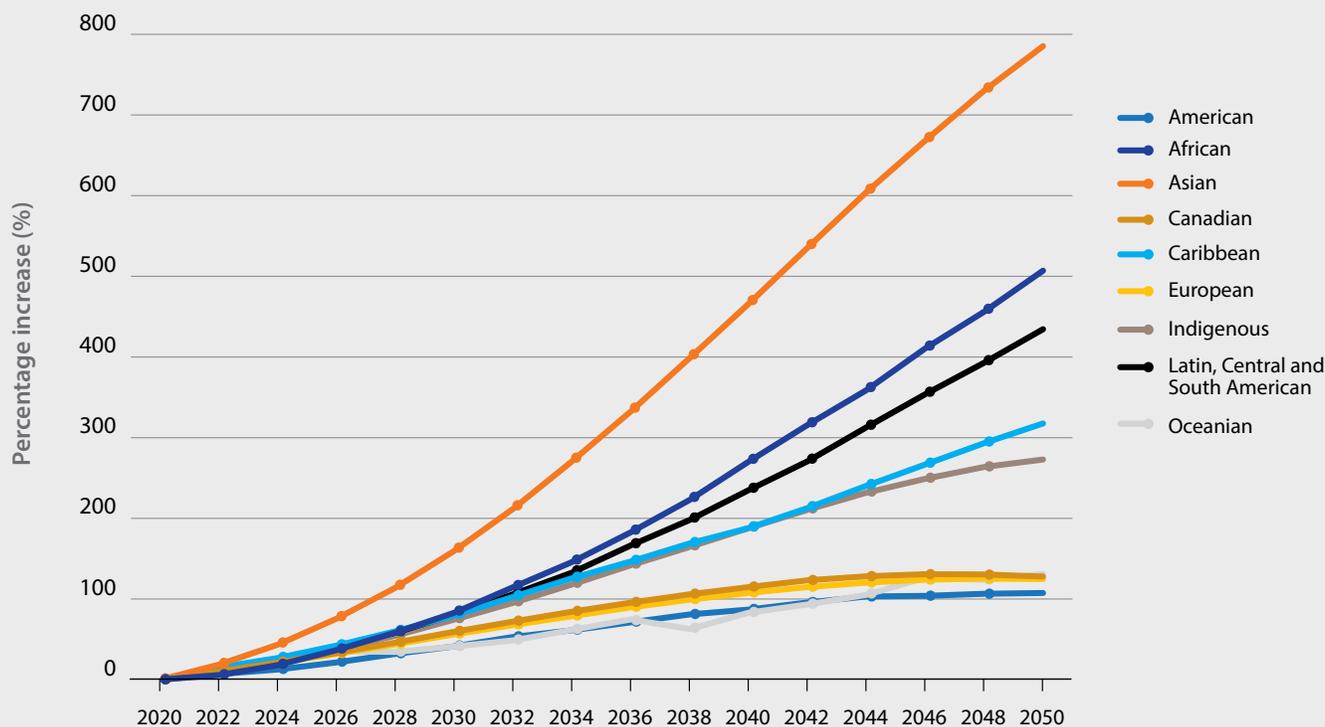
Also, projections by 2050 include a reduction of the proportion of people living with dementia who have self-reported European origins and people who have Canadian ethnic origins, along with increases in individuals with Indigenous, Caribbean, and African ethnic origins. These shifts reflect the diversity of older adults in Canada. With changing immigration patterns over the past number of decades, we are seeing a shift in the landscape of who develops dementia in Canada in terms of ethnicity and race.

Figure 8. Ethnic origins of people living with dementia in 2050 according to the Landmark Study model, using 2016 Canadian census categories



These shifts in proportions are a direct result of the differential rates of growth in population across ethnic-origin groups. Figure 9 illustrates the percentage increase from 2020. While there is growth across the board, the fastest growth occurs in individuals of Asian ethnic origins.

Figure 9. Percentage increase in number of people living with dementia from 2020 by ethnic origin, using 2016 Canadian census categories



With these differences in dementia growth and the appreciation that there are cultural differences in dementia care needs, health systems and health professionals will need to develop resources to better match the diversity of the population. This may include addressing language barriers, but should also include:

1. Efforts to reach underserved communities to address possible issues such as stigma, lack of knowledge of dementia, and different understandings of dementia.
2. Research to better understand how to meet both the care needs of individuals living with dementia and the needs of care partners who support them.
3. Developing culturally safe, accessible, and relevant resources and training for health-care professionals.

The Landmark Study model can also provide projections for the number of new dementia diagnoses across each ethnic origin category. According to the findings, the ethnic origin with the largest numbers of dementia people of European ancestry, followed by people of Asian ancestry and people of self-reported Canadian ancestry (refer to [Table 2](#)).

Table 2. Projected annual number of people with newly developed dementia in Canada (annual incidence) by ethnic origin and year (start of each decade), using 2016 Canadian census categories

ETHNIC ORIGIN	2020	2030		2040		2049	
	PEOPLE	PEOPLE	INCREASE	PEOPLE	INCREASE	PEOPLE	INCREASE
African	2,200	3,600	64%	5,200	136%	7,000	218%
Asian	12,600	29,500	134%	52,700	318%	71,200	465%
Canadian	25,100	36,100	44%	44,800	79%	44,100	76%
Caribbean	2,800	4,200	50%	5,400	93%	6,800	143%
European	72,700	101,700	40%	127,200	75%	129,300	78%
Latin, Central, and South American	1,700	2,800	65%	3,800	124%	5,100	200%
Indigenous	3,900	5,400	39%	7,400	90%	8,200	110%
Oceanian	200	500	150%	600	200%	800	300%
American	2,500	3,100	24%	3,700	48%	3,800	52%

Overall, these findings highlight the need to address, capture, and study diversity in all domains of dementia. From research studies to care systems, we need to work toward more inclusivity to optimize health and health care for all. More research exploring the lived experience of racialized groups with dementia is also needed to help understand qualitative factors impacting diagnosis, treatment choices, and access to health-care systems as well as to community resources.

With these findings, we have only begun to scratch the surface of the dementia differences that exist across ethnic and racial groups in Canada. Further work is needed to develop our understanding of the many differences that exist regarding the experience of dementia across population groups. Through intentional design, Canadian policies, programs, services and supports need to be tailored to meet the different needs across groups.

FACES OF DEMENTIA

ARLENE'S STORY

Here, Arlene speaks about being a caregiver during her parents' experiences with dementia, and she provides perspective on the need for culturally appropriate care and other dementia-care urgencies through a health-care worker lens.



"MY father was a lawyer in the Philippines, and my mother was an accountant. Both immigrated to Canada in 1974. My dad sacrificed a lot, because he had to leave his legal profession, which was his passion, to pursue a better future for his children in Canada. An aunt sponsored us, then we lived in a one-bedroom apartment, and a couple of months later we were able to get our own place.

For several years, Dad worked as a mortgage officer, then for the government for a bit, and on the side he pursued paralegal work. He assisted numerous Filipino Canadians to establish businesses, as well as incorporate associations and key organizations like the Philippine Chamber of Commerce and the Filipino-Canadian Nurses Association. He sat on the board of Scarborough Community Legal Services to help newly immigrated Filipino professionals secure employment and pursue accreditation of their degrees in Canada. He believed in unifying the Filipino

community and provided a platform for them to be recognized and taken seriously in Canada. At the age of 59, under Bob Rae's provincial leadership (which sought in part to increase employment equity in the justice system), my dad became the second Filipino Canadian justice of the peace of Ontario.

In 2017—he would have been 83 at the time—we started noticing some changes. He was making some poor decisions when driving. Once, he got lost, and he was driving around Scarborough (where we live) for five hours. He didn't take his insulin for a month. And he had a stage of delirium.

My mom, at the same time, was starting to have some memory issues as well. Her onset seemed to come after she had shingles, and other complications from her arthritis and newly diagnosed diabetes. She was

Story continues on next page

Photo: Courtesy of Arlene and family.

“I think I’d personally like to see more culturally specific approaches to informing people with dementia about dementia. As my dad’s dementia progressed, he kept defaulting to Tagalog. Having a language barrier may influence diagnosis or in explaining the condition to the person and the family, to help prepare them for what to expect.”

registered in a falls and balance clinic, and later participated in a memory clinic, as she was starting to forget things. For much of her life with dementia, she has actually had a very crisp memory—remembering birthdates, addresses, and activities when we were young. But her dementia challenges affected her short-term memory, and she would forget when to take medication, how to sequence activities, and what happened at recent events.

During the first few months of COVID, they stayed with me until it was safe for them to return to their condominium. We noticed then, as their memory declined, that they would require full-time care, which became a family affair complemented by caregiving support. Then we found out in December 2021 that my dad’s lung cancer had returned from 20 years prior.

While his dementia progressed, and he began to speak less and less, we still had special moments when Dad would surprise us with his wit and charm, making jokes and then more seriously asking us about our work and family. For the most part, while little was said, Dad just seemed happy, content, and enjoyed spending time with my mom. A short time before he died, he had the wherewithal to know and say in Tagalog, “Thank you, I want you to know that I’m really grateful for the care that you’ve provided me and Mom.” After I recorded that, I was joking with him. He said, “Did you record it?” I said, “Yes.” He said, “Okay, good. That’s what I want.”

Faith is important to my family; we would do the rosary, and Dad would say it with us. But towards the end, he was very weak. I remember us being with a priest; we did last rites the week before he died. My dad was so weak at that time. But he was present. He knew. He wasn’t eating. He was in a lot of pain. We were giving him lots of medication. Soon after, he passed.

Both my sister and I work in health care, and we have been fortunate to have access to physicians for those initial memory assessments for our parents and for other things, like social workers, palliative care information, neurology and more. But the actual process of caring for my parents has been fairly complex. My parents have been very fortunate to have three daughters to care for them—from health to finance to property and any administration required to manage my mom’s affairs. I think this is commonplace within the Filipino community, and an unsaid expectation and cultural value—to care for your elderly.

The care of my parents has truly been a family affair. Now, my mom lives part-time with each of us—taking turns living with each daughter. We take turns to be able to provide respite support to each other, and importantly to share some quality time with our mom. To help us, we have caregivers for 10 hours a day while we are working. When I say “family,” I also mean that we have been able to hire caregivers who are family—one is my best friend, another is my cousin, and the third is the nanny who took care of my boys when they were young. In our eyes, they are our family. It has always been important for us, and especially my mom, to be cared for by people who provided a sense of familiarity.

I think I'd personally like to see more culturally specific approaches to informing people with dementia about dementia. As my dad's dementia progressed, he kept defaulting to Tagalog. Having a language barrier may influence diagnosis or in explaining the condition to the person and the family, to help prepare them for what to expect. We need more physicians pursuing geriatric psychiatry, and we need to support training for those from diverse communities. In the interim, if that is not available, maybe have an advanced practice leader, social worker, or something like that—someone who comes in after the doctor speaks to the family, who has a conversation from a cultural perspective.

For example, in my culture and in my family, I have no problem having my 16-year-old and my 15-year-old take care of my mom and dad. Other cultures might say, "Oh they're too young, they can't do that." Another example: there are a lot of educational materials for dementia that talk about "the caregiver" as a single person, rather than as a network of family and friends. We need more experts and resources that are culturally appropriate.

I'd also say that, in the health-care system, we really need to take a hard look at patient support and dementia—and what that means for home care, where resources are very limited right now. We need more changes, more caregivers trained up and ready. What I think would be nice is if we could have some government subsidies to support home care for people with dementia. In a lot of ways, home care is about dignity—especially from a cultural perspective. Most long-term care homes don't offer our food or other ethnic foods. If you're at home, you can eat your cultural foods. You're still a person. You exist.

We also need to improve dementia care navigation. I've had a cousin reach out to me because he knows I work in health care, and he was having issues getting his dad diagnosed. I told him what he needed to do. But what about for people who don't have someone like me in their family? How are they supposed to know where to go get a memory test?

Also, we still have a shortage of family care practitioners, many physicians are retiring, and that influences dementia care and diagnosis right now. We're losing continuity of care. People are going to have to figure out how to do it on their own. But no one, really, should be alone with this."

"A short time before he died, he had the wherewithal to know and say in Tagalog, 'Thank you, I want you to know that I'm really grateful for the care that you've provided me and Mom.' After I recorded that, I was joking with him. He said, 'Did you record it?' I said, 'Yes.' He said, 'Okay, good. That's what I want.'"

FACES OF DEMENTIA AMA'S STORY

Ama is a caregiver for her father, who is living with dementia following a few strokes. Here, she talks about the importance of family and health-system support, the need for advocacy, and other aspects of her family's experience so far. She lives in Alberta.



Ama's father

"MY dad was a hard worker his entire life. He was an investment banker for many years, and he retired from that and took up a whole new career, where he started doing carpentry, and then scaffolding. He also used to work for a group home and take care of kids with special needs. And he also used to work in agriculture. He's got a few degrees. He'd always worked, and he'd always been a productive person.

Over the years, we noticed a decline in his health in general, and not being as productive. My mom started noticing that he wasn't paying bills on time, or he was putting additional money on bills because he didn't want anything to be past due.

He started burning things on the stove. I remember there was one time he pulled a bag from the fridge and put it in the microwave, thinking it was food, but it was actually his insulin.

I think it was when his main caregiver, my mom, went out of town two years ago to take care of her own mom for a few months that we—me and my sisters—saw more of a big difference and that he really wasn't okay on his own. I went to the house and I couldn't believe how run down it was. It was a real mess, and he just couldn't see anything wrong. He'd lost sight of what you need to do to take care of yourself.

Photo: Courtesy of Ama and family.

“He can remember, “Oh, it’s end of March, time to do my taxes!” And he will get his taxes all organized and ready. So he can function very well in certain areas, but in other areas he’s just not on top of it.”

So that’s when we arranged all these services to help, especially when my mom is away taking care of her mom. Now, we have home care come three times a day, because if nobody’s there, he won’t remember to take his medication, he may not eat, and he may overeat (which is harmful since he is diabetic). Home care also checks his blood pressure and his blood sugar. And we’ve hired someone to come in and clean once a week and prepare meals for him.

It’s still weird for me—it’s hard for him to grasp an understanding of what he’s sick with, and what he needs to do to take care of his health, but then he can remember, “Oh, it’s end of March, time to do my taxes!” And he will get his taxes all organized and ready. So he can function very well in certain areas, but in other areas he’s just not on top of it.

He got his licence taken away last year after they did a CT scan or MRI. He was becoming more forgetful and slow to react, so it wasn’t safe for him [to drive]. This was a big blow because driving was kind of the last part of his independence. He really loved to drive. It was a way for him to get out of the house. Now he’s home all the time and doesn’t have much motivation to get out and do things. It’s more us, his kids, and my mom, taking the reins and making sure he goes to appointments, and making sure he’s active.

Support is a big thing. I don’t know how people do this without help! My dad is very blessed—he has kids who all live in the same city. I’m glad I have my sisters to help. I couldn’t even imagine trying to do this by myself.

