We need to do better.
We can do better.

A Conversation with People **Impacted by Mild Cognitive Impairment and Dementia**

Independence, Resilience and Hope

CanAge

INTRODUCTION

Understanding the Journey: Insights into the Lives of People Living with Dementia

Dementia, often misunderstood and shrouded in stereotypes, impacts individuals in diverse ways. This report aims to shed light on these variances, exploring how those living with dementia navigate their lives, the support systems they rely on, and their aspirations; to unearth not just the challenges they face but also the opportunities for joy, independence, and dignity in their everyday lives.

By engaging directly with individuals, and those closely connected to them, this report captures a holistic view of their experiences. Through this report, we invite you as readers, whether you are part of the nonprofit sector, the business community, or an individual with a heart for making a difference, to join us on this enlightening journey. Let's explore together what it means to live with dementia and how we can collectively contribute to a world that respects, supports, and celebrates individuals in all their diversity.

KEY INSIGHTS SUMMARY

- Everyday moments some may take for granted represent vibrant, quality thriving for people living with dementia. There is a notion that there are worse things than dementia and ways to cope with the effects of dementia to cultivate a *'different but meaningful life.'*
- A dichotomy exists between fiercely wanting to protect their persona and preserve their personhood and their desire for deeper understanding and empathy about the realities of living with dementia by healthcare professionals, workplaces, and social networks.
- There is pride among people living with dementia in being able to live independently and interdependently upon the acceptance of help. There was great importance placed on available community support to retain autonomy and independence.
- There are also feelings of loss that may perpetuate a lack of urgency and reticence to be diagnosed and treated, fearing there is more to lose than gain including loss of employment, autonomy, and relationships.
- Without symptom management people living with dementia cannot be part of social networks which are essential to thrive. There may be a presentation of physical, cognitive, and emotional symptoms.
- Participants have empathy for people diagnosed with a mental health disorder yet seem to lack an appreciation for how aspects of mental health affect dementia.
- The diagnosis process can cause harm and trauma. How the diagnosis is delivered and supported defines how you navigate and experience the healthcare system. Trial and error are frustrating, creating despair where there need not be. A clearly defined patient pathway is absent, yet necessary and more appropriate person-centred processes are needed.
- Co-learning among people living with dementia, their care partners and peers fill an informational void not addressed through health system mechanisms.
- The opportunity to be assessed and cared for through a designated memory clinic, as experienced by one representative, improves the individual's experience, and streamlines the diagnostic process.

- Participants are excited about recent scientific advancements and there is a sentiment of hope spurred by the prospect of new disease modifying therapies.
- People living with mild dementia want to retain function and cognition for as long as possible. They wish to delay disease progression, preserve their personhood, and remain independent to the greatest extent.
- It became apparent that the needs and feelings of people living with dementia when telling people of their diagnosis are going underrecognized and unaddressed by healthcare professionals, family, and friends.

IMPLICATIONS AND CONSIDERATIONS

1. Mild cognitive impairment/mild dementia diagnosis is being ill conveyed and for the most part unsupported. A more timely, consistent, and streamlined diagnosis process will decrease apprehension and harm experienced by people living with dementia and their care partners. Aided by frank conversations with competent, curious, and compassionate healthcare professionals to facilitate a shift in the medical professional narrative from *"get your affairs in order"* to *"here are practical strategies for living well with dementia,"* would go a long way in diminishing potential trauma.
2. People diagnosed with mild dementia seek deeper disease acumen and affinity. They wish to understand what the possibilities are, what comes next and what is to be expected, acknowledging that each person experiences dementia uniquely. Sharing real life stories and scenarios will help paint a more accurate portrait of dementia. Articulating analogous paths experienced by individuals living with cancer, HIV or mental health disorders may help close the gap on the emotional need to identify with another established patient pathway where disease modifying therapies already exist.
3. The needs of people living with dementia, especially during MCI and earlier stages of AD, are under-recognized and often unaddressed by healthcare professionals, family, friends, and colleagues at the time of diagnosis disclosure. Developing and disseminating information on how to respond when someone tells you *'I have mild dementia'* and co-creating, with people with lived experience, coaching tools and tips will protect cherished personas and relationships.

4. The time is now to move dementia from the shadows to the forefront, heightening awareness about the signs and symptoms of mild cognitive impairment and inspiring public discourse with storytelling and dialogue.

