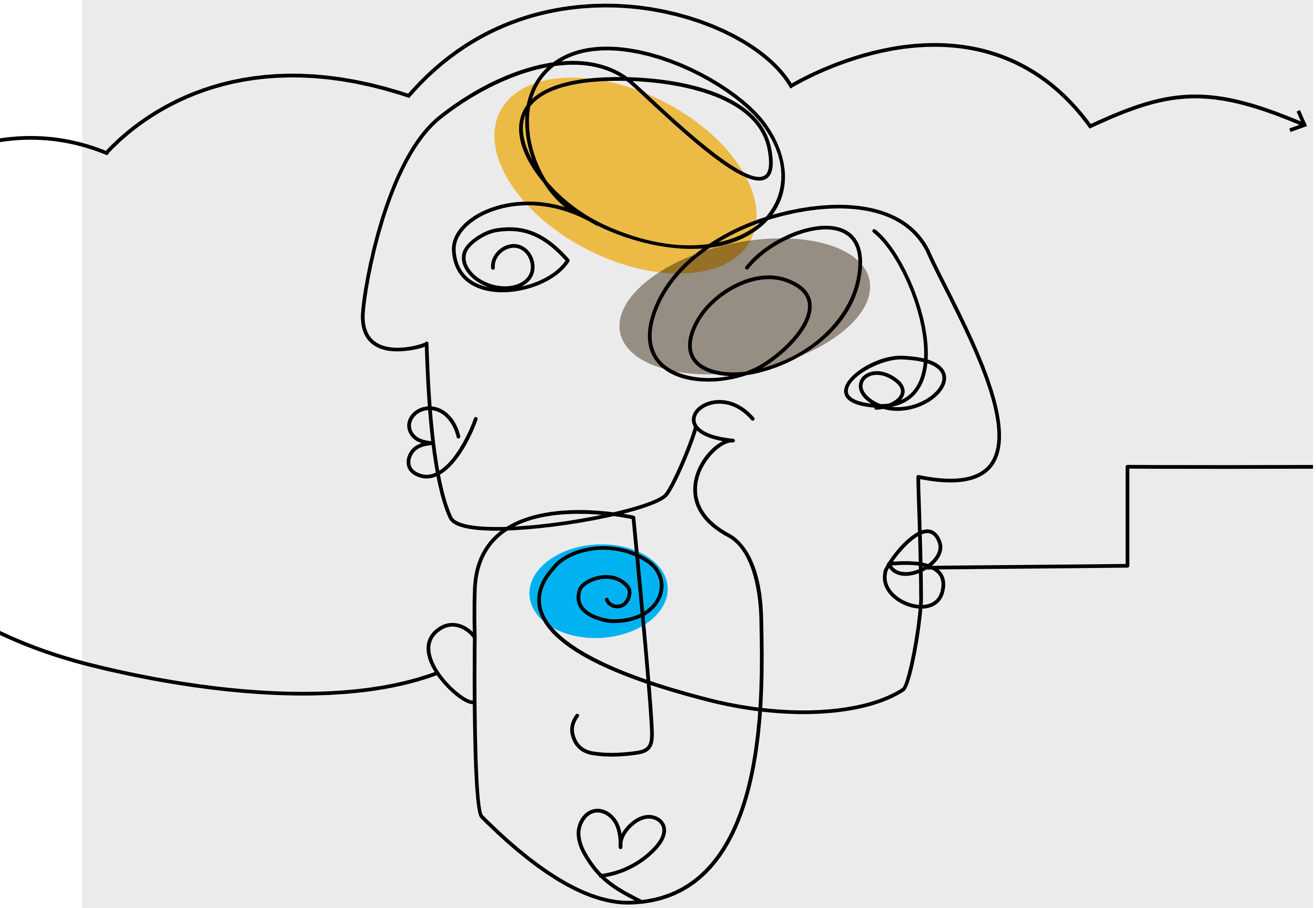
CHAPTER 1

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 e4). 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

