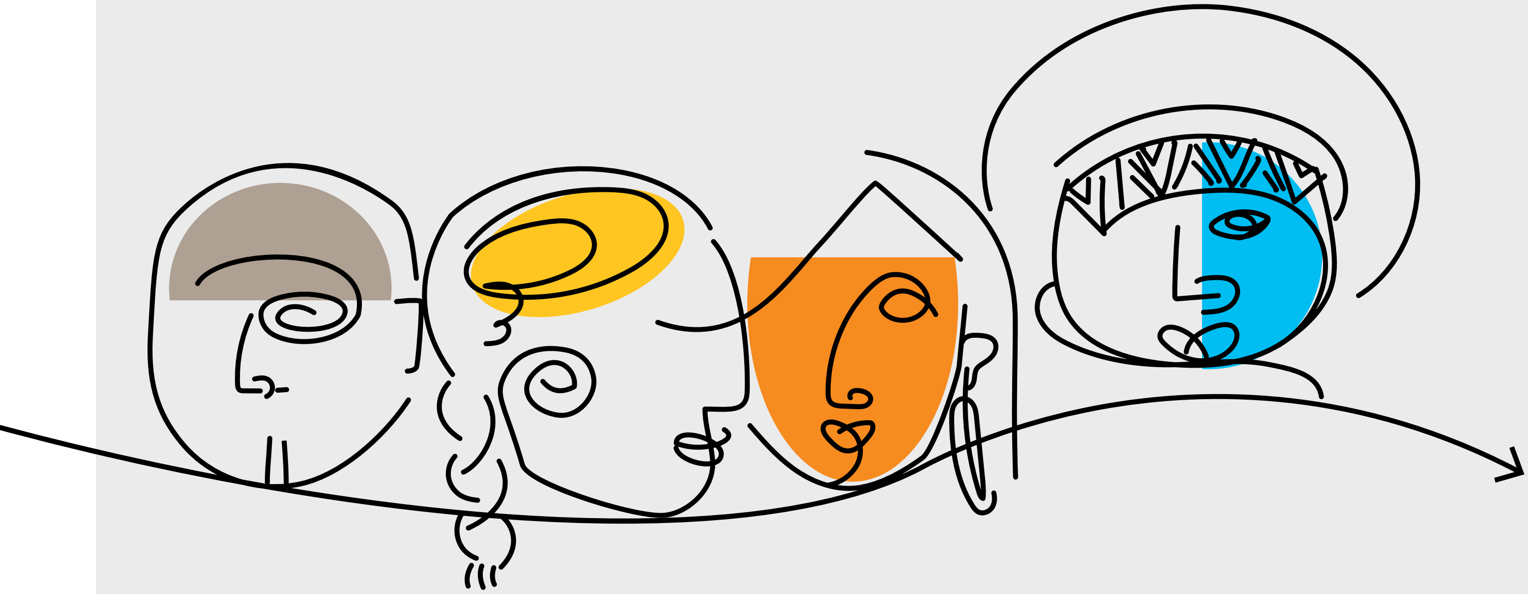
CHAPTER 2

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

- Income and income distribution
- Education
- Unemployment and job security
- Employment and working conditions
- Early child development
- Food insecurity
- Housing
- Social exclusion
- Social safety net
- Health services
- Geography
- Disability
- Indigenous ancestry
- Gender
- Immigration
- Race
- Globalization

