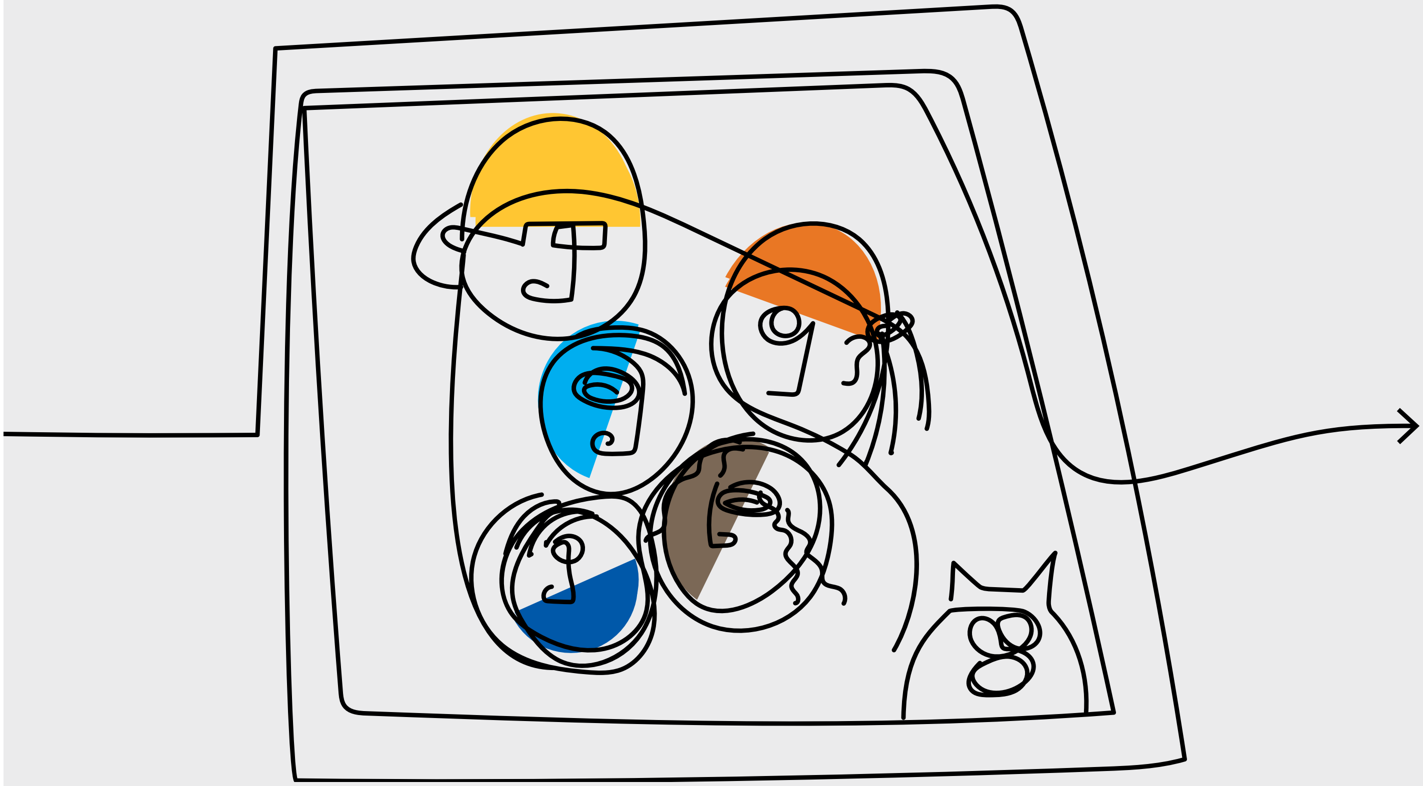
CHAPTER 5

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.

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.

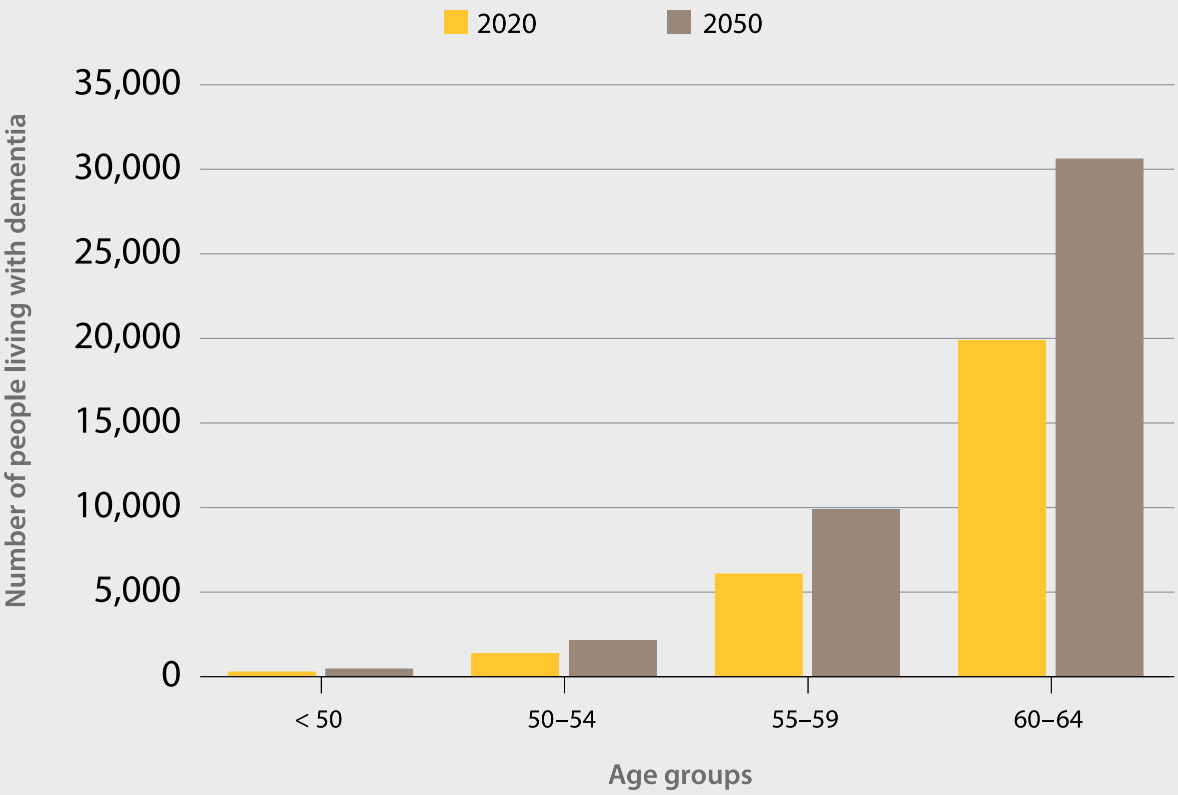
The results portrayed in this section are projections for the number of people with young onset dementia in Canada.

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.

Photo: Courtesy of Curt and Heather Sosa.

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.

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."