BACKGROUND

CanAge, Canada's National Seniors' Advocacy Organization is committed to improving the lives of older adults through advocacy, policy, and community engagement. We are a non-partisan, non-profit organization and backed by a broad pan-Canadian membership base.

In 2022, we released a report assessing Canada's level of preparedness to handle the massive influx of dementia patients that experts warn is set to overwhelm our health care system in the coming years. The first-of-its-kind report shows that Canada is falling behind in the global race to deal with the increasingly complex needs of a rapidly aging population—the latest census data shows people 85 and older are now one of the fastest growing demographics in the country (861,395 people in 2021). Not far behind, 7,021,430 Canadians are over the age of 65. Given that the risk of dementia doubles at age 85 (to 25%), the window of opportunity to get ahead of an inevitable health care crisis is growing alarmingly slim.

> **By 2050, 1 in 6 persons globally will be over the age of 65. But in Canada, we're already at 1 in 6 in most provinces, and in some provinces, were closer to 1 in 4.**

Evidence shows all levels of government are ill-equipped to handle the boom of dementia patients poised to overwhelm Canadian health care in the coming years. Through our months of data collection, we had the privilege of speaking to people who are living with dementia and their care partners. It was a humbling, and enlightening undertaking, one that underpins our work.

We are steadfast about continuing the conversation with a desire to change the conversation and inform public discourse anchored in the reality of living with dementia.

DIALOGUE AIMS

Learn

Gain a deeper appreciation for and better understanding of what a person living with mild cognitive impairment or mild dementia experience day to day; their hopes, concerns, needs and goals.

Explore

Talk about what it is like to live with mild dementia and the impact it has on their day-to-day living. Explore what worked well on their path to diagnosis and care and what did not.

Cultivate

Facilitate a virtual, lived experience dialogue, intended to surface insights that will seed public and policy discourse.

Envision

Consider what might have the greatest effect for people impacted by mild dementia to make diagnosis, disclosure, and treatment easier in Canada.

APPROACH

Four individuals living with mild cognitive impairment/ mild dementia participated in a confidential, roundtable dialogue hosted by CanAge and facilitated by Addis & Associates on July 31, 2023. The initiative was supported by Eisai Limited.

INSIGHTS AND THEMES

Day to Day Living is a Good Day

In past conversations with people living with dementia we asked them what they hope for. We heard that they wish for *more good days* and to participate in *normal daily activities* such as morning swims and having dinner out with friends. Reflecting on their personal experiences, dialogue participants enthusiastically remarked, *doing the day to day living things that everyone does makes for a good day, to live beyond existing.* Having a purpose, social interactions, encouragement of others and autonomy to plan for and fully experience the next day are indicators of quality living. They want others to know "there is life with dementia."

Key Learning: Everyday moments some may take for granted represent vibrant, quality thriving for people living with dementia. There is a notion that there are worse things than dementia and ways to cope with the effects of dementia to cultivate a *'different but meaningful life.'*

"Getting up, having my coffee with my husband, being able to do all of the living things everyone else does is a good day… to continue to live a complete life instead of being stopped from living."

"Going hiking with others and returning home for a good meal makes life vibrant."

"Interactions with other humans is vitally important."

Persons Living with Dementia

"Support Us, Do Not Deny Us"

Contributors shared a conviction that they wish to be encouraged to live fully and enabled to do so with *'gentle prompts' and 'practical supports'* that do not diminish their personhood. Perhaps summed up by one participant who cautions *"do not stop us from doing things, that's when the disease progresses quicker, support us but do not deny us."*

Personal reflections darkened and participants commented that life is heavy and draining when

"The healthcare system can work against us, disbelief by others and being dismissed like we are not there."

"Pretending everything was fine was exhausting."

Persons Living with Dementia

they are isolated, when they are restricted from trying everyday tasks, being ignored, dismissed, and disbelieved. The burden of pretending everything is normal is exhausting, weighing heavily on people living with mild cognitive impairment and dementia, further entrenched by fear of judgement, exclusion, and stigma.

Unexpected Insight: A dichotomy exists between fiercely wanting to protect their persona and preserve their personhood and their desire for deeper understanding and empathy about the realities of living with dementia by healthcare professionals, workplaces, and social networks.