Source: Raphael et al., 2020

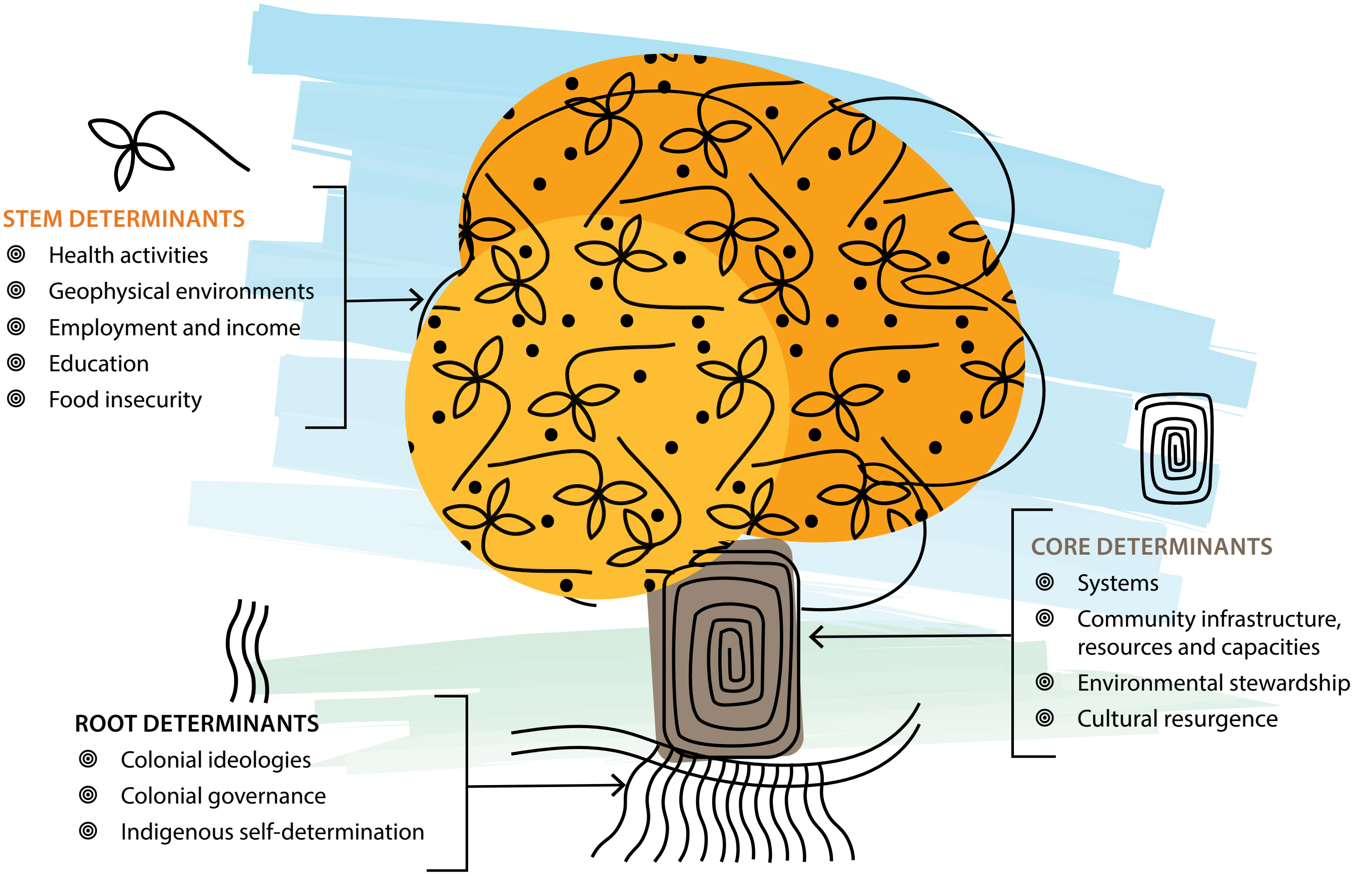
A social determinants of Indigenous health model to consider: root, core and stem determinants

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*.