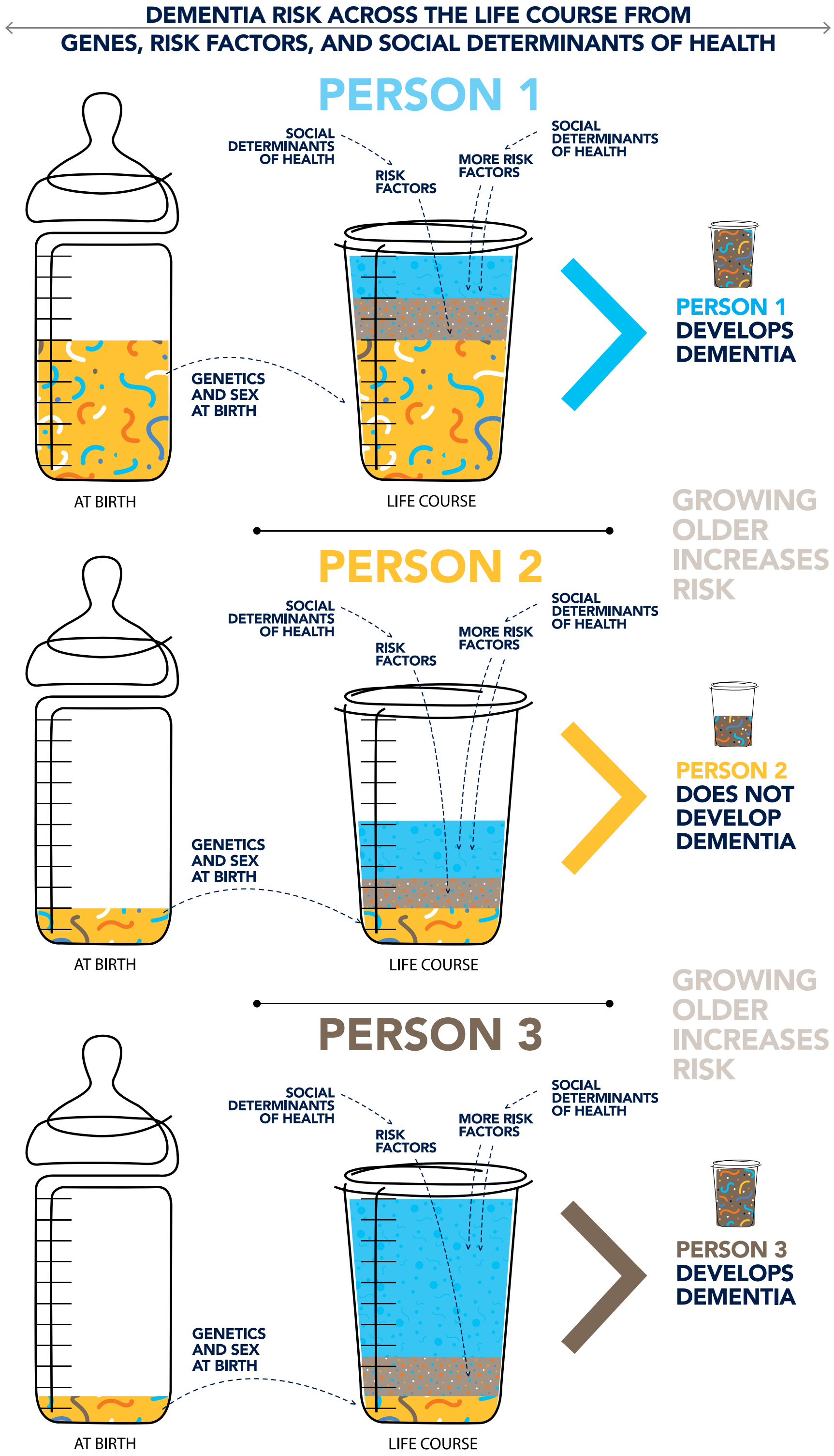
Potentially modifiable risk factors for dementia

- 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."