It’s also important to advocate for your family member. You have to have a voice and speak up! Home care is helpful but it’s not perfect; you only qualify for so much, so if you want more of one kind of service, they have to take something away. In some cases, we’ve requested things done by his doctor and they haven’t gotten back to us for days or weeks.

It’s frustrating, it’s time consuming, but that’s the reality: If you’re not happy with things and you need a change, you need to speak up. We are in touch with his case manager quite often, and his home care agency too, calling doctors and nurses, and following up if we don’t hear back.

I’d also recommend keeping notes—logs of what’s wrong, who the physicians are, where the person goes for care. Having all that stuff organized is helpful because it can get overwhelming. My sister is very organized in that aspect, she has a flowchart of my dad’s entire care plan.

If asked what I’d want other people to know about our dementia experience? Well, it’s not easy. I guess I would want people to cherish the time that they have now. Health is truly wealth. But also know that some things are out of your control. And if you don’t have family to help you, a lot of work likely goes into figuring out where you can get help, and what services are available to you.”

FACES OF DEMENTIA NAVJOT'S STORY

Here, family care partner and researcher Navjot Gill talks about experiencing barriers to culturally sensitive, South Asian–inclusive dementia care with her grandmother, who is living with dementia, and her parents, who are care partners. She also discusses her work in dementia research, trying to make future services better and more inclusive.



“**MY** journey with dementia started when my grandmother was diagnosed back in 2016. At that time, I had an understanding of what dementia was through my college studies in physiotherapy. Initially, when my grandmother was diagnosed, it wasn't that bad, in a way. You know, she still got by. But as it progressed, it just got to a point where one of us had to be at home all the time to ensure she was doing okay.

Early on, I tried explaining to my parents what dementia was. And that's when I started to see that there were many programs and resources in our area for people living with dementia, but they were not culturally appropriate.

Photos: Courtesy of Navjot Gill and family.

“What we need are more resources—on paper and on video—that have South Asian representation.”



I saw, for instance, information about sleep issues and dementia, and I thought, “Oh, this might be useful. Let me see if I can show my parents.” They were trying to manage some of that, but because it was in English and my parents aren’t completely fluent in English, that didn’t work.

And then I was like, “Okay, let me see if I can find something in Punjabi for them.” And we really needed that in terms of my parents’ understanding behaviour, such as losing one’s way and restlessness in the late afternoon. For instance, my grandmother often talked about her “babies,” not realizing they were grown-ups. In her mind, she is in her 40s, and my parents were like, “What are you talking about? Like, you

know, your daughters are married, you have grandchildren, you have great-grandchildren.” They would correct her every time. And I was like, “This is not what you’re supposed to do.” But there was no way I could explain it to them.

So I basically just searched, “Explain dementia in Punjabi.” And the UK Alzheimer’s Society has many resources. But their health-care system is different; their subculture is different; everything is different. I couldn’t really bring that over to my parents here in Canada and be like, “Okay. This fits.”

In the end, I did show them a dementia video that had been translated into Punjabi. It showed this European couple living in the suburbs, with a robotic voiceover in Punjabi—so the language was there, but my parents couldn’t connect with that; they didn’t see themselves being represented.

To me, that video, and others like it, have also reinforced this idea that exists in some South Asian communities—that dementia is a European disease and that it doesn’t happen to people of colour. In fact, after watching that video, my dad was like, “See, I told you, it’s a White couple.” So that put them off.

Story continues on next page

What we need are more resources—on paper and on video—that have South Asian representation. Not just a robotic voiceover. We need something that normalizes that a brown person can have dementia too. And it needs to address specific behaviours and tips, not just describe the condition.

Luckily, there is now work being done. Sheridan College [and the Alzheimer Society of Peel] recently released a dementia toolkit in Hindi, which kind of explains different scenarios and what you should be doing.

But there's still a long way to go in terms of services being inclusive and culturally sensitive.

I worked as a program assistant with the Alzheimer Society, so I had first-hand experience of the amazing programs that they had, and I would always wonder, "What if my grandma could be a part of this?" But if I tell her to go play bingo, well, bingo is a Western concept. She didn't grow up playing bingo. She never understood bingo. I can't just push her into these things.

Then also issues with home care services. We had a PSW come in, but the PSW didn't speak our language. She would speak English and then my mom—who was working full-time, as was my dad—would still have to be there to translate and manage everything. Instead of PSW relief being a time when my mom could get a break from providing care, she absolutely had to be there—and grandma would get even more anxious, in fact, because the PSW was speaking in English and then my mom was translating. It wasn't very clear and was concerning to her.

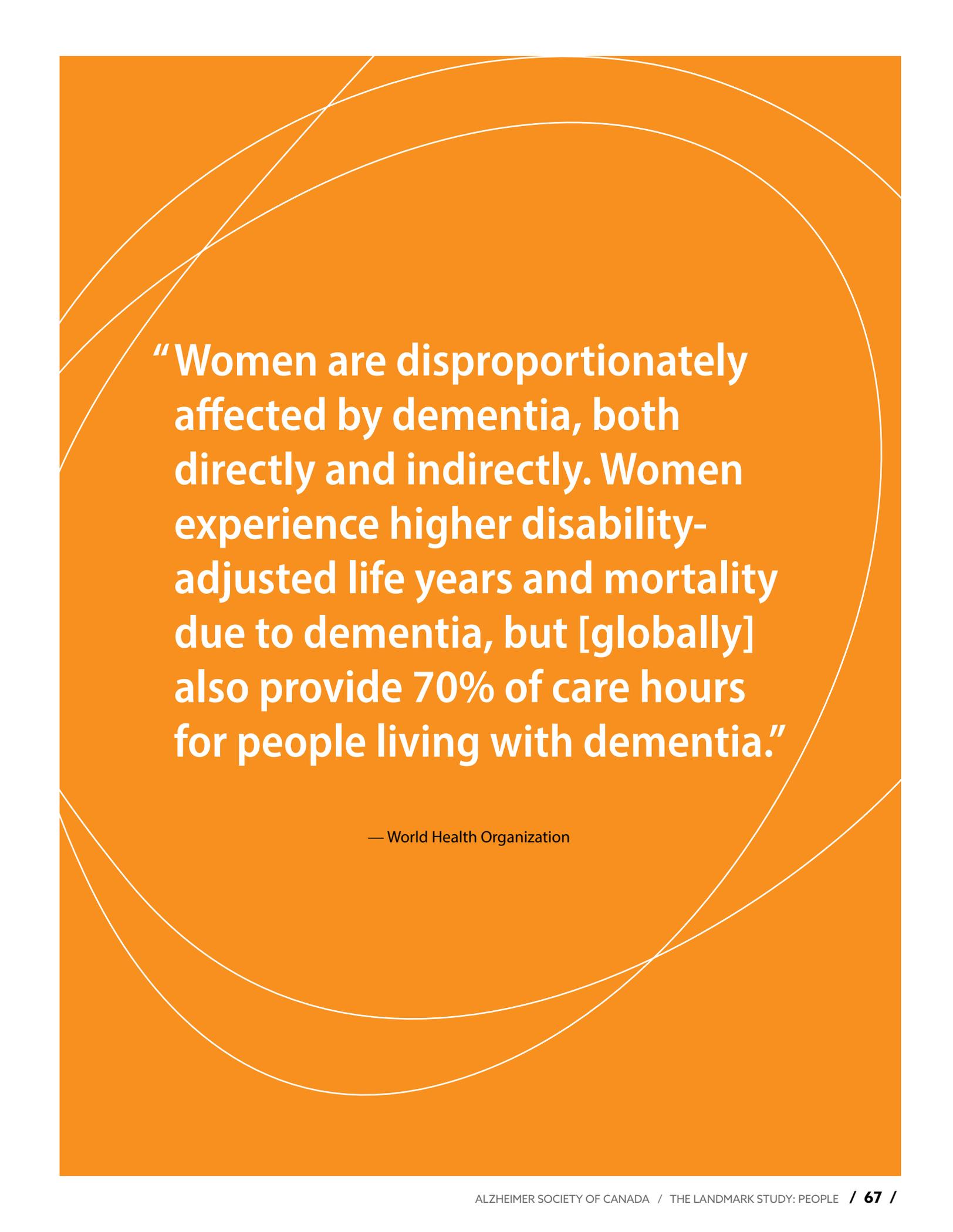
So my parents don't have any respite. They don't have those care partner support groups they can go to because we don't talk about it in our community. It's a huge stigma.

And there's also a stereotype some health professionals have around filial piety: "If this person is brown, they're going to take care of their own." So health workers don't really give out as many resources to our families; they just assume that they don't need it when that's not the truth.

In truth, our families need to hear, "We're not questioning your ability to provide care. We're telling you the truth that you can't do this on your own. There's no way you can manage your own life and take care of someone living with dementia full-time. It would be best if you had care. You need to be able to ask for help, ask for resources, and advocate for yourself."

That's where my research comes in. It is focused on exploring the experiences of South Asian Canadians living with dementia and their care partners. I'm interviewing people living with dementia and their families, offering interviews in English, Punjabi, Hindi, and Urdu, starting with the languages I can speak—to make the research more inclusive. I'm also talking to health professionals to see their understanding regarding culturally competent care and how we can make that shift.

I'm not saying my research will bring a wave of change. But potentially, it will start the groundwork, which still needs to be added."

The background is a solid orange color. Overlaid on this are several thin, white, curved lines that form a large, abstract circular shape, resembling a stylized 'C' or a partial circle. The text is centered within this shape.

“Women are disproportionately affected by dementia, both directly and indirectly. Women experience higher disability-adjusted life years and mortality due to dementia, but [globally] also provide 70% of care hours for people living with dementia.”

— World Health Organization

SEX AND GENDER DIFFERENCES IN DEMENTIA

There are many distinctions in dementia that matter when it comes to sex and gender.



Both sex and gender can shape a person's dementia experience, from prior to onset, through treatment and beyond. There are sex and gender differences in the number of individuals affected by dementia, the risk factors for developing the condition, how symptoms are expressed, and the needs for care and caregiving.

When seeking to understand why these differences occur, it is important to acknowledge that both biological and social factors play a strong role. Researchers have come to recognize that both sex and gender are important characteristics to consider when examining dementia outcomes and care needs.

Definitions of sex and gender used by Statistics Canada as of 2021

"Gender refers to an individual's personal and social identity as a man, woman or non-binary person (a person who is not exclusively a man or a woman). Gender includes the following concepts: gender identity, which refers to the gender that a person feels internally and individually; gender expression, which refers to the way a person presents their gender, regardless of their gender identity, through body language, aesthetic choices or accessories (e.g., clothes, hairstyle and makeup), which may have traditionally been associated with a specific gender. A person's gender may differ from their sex at birth, and from what is indicated on their current identification or legal documents such as their birth certificate, passport or driver's licence. A person's gender may change over time. Some people may not identify with a specific gender" (Statistics Canada, 2021a).

"Sex at birth refers to sex assigned at birth. Sex at birth is typically assigned based on a person's reproductive system and other physical characteristics. Sex at birth may also be understood as the sex recorded at a person's birth, for example, what was recorded on their birth certificate" (Statistics Canada, 2021b).

This chapter and the data in it reflect the fact that there are slightly different terms of reference for sex and gender, even at the national level, and that research and language continues to evolve to better reflect the realities and lived experience related to gender and sex.

Given this context, in this chapter we will outline some of the sex and gender differences in dementia. This will be followed by some of the findings related to sex at birth from the Landmark Study (no gender data was available for those study analyses).

Why do sex at birth differences in dementia rates exist?

Across many high-income countries, females outnumber males in dementia diagnoses at a rate approximately two to one (Niu et al., 2017; Rajan et al., 2021; Yoshitake et al., 1995).

This difference in dementia numbers between the sexes is often attributed to difference in life expectancy. In Canada, on average, females live four years longer than males—83.9 years versus 79.8 years according to Statistics Canada (Bushnik et al., 2018). And since age is the strongest risk factor for dementia in general, the lifetime risk of dementia is then greater for females. However, there is much more to the story of sex differences in dementia than just differences in lifespan.

While it is known that women across high-income countries experience more dementia than men, it is less clear whether women are at higher risk of developing dementia after accounting for differences in longevity. Some studies have found that women are at greater risk after accounting for life expectancy; other studies have found no such difference between the sexes (Mielke et al., 2022).

For example, research studies in the United States have repeatedly found no difference in the risk of onset of dementia (Bachman et al., 1993; Edland et al., 2002), whereas European reports have found women to be at a higher risk (Fratiglioni et al., 1997; Andersen et al., 1999).

These mixed results indicate that there are important differences between study populations and geographic locations that may be influenced by sex and gender (Andrew & Tierney, 2018). Based upon the many known differences between the sexes in terms of both biology and their engagements with the social, political and economic determinants of health, we believe that it is critical for dementia research that sex and gender differences be studied in much more depth.



Females have risk factors for dementia beyond longevity

Sex differences in dementia risk factors may help to explain why so many more females develop dementia in late life.

If you look at the scientific literature on dementia, sex differences can be found in many areas:

- genetic risk factors (APOE e4 confers greater risk in females; Altmann et al., 2014)
- rates of depression (more common in females; Kessler et al., 1993)
- levels of frailty—“frailty” is a term used by medical experts to describe a state of increased vulnerability to stressors (females report higher levels of frailty; Hubbard, 2015)
- prevalence of cardiometabolic risk factors (females experienced greater risk for all-cause dementia; Blanken & Nation, 2020)
- sleep apnea (more common in males; Bixler et al., 2001)

There are also sex-specific risk factors for dementia in females, including high blood pressure during pregnancy (preeclampsia; Fields et al., 2017), menopause (Galea et al., 2017), and bilateral oophorectomy (removal of both ovaries and both fallopian tubes) prior to age 48 without hormone replacement (Rocca et al., 2014).

A sex-specific risk factor for dementia in males is cumulative androgen deprivation therapy for prostate cancer (Jayadevappa et al., 2019) which is associated with higher risk of developing dementia.



Gender roles and experiences impact risk of dementia

Risk factors can also be related to social constructions of gender roles and differences across genders.

From low education (women have historically faced systemic inequities in access to education; Hasselgren et al., 2020) to reduced occupational opportunities (Qiu et al., 2003), many studies have identified dementia risk factors that align with restrictions around gender expectations, discrimination and roles.

Conceptions of gender- and sex-related risk factors are also growing and changing as sexism and bias within the research field itself is being confronted. For instance, at one point in time, traumatic brain injury was believed to be a risk factor for dementia primarily for men due to an assumed higher likelihood of being involved in physical altercations, accidents, military service and contact sports.

However, some women researchers and the Pink Concussions group summits (begun in 2016) have more recently found that women are exposed to more traumatic brain injury risk via intimate partner violence than men (Haag et al., 2022; Valera et al., 2021; Pink Concussions, n.d.-a).