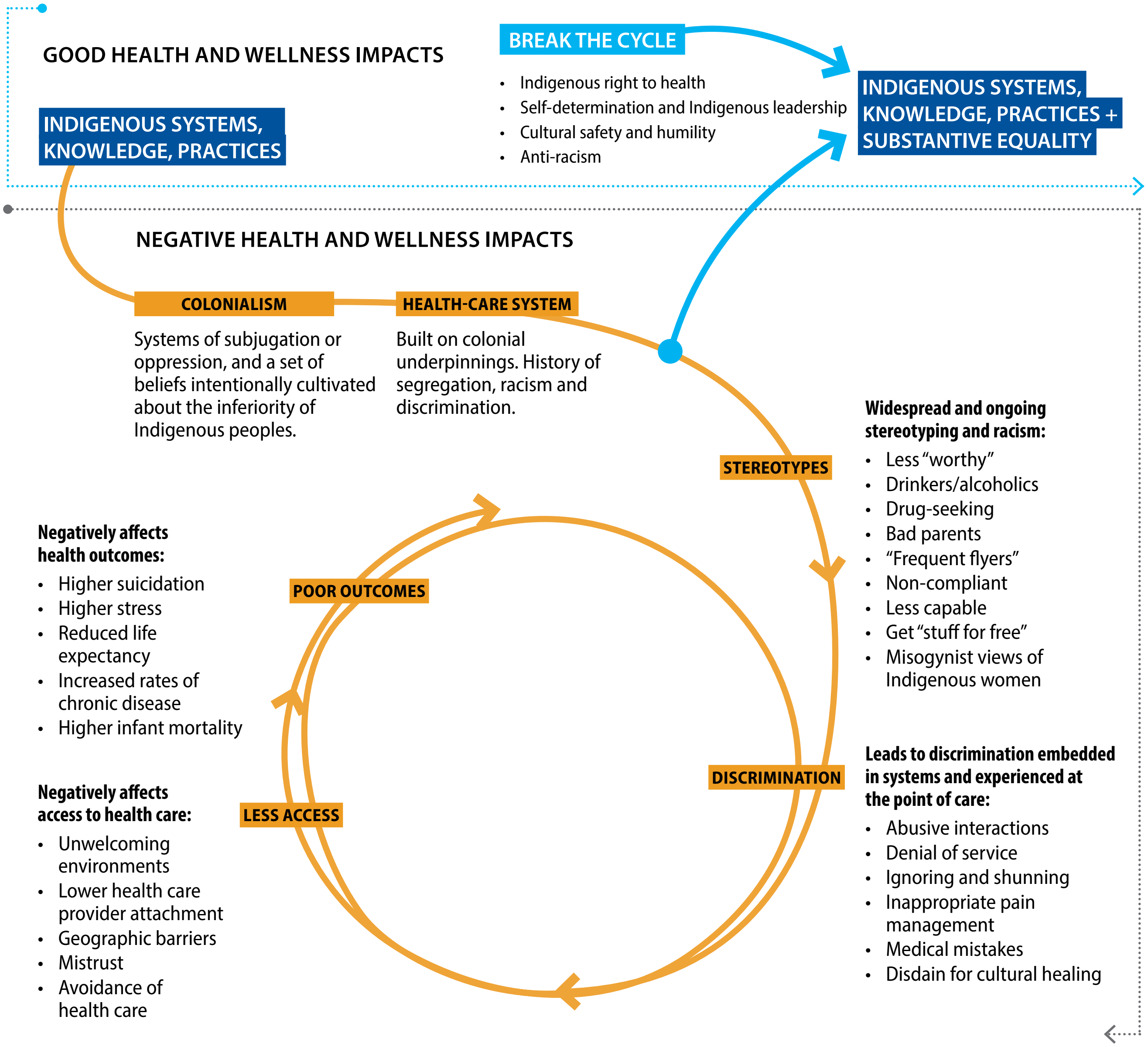
Through consultations with almost 9,000 people, including 2,780 Indigenous people and 5,440 health-care workers, the investigation found evidence of widespread systemic racism against Indigenous people in the health-care system. Of the Indigenous people interviewed, 84% shared personal experiences with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



GOOD HEALTH AND WELLNESS IMPACTS

INDIGENOUS SYSTEMS, KNOWLEDGE, PRACTICES

BREAK THE CYCLE

- Indigenous right to health
- Self-determination and Indigenous leadership
- Cultural safety and humility
- Anti-racism

INDIGENOUS SYSTEMS, KNOWLEDGE, PRACTICES + SUBSTANTIVE EQUALITY

NEGATIVE HEALTH AND WELLNESS IMPACTS

COLONIALISM

Systems of subjugation or oppression, and a set of beliefs intentionally cultivated about the inferiority of Indigenous peoples.