Significant Whole Person Impact

A striking theme underpinning our dialogue was how tightly held the fear of losing their independence was for the participants seemingly dreading lack of independence more than death itself. Preserving their persona was paramount. Participants disclosed they tried to portray their *'old selves'* to the outside world, not wanting others to see their decline and when that got too much to bear, they often retreated. All aspects of daily function are impacted by dementia, reported participants, and the journey to acceptance is unique.

> **"At first, for about two years, I withdrew, I did not feel comfortable anywhere, I was frightened. Through the support of others and support groups I gained acceptance."**

In the early days, uncertainty, shame, isolation, and apprehension gave rise to exploration and consideration of Medical Assistance in Dying (MAID) – *"how do I die?'*, slowly inching towards *"accepting new self, living with a brain that is different but ok"* – *"what are my options, what is the path forward?"* and then uncovering living well with mild dementia – *"how do I plan for something to look forward to tomorrow?"*.

Mild cognitive impairment/ dementia impacts day to day function reported contributors, the ability to communicate effectively, drive, cook and bank. The pressure to navigate daily tasks can be stressful, arriving at the grocery store only to find you are unable to maneuver the aisles or remember what you came to buy. Fearing that you may forget something critical like paying rent or picking up prescriptions. For one gentleman it was attending an event with his wife and not being able to coordinate his steps to get on the escalator. Everyday pleasures of the past such as cooking a family feast may be clouded with brain fog, anxiety, mobility impediments and confusion.

There is loss, *"my job disappeared, no one thought I was still capable, there were no modifications made at my workplace, you are told you are done that fuels despair."*

Participants were quick to point to *'work arounds and coping strategies'* that lift and enable them. For one respondent, acknowledging she can no longer prepare meals safely she engages meals on wheels. For another participant who often forgot to eat for three days at a time, she found gentle prompts from her partner and friends reminded her to prioritize nutrition.

Key Learning: There is pride in being able to live independently and interdependently upon the acceptance of help. There was great importance placed on available community support to retain autonomy and independence.

A Spectrum of Signs and Symptoms

We asked our dialogue participants if there are aspects of their disease or symptoms of mild dementia, they find most critical to control and found a spectrum of distressing signs and symptoms. Participants reported a range of effects from their condition including a reticence to engage, feelings of isolation, discomfort and apprehension, loss of direction and organizational skills impeded interaction with the world around them.

"I was acting out of character, I was suspicious and paranoid, being sneaky, it affected my relationship with my daughter, by getting on the drug Aricept to control my symptoms I could see my daughter, behave more like me."

> "I was working when I first noticed symptoms, I could no longer cash out at the end of the day, I did not know how to do the math anymore."
>
> "I used to be so independent now I may need help to figure out the TV gizmo or spend the first five minutes at a concert figuring out where the exits are to quell my nerves."
>
> Persons Living with Dementia

"I was not sleeping well, the next day I had trouble doing my tasks."

- Brain fog, confusion, and memory loss
- Sleep disruption
- Anxiety
- Word finding and difficulty finishing sentences

- Finding it hard to complete familiar tasks such as shopping or cooking
- Loss of direction and ability to navigate frequented areas
- Changes in mood and relationships, paranoia, and anger
- Loss of confidence

A breadth of symptoms reported by Persons Living with Dementia

Key Learning: Without symptom management people living with dementia cannot be part of social networks which are essential to thrive. There may be a presentation of physical, cognitive, and emotional symptoms.

A Haphazard and Unpredictable Path to Diagnosis

> **"You go home (after diagnosis), and you do not know how to live. The worst thing is not having Alzheimer's Disease it is the process to get diagnosed. I was told to get my affairs in order."**

The frustration and anguish were palpable when we probed participants' experience through the detection and diagnosis phase of their mild dementia journey. Perhaps the most distressing aspect of their condition arises from a lengthy, ad-hoc and uncertain assessment, testing and diagnosis process. Describing a lack of continuity or clarity during the detection and diagnosis of mild cognitive impairment with no sense of patient pathway or flow, participants often reflected a diagnostic period that included several disjointed health care providers spanning diverse specialties, providing differing diagnosis over a series of years leaving them more uncertain than they were before and prolonging an angst filled engagement with the health care system. It is not unusual for a confirmatory diagnosis to take 7 to 10 years, we were not surprised to learn some of the participants are still enduring a cycle of diagnosis, misdiagnosis, and re-diagnosis over an interval of years.