They have also highlighted earlier data from the American Medical Society for Sports Medicine (2012) showing that in sports with similar rules, female athletes sustain more concussions than their male counterparts; in addition, several studies show that female athletes experience or report a higher number and severity of symptoms, as well as a longer duration of recovery than male athletes (Pink Concussions, n.d.-b).

Thus, it's possible a different source and level of the risk related to traumatic brain injury—and in turn, dementia—is connected to gendered experiences in different ways than previously thought.

In another example, depression in later life (over the age of 65) is a known risk factor for dementia. Recently, research focusing on younger women has suggested that experiences of gender discrimination and sexism are linked to higher rates of depression (Vigod & Rochon, 2020; Stepanikova et al., 2020; Young Women's Trust, 2019). More research is needed on older age groups in this respect.

Likewise, a recent World Health Organization review of men’s health issues in the European region (2018) highlighted a few reasons depression may be underreported and underdiagnosed in men—reasons partly related to ideas and restrictions in roles of masculinity: “Analysis of coping mechanisms show that men (more than women) tend to cope with their problems and dilemmas by taking refuge in addictions or ignoring needs for treatment. Consequently, depression symptoms in men often remain undiagnosed” (Emslie & Hunt, 2009).

And clearly, again, more research is needed about the intersections of sexism, ageism, age, sexuality, class, culture and ethnicity (among others) in regard to even this one major dementia risk factor—depression—to better understand the complex ways gender and gender discrimination or roles can influence it, and the consequent dementia risk.

In Canada, a process called Sex- and Gender-Based Analysis Plus (SGBA+) has been promoted by federal health research funding bodies (Government of Canada, 2023). SGBA+ aims to ensure that researchers closely consider factors in their projects related to sex and gender, as well as factors related to race, ethnicity, religion, age, and mental or physical disability, so that the results are impactful to all people living in Canada and relevant to the diversity of the population.

Box 5. Some characteristics where sex and gender differences can impact dementia risk

DIFFERENCES THAT CAN IMPACT DEMENTIA RISK	
SEX DIFFERENCES	GENDER DIFFERENCES
<ul style="list-style-type: none"> + Stress response + Brain structure + Inflammation and metabolism + Pregnancy + Menopause + Frailty + Genetics and epigenetics + Prostate cancer + Obstructive sleep apnea + Hormones 	<ul style="list-style-type: none"> + Experiences of stress + Education + Occupation + Diet and physical activity + Smoking + Alcohol use + Social isolation + Gender-based discrimination + Traumatic brain injury

Why is this breakdown important? There are still many more important sex and gender differences that need to be better understood in the dementia sphere. The mechanisms, pathways and risk factors for dementia differ across sexes and genders—and they merit further investigation, as these differences may have consequences for future treatments and for fully understanding how dementia develops in humans.

The clinical presentation of dementia can differ across sex and gender

Each individual experiences dementia in their own way. However, when we examine the clinical presentation of dementia by sex and gender, we can find patterns that indicate differences in how dementia presents in terms of its progression, changes in behaviour, responses to treatments, and even in the diagnosis of the condition itself (refer to [Box 6](#)).

Box 6. Some of the clinical aspects of dementia where sex and gender differences have been found to occur

CLINICAL ASPECT	DETAILS
Rate of progression	<ul style="list-style-type: none"> ✦ Risk of mild cognitive impairment is generally higher in males (Brodaty et al., 2013; Roberts et al., 2012). ✦ Some studies suggest women progress faster or get a later diagnosis when compared to men (Sinforiani et al., 2010; Laws et al., 2016).
Changes in mood, personality and behaviour	<ul style="list-style-type: none"> ✦ Females experience a broader range of changes in mood, personality, and behaviour in relation to their dementia (Tao et al., 2018). ✦ Males can experience more severe apathy, whereas females can have more depressive symptoms, psychotic symptoms, delusions, and aberrant motor behaviour relative to males (Eikelboom et al., 2022).
Response to treatment	<ul style="list-style-type: none"> ✦ Research subjects for intervention studies have historically been primarily male, ignoring important sex and gender differences in dementia. ✦ Sex and gender differences may influence both responses to treatment and the decision to provide certain treatments (Ambrosino et al., 2020). ✦ Prevention and treatment may require a different approach depending on one's sex (Mielke et al., 2014). ✦ Frailty, on average, is higher in females, and higher levels of frailty can impact disease management decisions and ability to tolerate some treatments (Siebert et al., 2021).
Diagnosis	<ul style="list-style-type: none"> ✦ Sex and gender differences are seen in preclinical signs of dementia (impairment in memory and instrumental activities of daily living; Pérès et al., 2011; Cherbuin et al., 2015). ✦ Diagnosis relies on functional decline, and gendered differences in function after retirement can make it easier to notice a change in women (traditionally doing more work in the home) versus in men (if they focused function on working life and have limited functional expectations after retirement; Andrew et al., 2018).

People’s identities often can be consumed by a dementia diagnosis

When it comes to the experiences of people living with dementia, sex and gender are often not discussed. Gender neutral terms are often used, such as “person living with dementia” and “family caregiver.” Policies and programs often do not consider gender or sex, despite the many differences that can be found in dementia.

Research that includes sex and gender has found that the lived experiences of women and men can differ on health outcomes, social interactions, and service use (Bartlett et al., 2018), among other areas. Again, more research is warranted on the experiences of non-binary people in this respect.

A 2023 study sought to better understand how gender affected women’s dementia experiences (Wiersma et al., 2023). The women interviewed for this study discussed caregiver roles, perceptions of gender differences, the impact of dementia on families, and women’s strength and resilience. Wiersma and colleagues emphasize the importance of developing our understanding of diversity and gendered experiences for those diagnosed with dementia. These authors conclude that people’s identities can often be consumed by a dementia diagnosis and may weaken the important roles that women value in their lives.



Women and men have unique caregiving challenges

People living with advancing dementia often rely on a family member or friend to provide support and ongoing care. More than half of dementia care partners are women. Refer to Chapter 2 in the first Landmark Study report for a more detailed description of caregiving for people living with dementia (Alzheimer Society of Canada, 2022).

Men and women have unique challenges and needs when caring for people living with dementia. However, there has been little exploration of the sex and gender differences of care partners for people living with dementia. Caregiving is often described from a woman’s perspective, and women are more likely to take on caring roles than men (Sharma et al., 2016). The few studies that have focused on gender and sex differences in caregiving have focused on challenges of caring and coping strategies (Bartlett et al., 2018). Few studies have addressed the unique challenges non-binary people experience around caregiving (for more on this, refer to the following section).

One recent systematic review highlighted evidence of sex and gender differences in caregiving stress, the mental health of care partners (depression, psychological distress, guilt), and the physical health status of care partners (comorbidities, sleep, inflammation). Females were reported to experience greater caregiving challenges and depression compared to their male equivalents. However, the authors also reported that when studies accounted for other characteristics of the caregiver, findings on sex differences were less conclusive (Xiong et al., 2020). This conclusion underscores the importance of recognizing intersectionality and the need to consider the interconnected nature of social identity characteristics (including gender, class, and race) in dementia research. Refer to [Chapter 3, page 54](#), for more information on intersectionality.

Some other insights into intersectionality in dementia caregiving can be found in research by Dr. Danielle Alcock, member of Chippewas of Rama First Nation. Her 2019 doctoral research examined Indigenous female caregivers' experiences of caring for a family member with dementia. She found, among other insights, that "the gendered caregiving role needs to be examined to create financial supports and programs that contextualize that women are predominantly the caregivers for loved ones with [Alzheimer's disease and other dementias] and this is applicable in Indigenous communities where women are providing care with minimal to no resources."

Cultural, health, family and gender experiences can also create different kinds of challenges linked to gendered caregiving. A Chinese study about the experiences of male dementia caregivers found that sons who provided support to a parent living with dementia experienced more challenges when that parent had reduced functioning and apathy (Tsai et al., 2022). This same study also found that father and son caregivers experienced stress differently depending on the symptoms that were being expressed by the person living with dementia.

In this, as in other dementia realities, there is no one, single, universal experience—intersectionality and diversity of experience must be honoured both in future research and support planning.

Dementia research about non-binary and trans people is growing

There is a lot of necessary work to do to better understand sex and gender differences in dementia and dementia care. In this chapter we've highlighted a few of the many issues, and we want to acknowledge that dementia research at large hasn't yet begun to address the challenges and experiences that may face intersex, non-binary and trans people who develop dementia.

Some of the limited research that has looked at dementia risk factors in non-binary and trans people shows that they experience health disparities and additional psychosocial stressors that increase risk of cognitive impairment in later life (Cicero et al., 2021; Lambrou et al., 2021).

Dementia care concerns for trans and non-binary people also have some distinctive aspects. As David, a non-binary person living with dementia, puts it in a recent European report, "[Health and social care professionals need to] start by acknowledging the absolute failure of the healthcare system to adequately train healthcare providers in delivering holistic, integrated care to older queer folk that does not erase their sexual and gender identity. The 'we treat everyone the same' model is bullshit" (Alzheimer Europe, 2022).

Elsewhere in the report, David adds, "I am VERY concerned about not only homophobia/transphobia in eldercare, but also heteronormativity that is pervasive and is every bit as harmful. I want care services that acknowledge my sexual and gender identity as a central component, not as some sort of afterthought, or worse, totally ignored."

In Canada, some positive strides have been made to expand research and improve health-care training. In November 2022, Egale Canada and the National Institute on Ageing launched the National Resource Centre on 2SLGBTQI Aging. This centre supports and aggregates resources and research related to two-spirit and trans people's experiences of dementia, among other topics. In addition, one February 2023 resource, *Acting in Allyship with 2SLGBTQI People Living with Dementia: Guiding Principles for Healthcare and Social Service Professionals*, urges health providers to call out transphobic comments in their workplaces when they hear them, among other recommendations for making dementia care more inclusive.

More research and tools on this topic are needed. For more about sexuality and dementia in particular, please refer to [Chapter 6](#).

NEW FINDINGS FROM OUR LANDMARK STUDY

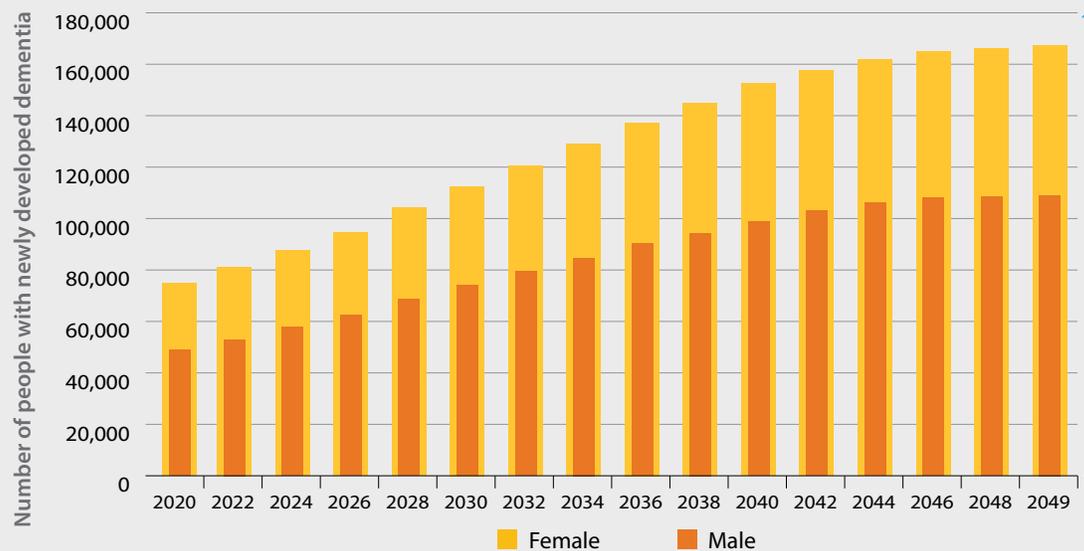
The Landmark Study is based on findings from a simulation model that combined data from the 2016 Statistics Canada Census and findings from the literature to estimate the impact of dementia in Canada over the next 30 years.

The results portrayed in this section only focus on differences in sex (female and male) as we were not able to incorporate differences in gender into the model due to limitations in the available data.

More females than males by almost a two-to-one ratio

The number of females who will be diagnosed with dementia is projected to exceed males by almost a two-to-one ratio. In 2020, an estimated 61.8% of persons living with dementia in Canada were female. By 2028, if current trends prevail, over 100,000 women will be diagnosed with dementia each year in Canada (refer to Figure 10 below).

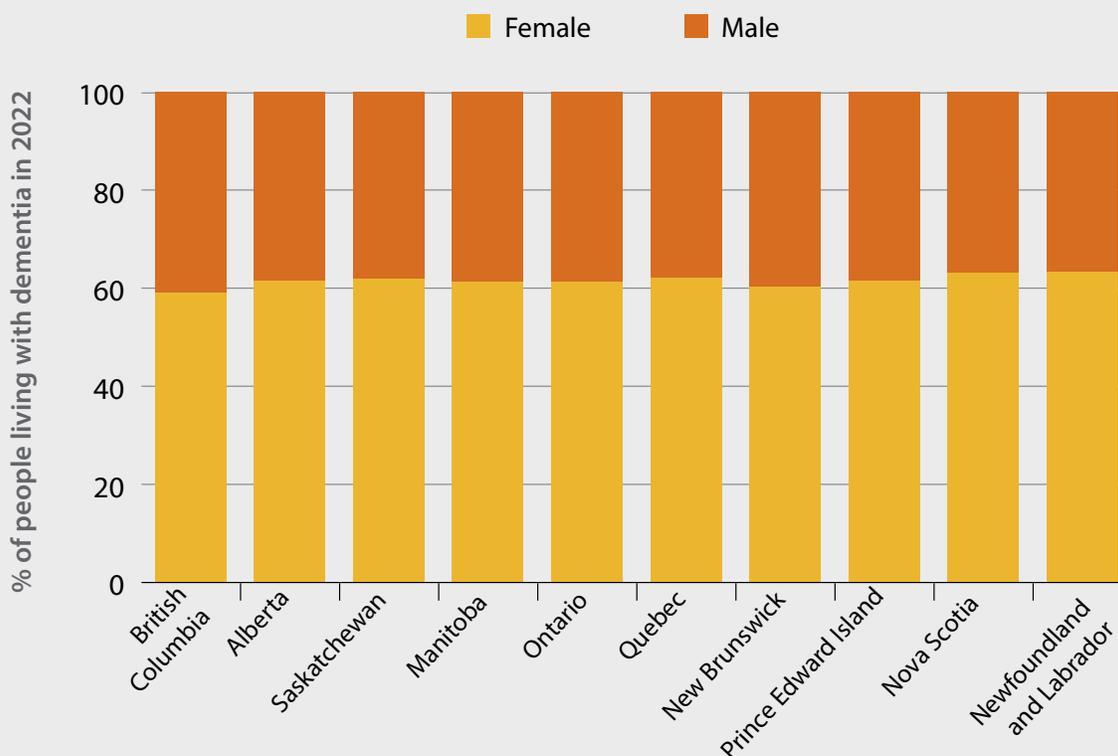
Figure 10. Annual number of people with newly developed dementia by sex, 2020 to 2049



Note that this figure and the model's overall analyses do not account for individuals who are born intersex. Statistics Canada does not currently collect information on intersex people for reasons related to the small size of the intersex population and challenges in identifying intersex people. Further, data on dementia outcomes for those born intersex is lacking. Approximately 1.7% of the population is born with intersex traits. While this may seem like a small percentage, from a national perspective, this is over 500,000 individuals (United Nations Free and Equal, n.d.).