HEALTH-CARE SYSTEM

Built on colonial underpinnings. History of segregation, racism and discrimination.

STEREOTYPES

Widespread and ongoing stereotyping and racism:

- Less "worthy"
- Drinkers/alcoholics
- Drug-seeking
- Bad parents
- "Frequent flyers"
- Non-compliant
- Less capable
- Get "stuff for free"
- Misogynist views of Indigenous women

DISCRIMINATION

Leads to discrimination embedded in systems and experienced at the point of care:

- Abusive interactions
- Denial of service
- Ignoring and shunning
- Inappropriate pain management
- Medical mistakes
- Disdain for cultural healing

LESS ACCESS

Negatively affects access to health care:

- Unwelcoming environments
- Lower health care provider attachment
- Geographic barriers
- Mistrust
- Avoidance of health care

POOR OUTCOMES

Negatively affects health outcomes:

- Higher suicidation
- Higher stress
- Reduced life expectancy
- Increased rates of chronic disease
- Higher infant mortality

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

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

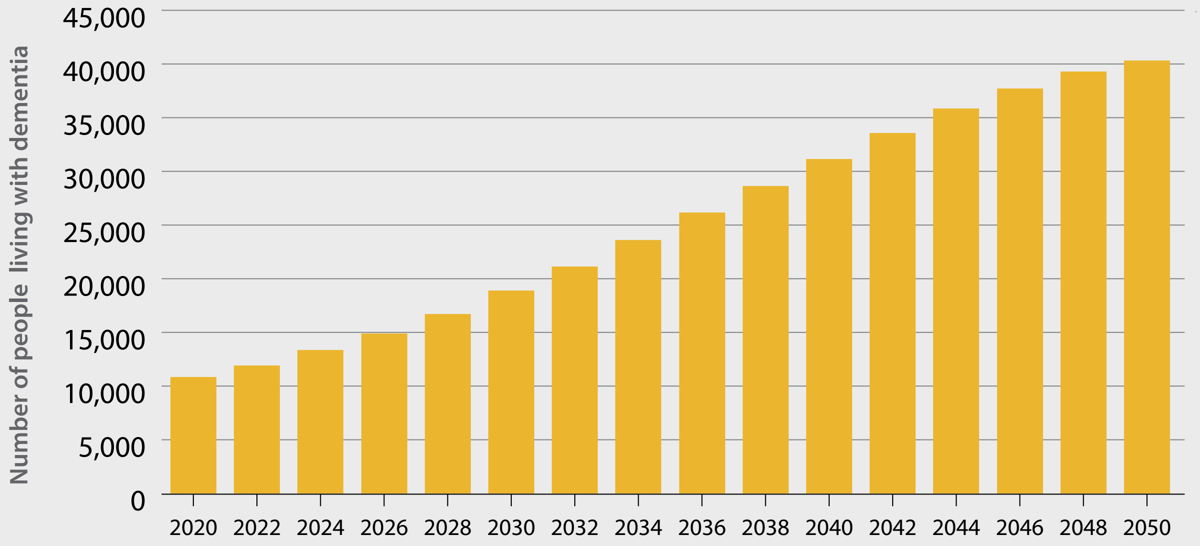
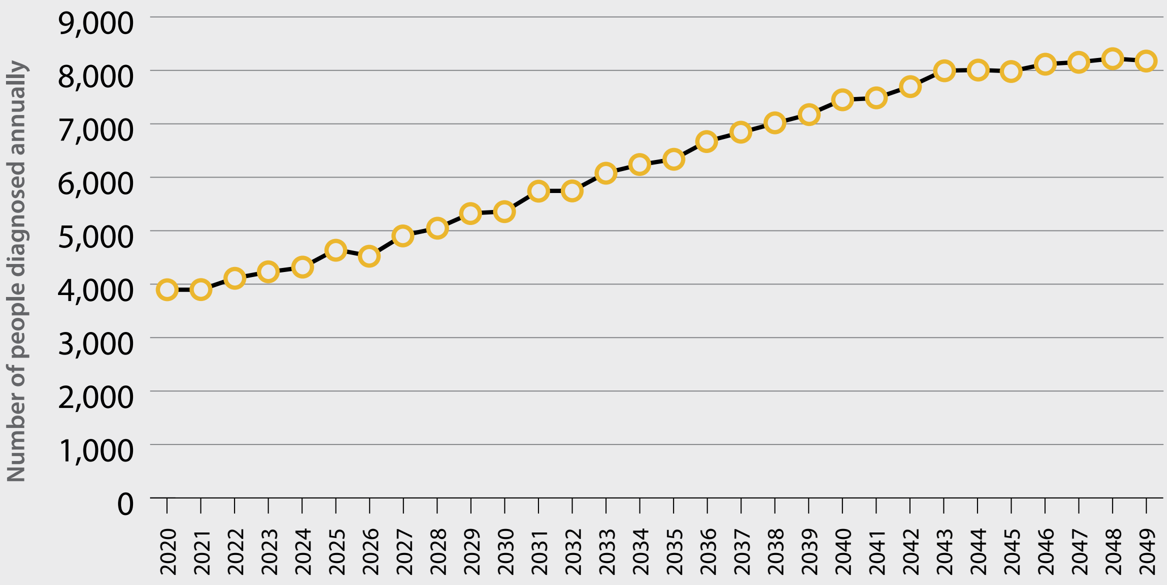
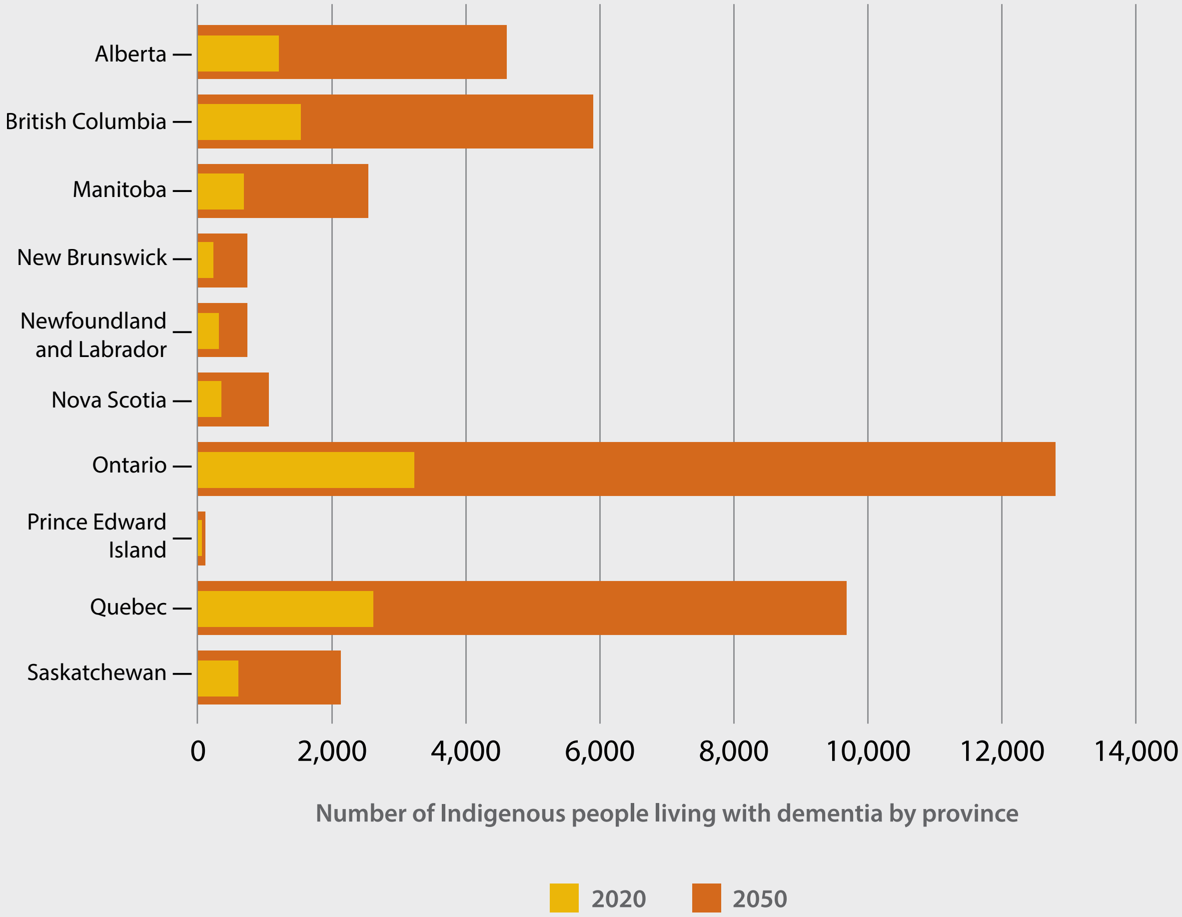