This pattern of differences between the sexes is consistent across all provinces of Canada, with only small variations that are dependent on the makeup of the province’s population (refer to Figure 11). Canada isn’t alone in this trend. When we look at dementia rates from the United States (Alzheimer’s Association, 2023) and Europe (Niu et al., 2017), females also experience dementia more often than males by a rate of almost two to one.

Figure 11. Number of people living with dementia in 2022 by sex and province



The one population in Canada where this pattern might not hold true is in Indigenous people. While much work is still needed to fully understand dementia in the First Nations, Inuit, and Métis communities of Canada, one study by Jacklin and colleagues (2013) indicated that Indigenous males may have a higher risk relative to Indigenous females. This finding is consistent with what has been found in First Nations people of British Columbia (British Columbia Provincial Health Officer, 2009) and in Indigenous people in Australia (Smith et al., 2008).



When looking at the projections over the next three decades, we can expect the sex difference to widen slightly from 61.3% females in 2020 to 62.8% in 2050.

Based on current trends, by 2050 over 1,000,000 females living in Canada will have dementia.



Table 3. Number of people living with dementia (all ages) by sex at start of each decade (2020–2050)

YEAR	FEMALE	MALE	TOTAL	FEMALE %
2020	366,400	230,900	597,300	61.3%
2030	610,900	379,700	990,600	61.7%
2040	900,700	541,100	1,441,700	62.5%
2050	1,075,300	637,100	1,712,400	62.8%
INCREASE FROM 2020 TO 2050	708,900	406,200	1,115,100	1.5%

Table 4. Number of people with newly developed dementia (all ages) by sex at start of each decade (2020–2049)

YEAR	FEMALE	MALE	TOTAL	FEMALE %
2020	74,900	48,800	123,800	60.5%
2030	112,600	74,200	186,800	60.3%
2040	152,400	98,700	251,100	60.7%
2049	167,200	109,000	276,300	60.5%
INCREASE FROM 2020 TO 2049	92,300	60,200	152,500	0.0%

Table 4 above highlights the expected number of new cases each year at the start of the next three decades. By 2030, over 100,000 females will develop dementia each year, whereas new diagnoses for males will surpass 75,000 new cases each year after 2030.

In addition to females experiencing dementia at much higher overall numbers compared to males in Canada, there are several important differences found between the sexes in relation to dementia. This includes differences across a wide range of key factors, including underlying biology (e.g., hormones, brain structure), prevalence of risk factors (e.g., education, heart disease), pathology (e.g., brain atrophy), and even in the clinical expression of dementia after accounting for neuropathology. Sex is a fundamental characteristic to be considered in studying all aspects of dementia—from the development of pathology within the brain to diagnosis to dementia care.

It is important to note that while many more females are projected to develop a dementia, **males are still greatly affected in large numbers.**

By 2040, over 500,000 males will be living with dementia in Canada.

Breakdown by sex for dementia care partners in Canada

The Landmark Study model can also be used to examine the sex of care partners for people living with dementia. Refer to the first report of the Landmark Study for more details on the projections for care partners in Canada. Similar to the above findings, we were not able to include gender in these estimates.

Table 5 breaks down these care partner numbers by sex and demonstrates that greater than half of all care partners for people living with dementia are female. Females also provide a greater share in the number of hours of care provided (Table 6). However, males will see a greater percentage growth in number of care hours from 2020 to 2050 (199% for males vs. 189% for females).

Table 5. Number of care partners for people living with dementia (by sex) at start of each decade (2020–2050)

YEAR	FEMALE	MALE	TOTAL	FEMALE %
2020	189,400	160,200	349,600	54.2%
2030	315,800	269,700	585,500	53.9%
2040	456,400	394,900	851,300	53.6%
2050	538,800	467,100	1,005,800	53.6%
% INCREASE FROM 2020 TO 2050	192%	184%	188%	

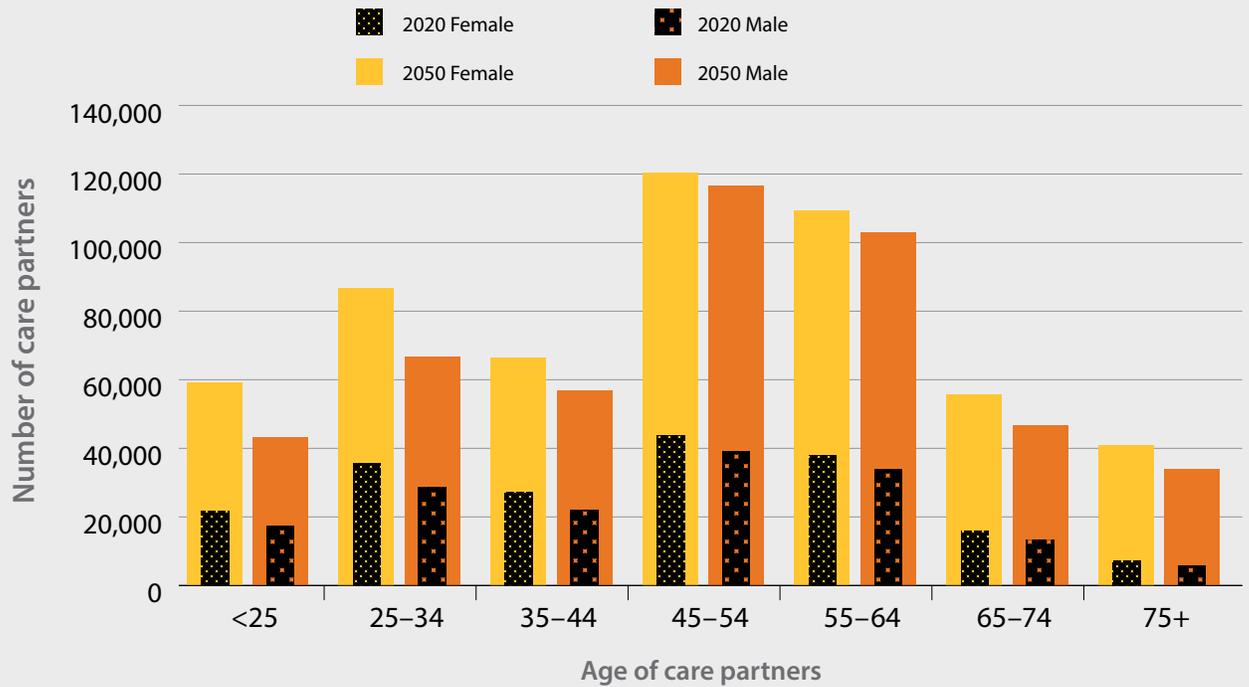
Table 6. Number of hours of dementia care per week provided by care partners (by sex) at start of each decade (2020–2050)

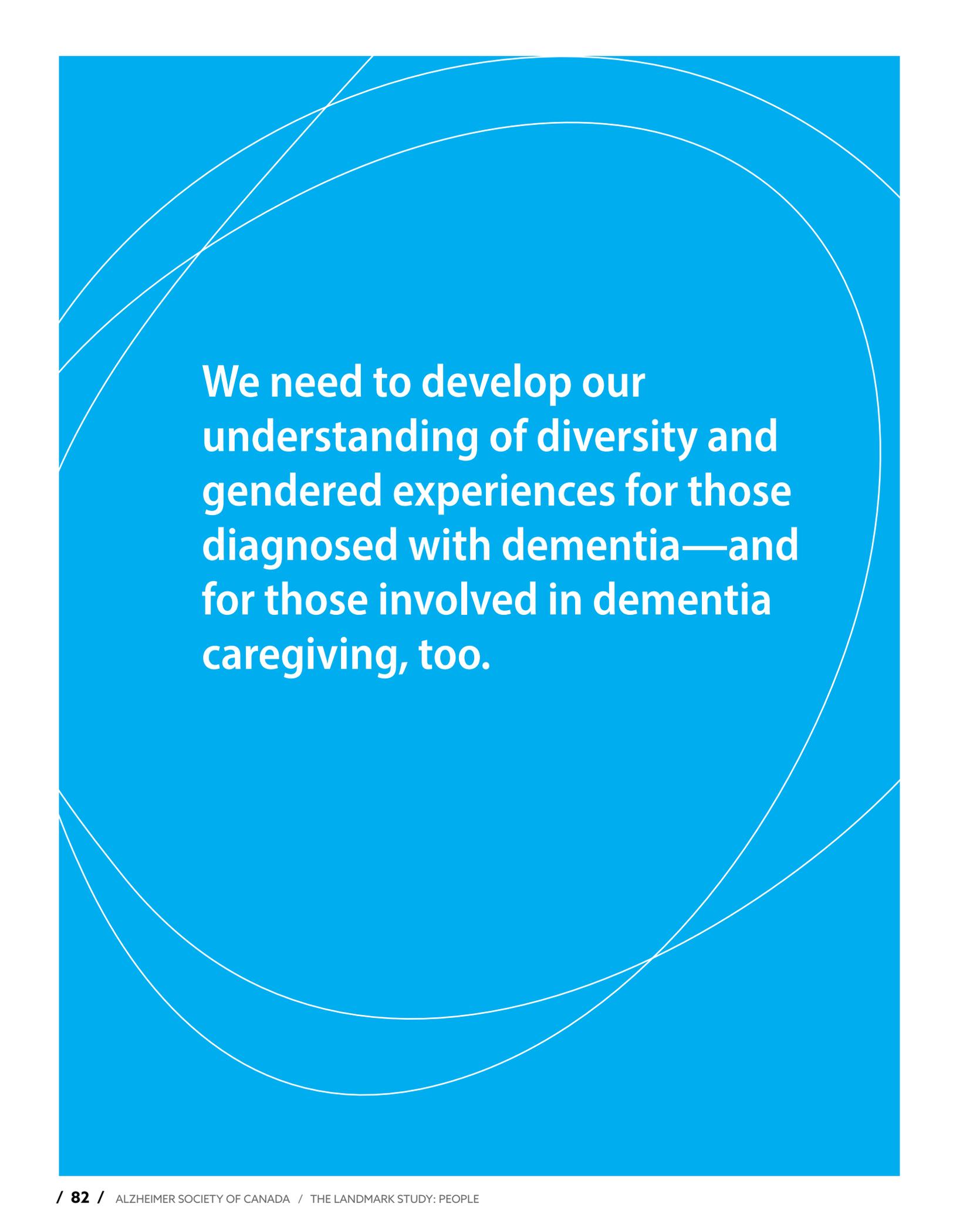
YEAR	FEMALE	MALE	TOTAL	FEMALE %
2020	5,357,800	3,730,500	9,088,300	59.0%
2030	9,021,300	6,366,300	15,387,700	58.6%
2040	13,102,800	9,394,400	22,497,300	58.2%
2050	15,496,200	11,151,400	26,647,600	58.2%
% INCREASE FROM 2020 TO 2050	189%	199%	193%	

Further differences are found between the sexes in the challenges and support needs for dementia care partners. Sex is a fundamental characteristic to be considered in studying all aspects of dementia—from the development of pathology within the brain to diagnosis to dementia care.

When we look at the Landmark Study estimates for care partners by age and sex, we see some of the greatest differences between the sexes in age groups under the age of 45. This may be driven by the adult daughters of people living with dementia taking on care responsibilities for their aging parents at a higher rate than adult sons.

Figure 12. Breakdown of care partners by age and sex, 2020 and 2050





We need to develop our understanding of diversity and gendered experiences for those diagnosed with dementia—and for those involved in dementia caregiving, too.

FACES OF DEMENTIA TYLER'S STORY

Tyler Redublo is a caregiver for his grandmother Alicia, who lives with dementia. Here, he shares some perspectives on dementia caregiving as a teenage boy and finding community in his 20s around these experiences.



"I'VE been a caregiver—more specifically a young caregiver—for my grandmother Alicia for almost 10 years now. My role as a caregiver started at 15 years old when I was still in high school. My grandmother's name is Alicia, but my siblings and I called her "Mum," and she was an extremely important part of our family. She was the primary person to pick my siblings and I up from school or to wait at the bus stop for us so that we could walk home together. She also cooked delicious Filipino food for our entire family and was an avid baker.

One of the first symptoms of dementia that we noticed was when Mum started misplacing things. On one occasion, I remember opening the oven to see if dinner had been prepared, and instead I was surprised to find couch cushions inside. It became clear that something was wrong. Another time, Mum was cooking a chicken recipe she had made for years, that she had perfected—I remember biting into it and it was raw, which was the first time that ever happened.

Story continues on next page

Photo: Courtesy of Tyler Redublo and family.

“For me, a challenging part of caregiving, especially in high school, was going home and not knowing what sides of Mum I would see that day, or what sort of situations I would face. To cope with these feelings, I tried to keep myself as busy as possible.”

In terms of my caregiving role, a lot of it involved supporting Mum and my own mother, Judy, who is her primary caregiver. In particular, Mum went to day programs offered by the Alzheimer Society. So, before I left for school, I was helping her to take medications, eat, get dressed, and walk her to the bus. After I came home from school, my siblings and I also made sure that she got back home safely.

Over time, we also learned to use de-escalation strategies when Mum became upset. One difficult situation we were often faced with was when Mum thought that our family members were stealing money from her. She would ask me, “Tyler, where did you put my bank card?” And I’d respond saying, “Mum, actually, it’s at the bank right now because we’re getting a new card for you.” Instead of reacting emotionally, doing this helped keep her to stay calm and reassured.

For me, a challenging part of caregiving, especially in high school, was going home and not knowing what sides of Mum I would see that day, or what sort of situations I would face. The uncertainty and progressive decline of Mum’s condition made me feel stressed, sad, angry and isolated. Because of these feelings, I was often uncomfortable to go home, knowing that it would be more difficult to study or focus on work.

In addition, to cope with these feelings, I tried to keep myself as busy as possible. For example, I joined sports teams, did extracurricular activities, and had a part-time job. In a way, those things were like a temporary escape from caregiving, and they helped me tremendously.

My caregiving role also changed my social life, which sometimes created barriers between me and my peers. Throughout high school, especially in the early stages of Mum’s condition, I didn’t want to share my caregiving experiences with anyone outside of my family. A lot of this was due to stigma, and feeling like people could not relate to me and my experiences.

But then, in the last year of high school, I finally built up the courage to tell two of my best friends about Mum and my family’s situation.