Figure 5. Projections for the annual number of Indigenous people with newly developed dementia, 2020 to 2049



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 Labillois, 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.

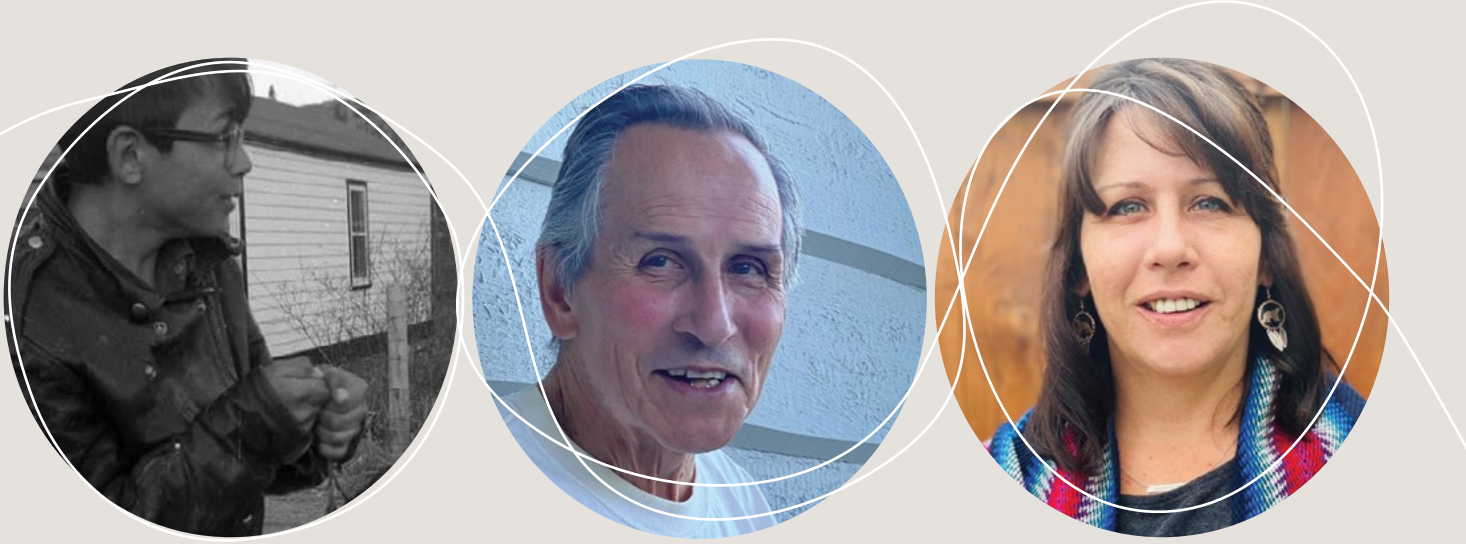
We are all connected in this circle of life. We come to a journey of birth, adolescence, adulthood, and elderhood. We need to educate ourselves on dementia to know the signs and symptoms, so that we can put resources in place before any abuse can happen to our respected Elders."

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."