I remember the moment very vividly; it was a summer night and we were sitting in a parking lot together. I told them that my grandmother was living with Alzheimer’s and that I was providing care to her, and it felt really liberating—like a huge weight was lifted off my body. However, it was also an important bonding moment for us because they revealed that they were also providing care for their grandparents who were living with dementia as well! It made me realize that dementia affects tons of other people, beyond my own family.

After high school, I went on to university, which is when I started to embrace the young caregiver role more, and I was more open and accepting of it. For example, when people asked me to hang out, sometimes I would tell them, “Sorry, I can’t, I’m helping my family with my grandma tonight.”

Something I would share with other young caregivers, or caregivers in general, is to try and connect with people who are able to listen and understand. You don’t have to carry the responsibilities by yourself if you don’t want to! So, try your best to stay connected. Also, while caring for another person, it can be very easy to neglect your own needs. Self-care is a really important aspect of providing good, consistent care, so make sure to be patient and caring to yourself as well!

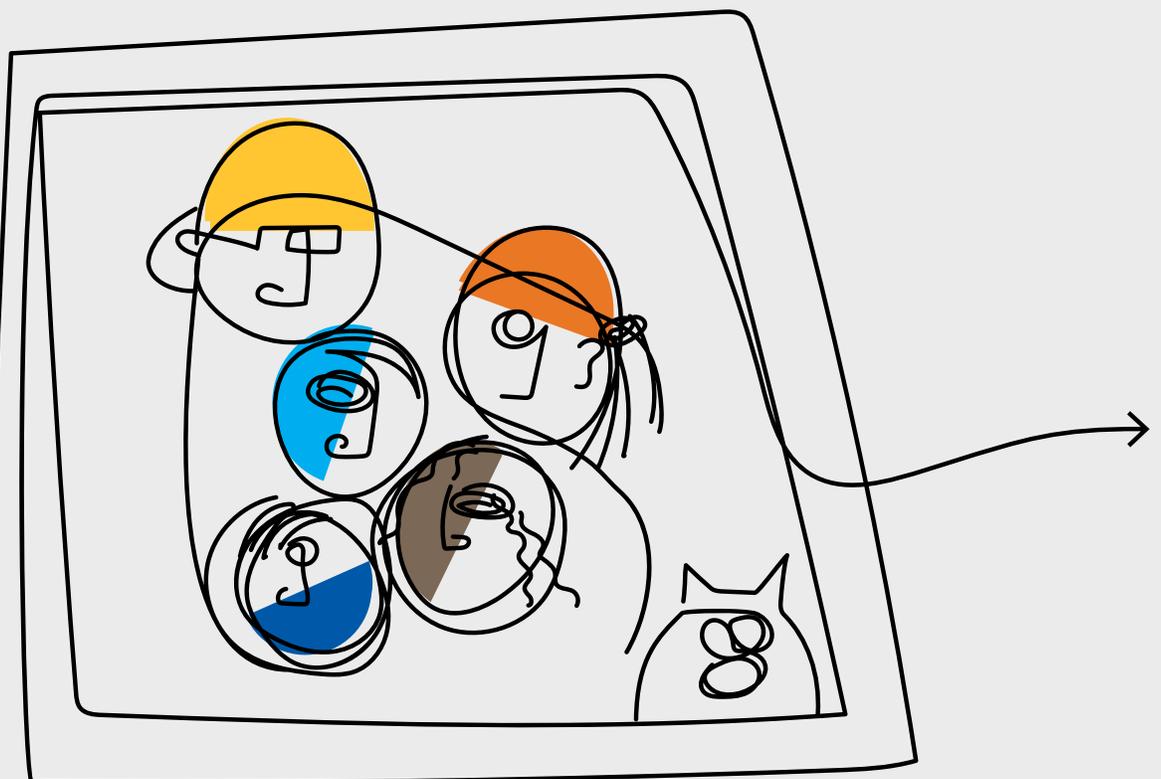
What I have found rewarding about caregiving was seeing little glimpses of Mum’s true self. When we would play a song that she knew and she would start singing along, for example. These moments bring up a lot of happy, positive memories and feelings.

If I could provide advice to my past self, I would tell him to be honest and open about his experiences. Also, I would tell him to consider connecting with other people that are like you— young caregivers, who will have useful advice, and similar experiences to relate to.”

“Something I would share with other young caregivers, or caregivers in general, is to try and connect with people who are able to listen and understand. You don’t have to carry the responsibilities by yourself if you don’t want to! So, try your best to stay connected.”

YOUNG ONSET DEMENTIA: DISTINCT CHALLENGES

The onset of dementia can be a challenge at any age, but when dementia symptoms develop in younger adults, it presents an overlapping range of unique challenges.



“Young onset dementia” is the term used when dementia symptoms develop before the age of 65. It is a relatively new term that has replaced “early onset dementia.” This change in terminology occurred because “early onset” can be confused with “early-stage dementia.” Internationally, some also use the term “young dementia.”

Although the term may be new, the phenomenon of young onset dementia is not—in fact, two of the first patients who helped Dr. Alois Alzheimer identify the condition we now know as Alzheimer’s disease in the early 1900s, Auguste D. and Johann F., were patients who developed symptoms in their 50s. (Hippius & Neundörfer, 2003; Klünemann et al., 2002). It is in part by seeing these patients and their dementia symptoms, and examining their brains after their deaths, that Dr. Alzheimer and his colleagues identified the hallmarks of Alzheimer’s disease.

Nonetheless, with age as the strongest risk factor for dementia, most cases of dementia continue to be seen in older adults past the age of 65—a phenomenon which has overwhelmingly driven care and research priorities, to the detriment of younger adults with dementia.

Most dementia care, for instance, is typically organized and designed for people in their 70s and 80s (Chemali et al., 2012; Cations et al., 2017). Research on dementia has also primarily focused on older adults and their challenges and care needs. Canada’s national dementia strategy recognizes that people with young onset dementia are a group that faces numerous barriers to equitable care (Public Health Agency of Canada, 2019).

The onset of dementia can be a challenge at any age, but when dementia symptoms develop in younger adults, it presents an overlapping range of unique challenges:

- the large variety of potential symptoms and their causes, which can lead to delayed diagnosis
- lack of awareness among many health-care workers about the existence of young onset dementia, which also leads to delayed diagnosis
- the unique care needs directly resulting from the time in the life course where the symptoms develop, for instance, the need to make sure school-age caregivers are supported or that active-lifestyle day programs are available
- the financial challenges many may experience if they have not been able, given their age, to accrue substantial retirement savings or pension access
- the additional financial challenges that adults living with disability face; for instance, 16.6% of people with disability in Canada live in poverty compared to 11% for the overall population (Government of Canada, 2020)
- the practical challenges of obtaining proper workplace accommodations for disability, particularly for issues that take years to diagnose (Morris, 2019)

With the number of persons with young onset dementia in Canada rising (Alzheimer Society of Canada, 2022) and with increasing dementia advocacy for all ages in Canada often being driven by people who have had young onset, this condition is now becoming more recognized as a growing public health challenge separate from the late-onset version of dementia.

In this chapter, we will briefly review young onset dementia and the distinctive challenges for both individuals and their care partners. We will conclude the chapter with some projections from the Landmark Study for the number of people who might develop young onset dementia by 2050 in Canada.



What causes dementia in younger adults?

Just as dementia is an umbrella term, young onset dementia is also an umbrella term that captures a range of conditions that impact the functioning of the brain.

The core features of dementia are the same no matter what the age—there is decline in one or more areas of cognition (attention, executive function, memory, learning, language, perceptual motor or social cognition) and interference with the individual's independence in everyday functioning.

Alzheimer's disease is thought to be the most common cause of young onset dementia. For individuals impacted by Alzheimer's disease before the age of 65, the first symptoms are similar to those of late-onset Alzheimer's disease: memory loss and difficulties finding words.

Frontotemporal dementia (FTD) is the second most common form of young onset dementia. This type of dementia is caused by a group of disorders that impact the frontal and temporal lobes of the brain. FTD is grouped into three main types:

- **Behavioural variant frontotemporal dementia:** The frontal lobe is compromised first, and initial symptoms include changes in personality, behaviour, emotions, and judgment.
- **Primary progressive aphasia:** The temporal lobe of the brain is impacted, and the key initial symptoms include changes in the ability to communicate; speaking, writing, reading, and understanding others can all be diminished.
- **Dementias associated with movement disorders:** This rarer form of FTD impacts specific areas of the brain, leading to movement-related disorders including corticobasal syndrome and progressive supranuclear palsy.

In addition to Alzheimer's disease and frontotemporal dementia, many other conditions are related to the development of dementia symptoms in people under 65. Some of these are listed in [Box 7](#).

Box 7. Conditions that can be related to young onset dementia

- ✦ Alcohol-related brain damage
- ✦ Alzheimer's disease
- ✦ Autoimmune encephalitis
- ✦ CADASIL (cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy)
- ✦ Corticobasal syndrome
- ✦ Creutzfeldt-Jakob disease
- ✦ Down syndrome
- ✦ Frontotemporal dementia
- ✦ Huntington disease
- ✦ Infectious processes (herpes encephalitis, syphilis, HIV)
- ✦ Lewy body dementia
- ✦ Logopenic progressive aphasia
- ✦ Multiple sclerosis
- ✦ Niemann-Pick disease type C
- ✦ Normal pressure hydrocephalus
- ✦ Parkinson's disease
- ✦ Posterior cortical atrophy
- ✦ Progressive dysexecutive syndrome
- ✦ Progressive supranuclear palsy
- ✦ Traumatic brain injury
- ✦ Vascular dementia
- ✦ Wernicke-Korsakoff syndrome

Some causes of cognitive impairment are reversible

It is important to note that while many forms of dementia are progressive, some forms of cognitive impairment can be reversed. Research indicates that treatable causes of cognitive impairment are more commonly found in younger individuals under the age of 65 (Kelley et al., 2008). Reversible causes of cognitive impairment include inflammatory diseases, increased pressure in the brain, infectious diseases, toxic/metabolic disorders, side effects of medication, hypothyroidism, and vitamin deficiencies, among other causes (Muangpaisan et al., 2012; Kuruppu & Matthews, 2013).

Because of this potential for effective treatment in some cases, it is important for physicians to try to determine the underlying cause of cognitive impairment as soon as possible, particularly in people who are younger.

Efficient diagnosis can be done using the following (Fatima et al., 2022):

- blood tests
- careful review of symptoms
- cerebrospinal fluid analyses
- neuroimaging
- tissue biopsies
- other medical tests

Despite the availability of these methods, diagnosis for young onset dementia often takes longer than for older onset dementias, a fact which complicates researchers' abilities to properly estimate the number of young onset dementia cases overall.

A helpful overview and further details on this topic are also available in "What is the most efficient way to diagnose dementia in a young person?" This expert essay was prepared for the 2021 World Alzheimer Report by Canadian researcher Mario Masellis.

Young onset dementia may be more common than previously thought

Relative to late-onset dementia, young onset dementia is rarer, and it occurs much less frequently across the population. The Canadian Institute for Health Information (2022) reports that approximately 3% of the people living with dementia in Canada are under the age of 65. In Canada, there has not been a lot of research on how frequently young onset dementia occurs in the population. At the end of this chapter, you can find our most recent estimates of young onset dementia numbers in Canada from the Landmark Study model.

Globally, a recent systematic review using data from around the world found that there are approximately 119 cases of young onset dementia per 100,000 people (Hendriks et al., 2021). These findings demonstrate that while still relatively rare, more people might be living with young onset dementia than we had previously thought.

Note: Gathering accurate statistics on young onset dementia in Canada is further complicated by the fact that currently there is no national system for tracking all cases of dementia more broadly, let alone for people who develop dementia under the age of 65.

Dementia diagnosis is more frequently mistaken and/or delayed in younger adults

Internationally and nationally, one of the challenges to knowing how many people live with young onset dementia is due to frequent misdiagnosis by physicians (Mendez, 2006).

This misdiagnosis likely occurs in part because of several factors:

- the wide range of potential causes (refer to **Box 7**)
- an absence of biomarkers for many kinds of dementia
- differences in presentation from late-onset dementia
- the co-occurrence of other neuropsychiatric disorders (Ducharme et al., 2020)
- a lack of public awareness
- a need for more education for health-care professionals (Kvello-Alme et al., 2021)

Due to these challenges, young onset dementia diagnoses are often delayed leading to an unnecessary lag in appropriate treatment and negative effects on the quality of life of the individual. Accurate diagnosis is crucial to rule out other potential and possibly treatable causes and to allow for appropriate planning for care and finances.

Financially, delays in diagnosis can impact the ability to access short- or long-term disability benefits and workplace accommodations. Anecdotally, some individuals and families with young onset dementia have shared that the affected person left their job while seeking diagnosis due to the way the condition was affecting their work, and thus became ineligible for certain benefits and accommodations that were only available after diagnosis.



Differences in the ways symptoms can present with young onset dementia

As with older onset dementia, the symptoms of young onset dementia are diverse and include a range of behavioural, cognitive, neurological, and psychiatric symptoms. However, there are some noted differences between dementias that occur before and after age 65.

“With [young onset dementia], we more often encounter atypical variants that can affect executive functioning, behaviour, language, and visuospatial capabilities, while leaving memory intact” (Mendez, 2017). As a result, and due to the lack of awareness that younger adults can also live with dementia, there can often be a great delay in reaching a diagnosis (Eriksson et al., 2014).

Anecdotally, for instance, some people living with young onset dementia have told us that they may have had issues learning a new system at work but had few problems otherwise. Again, because of lack of public and physician awareness, this type of cognitive difficulty was not immediately recognized as a possible symptom of young onset dementia.

In another type of example, some couples have ended up in marriage counselling due to what were later found to be behavioural symptoms of young onset dementia. Again, those symptoms were not identified clearly at the time by health-care professionals, and the diagnosis was delayed.

The need for specialized supports for young onset dementia

Research shows that people with young onset dementia can also have greater psychosocial problems because they may still be working and raising a family (Kaiser et al., 2012). These individuals may experience more depression (Rosness et al., 2010), typically have more aggressive progression of the condition (Tort-Merino et al., 2022), and face greater challenges with attention and fine motor movements (Tort-Merino et al., 2022).

At the same time, because young onset dementias are rarer, there may also be fewer specific psychosocial supports available to individuals and families even as they have greater need for them.

Where good models for such supports do exist, they have often been developed by affected individuals and families themselves. These include virtual support groups offered by Dementia Alliance International, as well as day programs created by YouQuest in Calgary and Young Onset Dementia Association in Waterloo.

An increasing number of Alzheimer Society teams in Canada also offer young onset-specific support programs, as does Rare Dementia Support Canada for certain kinds of young onset dementia. In future, such models need to be emulated more widely and such supports need to grow.



Care partners of people living with young onset dementia are often younger too, and have different challenges

Young onset dementia can have a significant impact on families and the care partners who provide much-needed support outside of the health-care system. Caregiving for young onset dementia has been associated with high reported levels of burden, stress, and depression (van Vliet et al., 2010). Care partners for people living with young onset dementia have also reported experiencing relational problems, family conflict, problems with employment, financial difficulties, and problems concerning diagnosis.

Since young onset dementia affects individuals at younger ages, care partners can also be younger. Kids, teens and young adults can be faced with taking care of a parent due to young onset dementia.

Just recently, the Young Caregivers Association in Canada launched a knowledge hub for younger care partners in general (not solely for dementia), as well as some related virtual programs. This is a helpful step for care partners age 15 to 24. Young care partners for those with young onset dementia in Canada may also be able to access monthly virtual support groups through Lorenzo's House, a Chicago organization that focuses on young onset dementia support. They have support groups for young care partners age 9 to 30.

Again, these are promising programs, and more are needed.

Young onset dementia in Indigenous people in Canada

A 2013 study examining data from Alberta (Jacklin, 2013) found that First Nations people are diagnosed with dementia at younger ages compared to the non-First Nations population.

While dementia is greatly under-studied within Indigenous populations, these findings indicate that young onset dementia may be occurring at an increased rate among First Nations, Inuit and Metis people in Canada.

Given the intersecting barriers many Indigenous people face in the Canadian health-care system, there is warranted concern that the challenges of young onset dementia and lack of timely diagnosis could be exacerbated for Indigenous people with young onset dementia who may be hesitant to seek medical care.

This perspective is illustrated in a recent study of urban Indigenous people living with young onset dementia in Calgary (Ody et al., 2022). Alice, a person of mixed First Nations and non-Indigenous descent and a friend of someone with this form of dementia, shared her thoughts: “I think talking about specifically Indigenous people’s trauma in Canada, you know thinking about colonization and the Indian Act... And I think you know a lot of maybe fear of seeking medical attention—you know that is a lot of common experience that is shared.”

Refer to [Chapter 2](#) for a more detailed review of some of the issues related to dementia faced by Indigenous people in Canada.



Young onset dementia in people with Down syndrome

The development of Alzheimer’s disease in people with Down syndrome is greater than in the general population (Ballard et al., 2016). On average, Alzheimer’s disease can present itself 20 years earlier for people with Down syndrome than it would for the general population. Symptoms of Alzheimer’s disease may start to appear around the mid-50s or even earlier for people with Down syndrome.

In an essay from the 2021 World Alzheimer’s Report, researchers state that “virtually all adults with Down syndrome develop the hallmarks of Alzheimer’s disease pathology by age 40, and the lifetime risk of dementia is estimated to be well over 90%.” These researchers also point out that the life expectancy of adults with Down syndrome has dramatically increased over the last decades due to improved health care, and now approaches 60 years of age in high-income countries. Thus, more people in this group are likely to develop Alzheimer’s dementia and other age-associated disorders in the future, and dementia due to Alzheimer’s disease is now considered the main cause of death in adults with Down syndrome (Fortea and Strydom, 2021).

The link between Alzheimer’s disease and Down syndrome lies in the twenty-first chromosome, which people with Down syndrome have an extra copy of. The over-production of a protein linked to that chromosome can lead to the development of amyloid plaques in the brain—a hallmark characteristic of Alzheimer’s disease.

The first sign of dementia in individuals with Down syndrome is often changes in their behaviour and personality. In an individual with Down syndrome, it is essential to pay attention to changes such as reduced empathy, social withdrawal, emotional instability and apathy. Another warning sign can be if an individual with Down syndrome is experiencing seizures for the first time in their life.

One of the main challenges people with Down syndrome face around dementia is underdiagnosis and/or misdiagnosis (Fortea & Strydom, 2021). Sometimes early symptoms of dementia may be confused with Down syndrome symptoms. Likewise, because Alzheimer's disease is well known to be connected to Down syndrome, medical professionals rarely pursue other diagnoses beyond Alzheimer's disease when a person with Down syndrome begins to show signs of dementia.

To hear directly from people living with Down syndrome about this situation, we encourage people to read the online booklet *Today & Tomorrow: A Guide to Aging with Down Syndrome* by the Canadian Down Syndrome Society (2020). The Canadian Down Syndrome Society is a strong information source and advocate for the needs of people with Down syndrome as they age.



Many unique challenges related to young onset dementia

In summary, the onset of dementia under the age of 65 is associated with several distinctive challenges beyond the difficulty of getting an accurate diagnosis. People who develop young onset dementia are often in an active phase of their lives, in the middle of their careers while also taking care of others (e.g., children, aging parents). The development of cognitive and functional decline often impacts work performance (Evans, 2019), financial security (Kilty et al., 2023), and self-esteem (Harris & Keady, 2009).

Persons with young onset dementia are often forced out of employment if their workplaces are unable to adapt to their changing needs—especially in the absence of a clear diagnosis that can bring workplace accommodations or disability programs. This can create financial insecurity and impact the individual's sense of purpose. Additionally, this can lead to changing social roles and have an adverse impact on family relationships (Harris & Keady, 2009).

Dementia services are also often geared toward older adults and are typically not designed to address the needs of someone living with dementia who may also have dependent children and a partner who needs to continue working (Mayrhofer et al., 2018). The lack of day programs and other community supports adapted for younger people with dementia is a major gap in current services.

Furthermore, intersecting biases and factors can exacerbate challenges to diagnosis, care and specialized support for Indigenous people and people living with Down syndrome who are at greater risk for young onset dementias.

NEW FINDINGS FROM OUR LANDMARK STUDY

The Landmark Study is based on findings from a simulation model that combined data from the 2016 Statistics Canada Census and known rates of young onset dementia from the scientific literature to estimate numbers in Canada over the next 30 years.

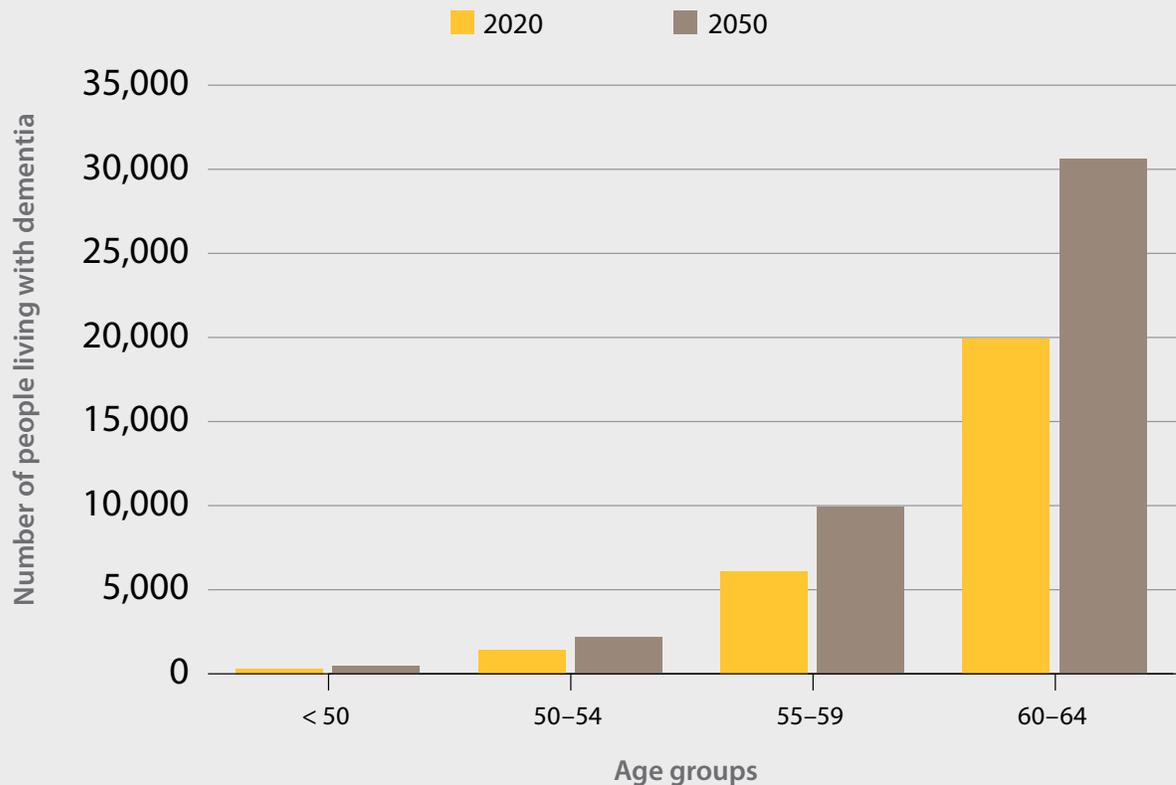
The results portrayed in this section are projections for the number of people with young onset dementia in Canada.

Young onset dementia affects many people living in Canada

While most cases of dementia are in older age groups, **by 2050, the Landmark Study projections estimate that there could be over 40,000 people under the age of 65 living with dementia compared to 28,000 in 2020.**

To better understand the factors driving young onset dementia and identify any differences in risk factors compared to later onset dementia, additional research is required. This is particularly important when it comes to informal caregiving since many more years of care may be required.

Figure 13. Young onset dementia rates, 2020 and 2050



As the population of people with young onset dementia is unequally distributed across the country, the absolute number of individuals under the age of 65 varies widely, as does the expected growth in numbers over the 30-year time period. The province with the greatest number of individuals living with young onset dementia is Ontario, followed by Quebec and British Columbia.

The greatest growth in numbers is expected in Alberta, with numbers of young onset dementia more than doubling by 2050. This is likely due to the underlying population age structure of the province.

Table 7. Number of people under the age of 65 living with dementia by province, 2020 and 2050

PROVINCE	2020	2050	% INCREASE
Alberta	2,700	5,600	107%
British Columbia	3,500	6,400	83%
Manitoba	800	1,200	50%
New Brunswick	500	500	0%
Newfoundland and Labrador	300	300	0%
Nova Scotia	700	800	14%
Ontario	11,600	18,400	59%
Prince Edward Island	100	200	100%
Quebec	6,600	8,600	30%
Saskatchewan	800	1,300	63%

These findings indicate that there will be a growing need to address the unique challenges faced by people with young onset dementia and their care partners.

FACES OF DEMENTIA ANDREA'S STORY

Here, Andrea describes part of her journey so far living with young onset dementia as an 2SLGBTQI+ person and parent.



"IT started with little things. People I used to work with would show up at the school I worked at and I didn't recognize them. I'd leave letters or words out when I was writing.

And then there were some things—things I've done my whole life—that I couldn't do anymore. I've always ridden a unicycle. Since Grade 4. Well, I'd get my unicycle out and I didn't know how to get on it. It was really weird given that I'd spent 40 years riding it. And drawing—I'd always been a portrait artist, and all of a sudden, I couldn't draw. My drawings looked crummy.

Story continues on next page

Photos: Courtesy of Andrea and family, and Faces of Dementia/Hamilton Council on Aging.

So we went to the doctor. My first doctor that I remember going to said, "There's nothing wrong with you because you're wearing makeup." I used to wear a lot of makeup, with liquid eyeliner and everything. She was like, "There's nothing wrong with you if you've got makeup on."

Then we just went down a road of psychiatrist after psychiatrist. They just kept naming psychiatric problems and heaped on the medication. Which really didn't help. It made it awful.

And then finally, I was at a neurologist, and I said, "There is something seriously wrong with me. Nobody's listening." He said, "Well, what do you want me to do? Do you want a brain biopsy?" And I said, "Sure."

So that's what I did. I had a brain biopsy. And it's showed the [beta-amyloid] plaques. That's when it was diagnosed.

But the neurologist didn't even tell me about the diagnosis—a movement specialist did. I'd been having trouble walking. The specialist looked at my chart and said, "You have Alzheimer's." And I said, "I didn't know that." He said, "Oh, yeah. It's on your post-surgical record."

That was literally all we got. My partner was there, and we walked out, and I thought, "I guess I have Alzheimer's." I was 48 years old.

In fact, the diagnosis since changed. Now I know I have frontotemporal dementia. Which I always say is "Alzheimer's with a little bit of an extra kick." I joke about it, but it's not easy.

Around the time I was diagnosed, a lot of other things were going on. My mom had Alzheimer's disease. After we moved her into assisted living, I'd visit her every day on my way home from work.

Even for me, who now has dementia and is trying to encourage people to think about dementia differently, it's hard for me to remember my mom apart from the more severe symptoms she had. It's hard for me to remember that she was really smart and spoke Latin and she read books like they were water. One of the smartest people I'd ever met.

Anyway, my mom died a couple months after my diagnosis.

I'd also gone back to school and was finishing my social work degree. I was raising triplets around that time. Now, my degree hangs over my toilet! It was a joke, since I didn't get to practice. Given that I have a disability, my partner now works practically seven days a week.

"I really think we need to bring dementia, and stories about dementia, into this time period. A lot of the ways it's talked about are so dated and old-fashioned."

“I have to say, my partner has helped me a lot. She’s always there for every appointment. Though there’s nervousness that can come up around medical visits because most medical personnel or service workers say, ‘Is this your sister?’ Then I say, ‘This is my partner.’”

It has been challenging. I have to say, my partner has helped me a lot. She’s always there for every appointment. Though there’s nervousness that can come up around medical visits because most medical personnel or service workers say, “Is this your sister?” Then I say, “This is my partner.” Then there’s this uncomfortable silence. Some doctors have even asked her to leave the room!

But that’s not all doctors. I actually have some pretty great doctors now.

One doctor took me off all of the psychiatric meds that I didn’t need, from when some specialists thought my problems were all psychiatric. It was a long process to get off of them, and an amazing transformation.

For a while, I couldn’t walk. I needed canes, a wheelchair for rheumatoid arthritis. I had a bunch of different symptoms—memory, hearing, movement, speech—that I didn’t know could all fall under the dementia “umbrella.”

Now I can speak more clearly. Now I’m walking better. I’ve regained a lot. Sure, I’ve lost some other things. But I’m certainly back to living an active life.

I still do a lot of art. I entered the mural contest for MICE [Memory Inclusive Communities Everywhere], a group we started in Haldimand. So now there’s a mural in town that has one of my pictures on it, which is exciting.

In terms of my kids, they were 16 or so when I was diagnosed. Now, one’s in college, one’s in university and one is working. Two of my kids don’t always get it. It’s hard for them. They don’t understand that some of my behaviour is because of the frontal lobe changes. I’ll admit it: I have little tantrums when I get frustrated. They think it’s on purpose, but it’s not. My kids are still very supportive and are learning how to deal with frontotemporal lobe dementia.

The triplets are all creative. We do ceramics, go thrift-store shopping, painting. Another is into woodworking, making monsters and creatures and props. And another is 100 percent into plants, gets on my iPad and shows me pictures of leaves; he preserves leaf skeletons, temperature-controls his room for their plants.

I really think we need to bring dementia, and stories about dementia, into this time period. A lot of the ways it’s talked about are so dated and old-fashioned. You can still be a smart, interacting human, no matter what your age, with or without a dementia diagnosis.”

FACES OF DEMENTIA

HEATHER & CURT'S STORY



Curt lives with young onset Alzheimer's disease in BC. Here, Heather, his wife of 33 years, relates part of their journey.

"I'M 61 and my husband, Curt, is 64. Around 2008 or 2009, Curt had a head injury at work. Some of [what I now see as dementia-related] behaviour started then. We'd just bought my mom's place on an island, and he was excited about us having this place and working full-time and working towards us being there and fixing it up. But after that head injury, he got weird about work and going to work. And he also started having delusions regarding me.

I kept trusting that his family doctor at the time was taking care of everything. I remember being confused; I thought, how does somebody suddenly get what looks like mental health issues? And then the symptoms stopped suddenly. I remember talking to my family doctor and asking, "How does that just stop without treatment?" She said the problem had just been temporary. But now, looking back, I think, Why didn't anyone think about dementia? He even saw a neurologist back then. They should have looked into it right away based on his age and head injury.

Photo: Courtesy of Curt and Heather Sosa.

In 2021, Curt was diagnosed with young onset Alzheimer's disease. One thing I've really become aware of through all this is how uncomfortable people are about this condition. People just avoid talking about it. Especially as his symptoms get worse. Why? *Because* no one talks about it, *because* no one hears about it. So I honestly am going to make it my mission to be very vocal about this.

I often say, "I have every emotion you can possibly have every day."

In terms of our age, there's just nothing out there for us. Even when I was able to go to caregiver support groups, I was the youngest one there. People would say, "Oh, you remind me of my daughter." I never found anyone like me, except online.

Last year Curt was in a program that was set up for a lot of physical activity, and it didn't work out for him. It was also expensive. Now he goes to another program three hours a day twice a week. I drop him off on the way to work, and pick up after. There, most of the people are quite elderly and less mobile than he is.

Most workdays, I work a few hours at the office and then go home to work from home. If there's no program going on, my son is with Curt when I'm at work. And our son is so patient—but I know it's taken a toll on him too.

Financially, I had to sell the property that we were planning on keeping to pay off debt. The program he goes to is \$10 a day for the program, but I have to park every time I take him. So that alone is now \$200 a month for him to go two days [a week] to the program. One day I'll have to pay for the home care, too.

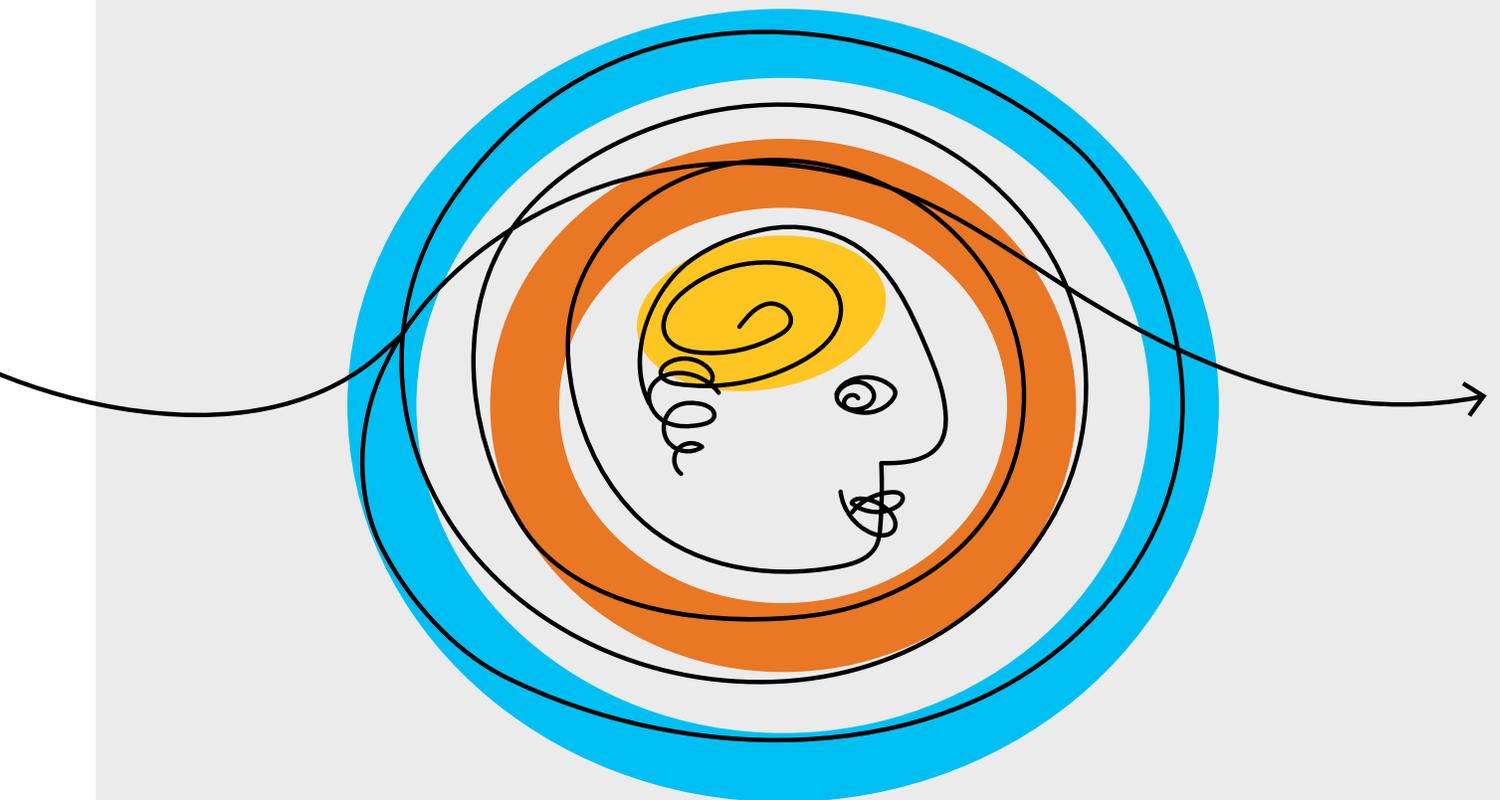
I'm working, but I'm not eating well, I'm not taking care of myself. I think, Should I go part-time? But then it will be financially harder, I might not be able to keep the car. We have his Canada Pension Plan Disability payments, but how does that roll into taxes? There's a lot of information I wish someone had just told me from the get-go.

There's just this constant adapting throughout the day. Learning to live a new way with this person, but also still remembering all the old ways. There's so much that I'm going through. And always just trying to find that happy place, wherever I can."

"One thing I've really become aware of through all this is how uncomfortable people are about this condition. People just avoid talking about it. I honestly am going to make it my mission to be very vocal about this."

PROMOTING INCLUSION FOR ALL PEOPLE LIVING WITH DEMENTIA

There are many more
diversity dimensions
to consider, and
recommendations to act on.



With this report, we call attention to the diversity of people in Canada who have been and will be affected by dementia over the next three decades. We believe that it is important to develop and design our health-care systems, health policies, and supportive resources to match the diversity and distinct needs of all people in Canada.

Research on dementia should also aim to be more inclusive. Studies should include participants from a wide variety of backgrounds and examine dementia across population subgroups that vary by sex, ethnicity, race, age, and gender, to name just a few.

Based on the findings from the Landmark Study, we can expect increasing numbers of people living with dementia across Canada over the next three decades. The growth in numbers is not equal across population groups. We expect a 273% increase in dementia numbers for Indigenous people. Dementia will likely become a growing public health challenge for Indigenous communities as their populations age and continue to face health challenges.

Among ethnic and racialized groups in Canada, growth in dementia numbers will likely occur fastest in individuals of Asian descent, followed by African, Latin, and Caribbean populations. This will lead to a shifting of the ethnic makeup of the population of people living with dementia in Canada. Clear differential outcomes across population subgroups point to the need for more research to understand these ethnic and racial differences in dementia. These findings also reveal that much more work is needed to design and deliver care and support services that are culturally appropriate to the growing number of people developing dementia with origins that are non-European.

When it comes to sex differences, the findings illustrate that dementia is more common among females compared to males. While the difference in risk might primarily be driven by the longer life expectancy of females, more research is needed to unravel all the complexities that occur due to sex differences in biology and gendered experiences across the life course. This research should also include understanding differences in dementia onset, diagnosis, treatment, care and improved support for people who are intersex, trans, non-binary and gender-diverse.

The Landmark Study also provided estimates for the number of people likely to be diagnosed with young onset dementia over the next three decades. These findings highlight that at a national level, there will be a large number of middle-aged or younger adults who will develop dementia. These individuals will likely face additional challenges getting a diagnosis and support, as symptoms of young onset dementia are different than dementia presentation in people 65 and older, and health-care workers have less knowledge of dementia in this population. We need to develop a better understanding of the dementia experiences within this population and adjust our dementia services to meet their unique care needs.

Diversity in dementia doesn't stop at Indigeneity, sex, ethnicity and age

The Landmark Study model is limited by the data, level of data and evidence that is currently available on the Canadian population and trends in dementia—Indigeneity, ethnicity, sex and age. While the report takes an examination across various groups in Canada, the microsimulation modelling approach can't address other important characteristics of people living with dementia and their care partners.

For example, we have no data available to incorporate people into the simulation model according to sexual orientation; on the basis of intellectual or other disabilities; or more granular data on ethnicity or individuals who are non-binary, gender-diverse, trans or intersex. Nor is there much data available on people living with dementia who are incarcerated, are underhoused or homeless, or have addictions. These factors can influence dementia risk, experiences with the condition when it develops, and care needs. If we are aiming to optimize care for all people living with dementia, these circumstances should also be recognized and carefully considered.



Sexual orientation and dementia risk, care and support

2SLGBTQI+ adults have been found to have higher rates of cognitive impairment when compared to heterosexual or cisgender people (Flatt et al., 2018). While more research is needed to determine why this is, risk factors in this population such as depression, social isolation, and chronic minority stress may be strong contributors to brain aging (Correro & Nielson, 2020).

Research has also found that members of 2SLGBTQI+ communities do not receive access to high-quality health care (Fredriksen-Goldsen et al., 2013), receive incomplete assessments and inadequate communications with health-care professionals (Fredriksen-Goldsen et al., 2013), and have unequal access to dementia services and benefits (Fredriksen-Goldsen, 2011). Canada's national dementia strategy has also identified that 2SLGBTQI+ communities face barriers to equitable care (Public Health Agency of Canada, 2019).

Moreover, individuals from 2SLGBTQI+ communities have unique issues around the care they receive, facing discrimination within health-care services, medical communications, and long-term care homes. With the growing number of older 2SLGBTQI+ individuals with dementia, research is needed into more inclusive models of care. There is critical need for increased attention to all aspects of a person's identity—people living with dementia are much more than their medical diagnosis.

One step toward a better understanding of dementia care for 2SLGBTQI+ communities is found in a 2022 report by Egale Canada and the National Institute on Ageing: *Coming Out and Coming In to Living with Dementia* (Flanagan and Pang, 2022).

2SLGBTQI+

2SLGBTQI+ is the acronym used by the Government of Canada to refer to the Canadian community.

2S: at the front, recognizes Two-Spirit people as the first 2SLGBTQI+ communities;

L: Lesbian;

G: Gay;

B: Bisexual;

T: Transgender;

Q: Queer;

I: Intersex, considers sex characteristics beyond sexual orientation, gender identity and gender expression;

+ is inclusive of people who identify as part of sexual and gender diverse communities, who use additional terminologies (2022).

One of the participants interviewed for the report commented: “You’re stigmatizing a segment of the population because they have dementia. And then you’re double hit, because you’re gay, and you have dementia. That’s a big whammy. And I don’t know that there’s enough education on what it means to be queer and to have dementia” (Flanagan and Pang, 2022).

Recommendations from that report included building inclusive dementia-related services for 2SLGBTQI+ people in community spaces, increasing recognition and support for care partners, enhancing supports and reducing barriers to access, and broadening perspectives for future critical research in the area (Flanagan & Pang, 2022).

Additional useful resources are available via Egale Canada and the recently formed National Resource Centre on 2SLGBTQI Aging. It offers research and resources related to this community, such as a toolkit for health-care workers: *Acting in Allyship with 2SLGBTQI People Living with Dementia: Guiding Principles for Healthcare and Social Service Professionals* (2023).



Dementia experiences of people with intellectual and developmental disabilities

Despite the fact that aging occurs across the entire population, little research has focused on the relationship between individuals with intellectual and developmental disabilities and dementia outcomes. The 2019 national dementia strategy included people with intellectual and developmental disabilities as a group that is at higher risk of both developing dementia and facing barriers to equitable care (Public Health Agency of Canada, 2019).

As we covered in Chapter 5, research has demonstrated that adults with Down syndrome are at high risk for developing Alzheimer’s dementia (Prasher, 2005), with about 70% of persons with Down syndrome developing the condition (Beaumont & Carey, 2011; Glasson et al., 2014; Hartley et al., 2015). While these findings show a strong connection, the reasons for this relationship are not yet fully understood (Prasher, 2005).

Generally, individuals with intellectual and developmental disabilities may be at increased risk for dementia as a result of some common characteristics or symptoms found across the various conditions. This includes disrupted brain function, malnutrition or obesity, polypharmacy, and inactive lifestyles (Sauna-Aho et al., 2018).

It is currently unclear whether autism spectrum disorder is associated with a higher risk of being diagnosed with dementia (Vivanti et al., 2021). For the few dementia studies that have examined the co-occurrence of autism, results have been inconsistent. One American study of individuals with cognitive impairment found that participants with autism spectrum disorder developed symptoms at a younger age and had more severe cognitive impairment (Rhodus et al., 2020).

Intellectual impairment does raise some challenges in measuring declines in cognitive function, making it complex to determine dementia status. A recent systematic review found that cognitive assessment tools are lacking for adults with intellectual and developmental disabilities, and the authors suggest that this may lead to delayed access to care and treatment (Janicki et al., 2022).

For more information about available tools for assessment of dementia in people with intellectual disabilities, refer to the publicly available paper by Zelinger and colleagues: *Informant-Based Assessment Instruments for Dementia in People With Intellectual Disability: A Systematic Review and Standardised Evaluation* (2022).

Dementia experiences of people who are incarcerated

One population that is known to not receive adequate dementia care is people who are incarcerated.

Canadian researcher Dr. Adelina Iftene of Dalhousie University described some of these issues before a special parliamentary committee in October 2022: “It’s very difficult. Many times, in prisons, dementia and other major cognitive impairments are misdiagnosed, because first responders tend to be officers. They obviously do not have any expertise in this. Even the prison physician, who might have access to seeing these people, does not have the expertise necessary to diagnose these issues. What we end up seeing, many times, is people who may have had dementia for a number of years, but who were misdiagnosed as having alcohol withdrawal” (Special Joint Committee, 2022).

In 2019, Iftene wrote, “The proportion of people in federal institutions who are over 50 (considered the start of being a “senior” in prison research because a prisoner tends to have the problems of someone in the community who is 10 to 15 years older) has more than doubled in the last decade and now stands at 25 percent. While the overall incarceration rate of Canadians has remained stable for decades, the prison groups that are increasing in number are those marked by vulnerabilities: older prisoners, women and Indigenous persons.”

Improved health services within correctional institutions and expedited access to compassionate release of older incarcerated individuals, especially those living with dementia, should be sought to address some of the dementia-related challenges that face the aging prison population in Canada.



Homelessness as risk factor for dementia

People who lack housing and are living with dementia make up another stigmatized and marginalized community that needs considerably more research (Beard et al., 2022); homelessness and dementia has been called “an unspoken and complicated epidemic” (Babulal et al., 2022).

A review found that the association between dementia and homelessness was complex due to the role that other chronic conditions or disorders (e.g., mental illness, addiction, brain injuries) also play (Babulal et al., 2022). For now, homelessness itself is likely a risk factor for developing dementia.

To understand this issue better in the future, improved counts and censuses of underhoused populations should be done. As well, increased dementia screening is needed in homeless populations (Babulal et al., 2022). Without a closer study and consideration of housing as a component of better health care (Hanssman et al., 2022), future dementia strategies will continue to overlook this likely risk factor.

Dementia and substance use

When addictions, and health-care stigma around addictions, intersect with dementia and dementia care, the result is that people living with addictions and dementia go underdiagnosed, undertreated, and under-cared-for.

A case study in Dr. Danielle Alcock's doctoral thesis (2019) focused, in part, on families impacted by alcohol-related dementia. She explored gaps in health care related to supports and services for older adults with substance use issues. She found that "health care workers are not addressing it because of ageism and a lack of education. This creates barriers... for accessing services and supports."

Because alcohol misuse tends to be underdiagnosed in seniors, accurate diagnosis of this—and reducing stigma around it—could help improve accuracy of diagnosis around cognitive impairment in seniors. It could also help doctors identify whether a cognitive issue is rooted in dementia per se, in addictions, or in some other health problem such as a brain tumour or infection.



More opportunities to address diversity in dementia

While a cure or an effective pharmacological treatment for most dementias not yet been discovered, there are a wide range of actions to create positive outcomes for people living with dementia and their care partners.

There are many opportunities to better address issues related to the diversity found in the people living with dementia in Canada. While this report highlights some of the diversity of dementia examined through the Landmark Study findings, diversity doesn't stop at Indigeneity, sex, ethnicity and age. As emphasized by the Canadian national dementia strategy (Public Health Agency of Canada, 2019), there is much more that needs to be and can be done to be more broadly inclusive for those at increased risk and those experiencing dementia, such as people living with dementia from the 2SLGBTQI+ community and those with intellectual disabilities.

In this final section of the report, we bring attention to the opportunities where we can optimize our health-care systems and supports for the wide range of people who will experience dementia in the coming years. We are all unique, but our shared characteristics and differences are important to recognize when planning future supports.

In addition, there are actions that we can take as individuals to educate ourselves and support the diverse people in Canada currently living with and who will develop dementia. Learning that race, ethnicity, sex, gender and dementia intersect, and understanding the impact of colonization as a determinant of health in Indigenous communities, are important first steps.

The following recommendations, organized by chapter topics, are just a start to how we might best address issues related to the diversity of dementia in Canada. Of note, we want to recognize that there is good work underway in pockets across the country, however, these are not consistent nationally, creating inequity in access and support for many people in Canada living with dementia.

FACES OF DEMENTIA

BOB AND RON'S STORY



Here, Ron Stewart tells us about the experiences of his father, Bob, who was born Deaf. Bob faced obstacles throughout his life with respect to communication and employment barriers—as well as barriers to dementia treatment and support.

“DAD was born in the 1930s and, as you can imagine, support was limited for Deaf individuals. His parents decided that he should go to the residential part of what was then known as the Ontario School for the Deaf in Belleville, Ontario. The school was located three hours away from his home and he stayed there for several months each year, for 12 years of his life. Each trip back and forth, which he took on the train, also involved struggling to communicate and navigate.

Upon finishing school, his father encouraged him to seek training in a trade. He attended H.B. Beal Secondary School in London, Ontario, to learn auto mechanics. His father was a strong advocate for him and he persuaded the school to allow him to do a practical hands-on testing in order for him to achieve his Class A mechanics' license. With this, he passed his testing to become one of the first Deaf individuals to obtain this type of licensing in Ontario.

Photos: Courtesy of Ron Stewart and family.

“In 2015, Dad received a diagnosis of Lewy body dementia. Often there are no words in American Sign Language for such clinical terms.”

Upon entering the workforce, my dad endeavored to communicate with employers and co-workers who did not know sign language. He would often write on paper or try his best to understand people gesturing with their hands. Small companies didn't see the need for—or simply didn't know that—an interpreter would have been helpful for team meetings. It wasn't until he was hired at the Diesel Division of General Motors, in London, that interpreters were brought in to assist during meetings.

In 2015, Dad received a diagnosis of Lewy body dementia. Assessments and diagnosis were difficult for him to understand because he had the academic education equivalent to that of a Grade 2 student. Often there are no words in American Sign Language for such clinical terms. The initial symptoms he experienced included hallucinations of seeing small animals (like mice) or other people in his home. This caused a lot of stress for Mom, who took it upon herself to care for him; she tried to help him understand his diagnosis and what he was experiencing.

Mom was encouraged to enroll him in a day program to give her some respite. He tried attending one, but it didn't work out as there was no one to communicate with him and no funding for interpreters to help him understand what was happening. The staff tried their best by pointing at him and then at various objects. He found it to be very frustrating. He never wanted to cause trouble (or to get in trouble) so he would often nod and pretend he knew what was happening. Staff would always comment on how friendly he was.

I tried advocating for him by contacting various levels of government and local supports to see if something could be done. We knew that one day he would be in a long-term care facility. We feared that he would be isolated, and that he would have no one to communicate with. I remember him saying to me that his biggest fear was to be locked up in jail or in a psychiatric hospital—he was scared of isolation.

I had a government contact recommend that we should send him to a Deaf long-term care facility in Barrie, three hours away from home. I was furious that it was even suggested to us. How would my family support him if he lived three hours away?

Story continues on next page



Mom was offered increased hours through PSW support. There are only a few PSWs who can sign and as a result this meant he didn't receive the required care. Often he was assigned PSWs who couldn't sign or didn't have the ability to communicate with him.

Dad had a Geriatric Specialist who was very eager to work with him: she tried her best to understand his situation and to communicate with him. She and her assistant took it upon themselves to learn basic sign language so they could help him feel at ease. They also knew the importance of having an interpreter present for all of his appointments. This was very welcoming for my parents. Mom would often comment how wonderful their appointments were, even if she had to hear that things were deteriorating.

Dad ended up in long-term care in January 2020. He felt isolated and very angry; this was the closest he had come to his biggest fear: being locked up. One nurse tried his best to learn sign language (ASL), but Dad's dementia was at its worst and he became suspicious of this person's efforts, which led to more issues. We recognize that the staff did their best, and they were appreciated for their efforts.

Dad passed away in April 2020 from natural causes. And as much as we miss him, I'm thankful he doesn't have to feel isolated any longer, or deal with the hallucinations from his dementia.

I have tried to estimate how many Deaf people there are in Ontario or in Canada; firm statistics are not available. The rough estimate tends to be that 1% of the

population identifies as Deaf. This would approximate to some 153,000 Ontarians and some 396,000 Canadians. In addition to this, sources estimate roughly 3.2 million Canadians are hard of hearing.

The Canadian Association of the Deaf has encouraged federal, provincial and municipal governments to provide supportive living arrangements for Deaf older adults that are Deaf-aware environments designed and intended for their needs—including the company of other Deaf residents. The association also advocates for special training to be provided to workers who support Deaf older adults in various care settings. This could include a requirement to take a basic course in sign language and Deaf culture.

Today in 2023, three years after Dad's passing, appropriate dementia supports are still very much needed for Deaf individuals and their families. We are still waiting. I share my dad's story because I hope it can promote change and help others who find themselves in a similar situation."

Adapted and expanded from an article in Behavioural Supports Ontario Provincial Pulse with the permission of Ron Stewart.

RECOMMENDATIONS

Recommendations for addressing dementia in Indigenous populations

Overall, for dementia in Indigenous people, we recommend that all levels of government and those who can effect change continue to work toward addressing the Truth and Reconciliation Commission of Canada's 94 Calls to Action, with specific focus on Calls to Action 18 to 24 that relate to health and health care.

What can Alzheimer Societies do?

- ⦿ Take further steps toward **building relationships of trust and learning** with Indigenous communities to enhance outreach.
- ⦿ Continue to **support the development and distribution** of dementia education, tools, and resources created by and for Indigenous people.

What can health-care systems do?

- + Improve access to and use of **culturally appropriate dementia testing options** across all First Nations, Inuit and Métis communities.
- + **Train all staff and professionals** to deliver culturally appropriate dementia testing and care across Indigenous communities.
- + **Systematically address racism** towards Indigenous people in health care and social support systems.

What can the federal government do?

- 🏛️ Working with Indigenous people, continue investing in the Enhanced Dementia Surveillance Initiative for the collection of **reliable national data** on brain health and dementia in Indigenous populations.
- 🏛️ Increase **funding for brain health and dementia research by and for Indigenous populations**.

- 🏛️ Increase resources dedicated to addressing the **social determinants of brain health** for Indigenous populations through the development of new policies, programs and supports.
- 🏛️ Enhance existing efforts to **improve access to culturally appropriate dementia testing options and care** for Indigenous communities under federal jurisdiction.
- 🏛️ Build on recent efforts to **increase awareness and actively address stigma related to dementia**, if and when such stigma may exist in communities.

What can provincial and territorial governments do?

- ⚙️ Develop new strategies and increase resources to Indigenous communities to address the **social determinants of health and brain health** in culturally relevant and safe ways.
- ⚙️ Advance the understanding of **colonization and anti-Indigenous racism as a determinant of health** in Indigenous communities.

What can researchers do?

- 🔗 Actively **recruit more Indigenous people** in research studies.
- 🔗 **Support Indigenous researchers and Indigenous communities** in conducting more research on dementia.
- 🔗 Develop research projects to enhance the understanding of **social determinants of brain health** across Indigenous communities.

Recommendations for addressing dementia across ethnicities and across racialized communities

What can Alzheimer Societies do?

- ⦿ **Enhance outreach to build relationships of trust across ethnicities and across racialized communities;** address stigma through dementia education efforts.
- ⦿ Continue to **support the co-design of and access to dementia education** resources and programming in communities, ensuring that materials are **culturally sensitive and available in all major spoken languages** in Canada.

What can health-care systems do?

- + **Collect race-based data** within health-care information systems.
- + **Involve community members in the co-design** of culturally appropriate dementia resources for health-care professionals.
- + Improve access to **culturally appropriate dementia testing options and care** in any underserved communities.
- + **Systematically address racism** in health care and social support systems.

What can the federal government do?

- 🏠 Enhance the national dementia strategy's existing efforts to **raise further awareness of ethnic and racial differences in dementia and in social determinants of brain health.**
- 🏠 **Improve the collection of reliable, national race-based data** related to brain health and dementia.

- 🏠 Increase funding for research that explores **the overlap of race, class, gender and other characteristics in the dementia experience.**

What can provincial and territorial governments do?

- ⚙️ **Increase resources dedicated to addressing the social determinants of brain health** across communities through the development of new policies, programs and supports.
- ⚙️ **Address cultural and linguistic barriers** to optimal dementia care to help improve outcomes for individuals from all ethnic and racial backgrounds.

What can researchers do?

- ⚙️ **Actively engage a wider range of ethnicities and racialized populations** in research studies.
- ⚙️ **Support and co-design with impacted communities in conducting more research examining the overlap of race, gender and other characteristics** in the dementia experience.
- ⚙️ **Consider the various languages** spoken by people living in Canada when conducting dementia research, especially when developing new tools for use within the health-care system.
- ⚙️ **Incorporate analyses related to race and ethnicity** in dementia research studies.

Recommendations for addressing sex and gender in dementia

What can Alzheimer Societies do?

- ⦿ Continue to recognize that the experience of living with dementia and caregiving may affect women, men and nonbinary people differently.
- ⦿ Adapt dementia education, resources, programs and support services with sex and gender differences in mind.

What can health-care systems do?

- + Develop education for health-care professionals to deliver holistic, integrated dementia diagnosis and care that recognizes individual differences in sex, gender, and intersectional identity.
- + Expand dementia supports with sex and gender differences in mind.

What can the federal government do?

- 🏛️ Address structural inequities in policies and programs to better address sex and gender differences in caregiving and in risk factors for dementia.
- 🏛️ Continue to support research that examines sex and gender differences across all aspects of dementia.
- 🏛️ Raise further awareness of sex and gender differences in dementia.

What can provincial and territorial governments do?

- ⚙️ Actively promote brain health with sex- and gender-specific campaigns through their public health services.
- ⚙️ Address caregiving needs through sex- and gender-specific lenses.
- ⚙️ Ensure that sex and gender differences are deeply considered in the design of dementia risk reduction activities.

What can researchers do?

- ⚙️ Ensure sex and gender are integrated into all dementia-related research design and research practices.
- ⚙️ Conduct more research on sex- and gender-specific modifiable risk factors for dementia.
- ⚙️ Conduct research that further explores the experiences of gender diverse and 2SLGBTQI+ individuals who live with dementia or support individuals living with dementia.

Recommendations for addressing young onset dementia

What can Alzheimer Societies do?

- ⦿ **Provide consistent support programs** for people living with young onset dementia and their care partners.
- ⦿ Continue to **work with community partners** to develop age-appropriate activities and supports for those with young onset dementia.

What can health-care systems do?

- + **Improve timeliness of diagnosis** for young onset dementias by increasing awareness and education for health-care professionals to improve care.
- + **Collect reliable health service data** in young onset dementia populations.
- + **Increase education to health-care professionals** about the symptoms and clinical conditions of young onset dementia.
- + **Provide more consistent services and supports** to meet the needs of people with young onset dementia and of their care partners, which are different from people with older onset dementia.

What can the federal government do?

- 🏛️ **Collect reliable national data on young onset dementia** through further investments in the Enhanced Dementia Surveillance Initiative.
- 🏛️ **Enhance disability policies, benefits and financial tools** for people with young onset dementia.

What can provincial and territorial governments do?

- ⚙️ **Enhance and enforce employment accommodations** to include people with young onset dementia.
- ⚙️ **Increase care coordination and supports for living accommodations** given the differing needs of people with young onset dementia.
- ⚙️ **Improve supports designed for care partners** of people with young onset dementia.

What can researchers do?

- 🔍 **Conduct research to understand factors driving young onset dementia** and differences in risk factors compared to later onset dementia.
- 🔍 **Actively engage individuals living with young onset dementia** not just as research participants, but also as members of the research team (e.g., community advisory committees).
- 🔍 **Conduct research further exploring the experiences of individuals who live with young onset dementia** or who care for and support family members living with young onset dementia.

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