The variance in how individuals come to diagnosis was telling and significant. As one participant noted *"how the diagnosis is delivered determines how you navigate through the rest of it, if you get tools and resources at the time of diagnosis you can manage better."* Another participant *described a straightforward path to diagnosis through his memory clinic* with a knowledgeable physician although the communication was clinical, a bit cold, lacking empathy and not as "warm and fuzzy" as he would have expected, he appreciated the clarity and felt he received good care. Since that time, he and his wife have searched for support, resources, and information. Seeking information and resources is not atypical as individuals living with dementia and their care partners gain acumen through their experiences. There are indications of co-learning with the community they connect with signaling a flow of information that is socially based not medically facilitated.

> "The way we diagnose must change; it is horrendous. We have dementia we are not stupid; if the doctor would only listen to us."
>
> "It was the worst experience ever; I have empathy for people with mental health issues now and what they go through to get diagnosed."
>
> Persons Living with Dementia

Key Learning: The diagnosis process can cause harm and trauma. How the diagnosis is delivered and supported defines how you navigate and experience the healthcare system. Trial and error are frustrating, creating despair where there need not be. A clearly defined patient pathway is absent, yet necessary and more appropriate person-centred processes are needed.

Unexpected Insight: Co-learning among people living with dementia, their care partners and peers fill an informational void not addressed through health system mechanisms.

Treatment — What Matters

Today, dialogue participants are managing mild dementia symptoms through diet, exercise, and staying mentally and socially active. They are treating their mild dementia symptoms such as sleep disruption, anxiety and memory loss with prescribed medicines but are not treating the underlying disease. They acknowledged recent scientific advancements with anticipation and excitement and shared aspirations for a therapy that will slow cognitive decline and provide a cure for the next generation.

> **"I am excited about the new Alzheimer's Disease treatment that treats the disease and the progress in science. Right now, I only treat the symptoms."**

Retaining day to day function and cognition is top of mind for the dialogue participants, for two members their symptoms are diminished by Donepezil (Aricept) to treat their confusion and awareness, *"I was so confused at first, I did not know what was going on, some days I did not know how to put toothpaste on my toothbrush."*

In unison, contributors voiced their desire to be *'treated like a human being who has an issue'* as we would someone living with another serious condition such as cancer. They want medical professionals to counsel newly diagnosed individuals on how to live well with dementia and set them on a clear path to accessible information and services rather than having to seek and search.

There was a sentiment of hope spurred by the prospect of new disease modifying therapies.

> **"I really think the new medicines provide hope for my daughter and grandchildren, they will know they have the protein through testing. Generations that have gone before having set the path for them, telling our story, ...my mom's, aunts' and mine helps."**

Key Learning: People living with mild dementia want to retain function and cognition for as long as possible. They wish to delay disease progression, preserve their personhood, and remain independent to the greatest extent.

We Need to Do Better, We Must Do Better

Detection and Diagnosis

Participants described a pressing need for change most adamantly regarding mild cognitive impairment detection and diagnosis, stating *"we must do better, this is not acceptable"* seeking to shift the doctors' attitudes and reticence to diagnose people with dementia. When further probed about what they wished they had at time of diagnosis to lessen apprehension and make things easier, representatives agreed increased empathy and compassion by health care providers would improve comfort. They seek honesty, frank conversations and active listening from their health care providers indicating they hoped healthcare members would ask questions that surface their real day to day struggles such as *"What is happening in your life that has alerted you to changes in your cognition? What is going on in your daily routine that has you concerned?"* Participants are keenly aware the healthcare system is stretched and that patients are consulted for a matter of minutes. Acknowledging time is not kind to the dementia assessment process, contributors ask *that "Doctors do not diagnose before you truly listen to the individual with concerns."*

> **"The diagnostic process is disheartening and that is not ok."**

Key Learning: The opportunity to be assessed and cared for through a designated memory clinic, as experienced by one representative, improves the individual's experience, and streamlines the diagnostic process.

Integration of Lived Experiences

Respondents called for more preparation through medical education and professional development for health providers to gain a deeper understanding of what it is like to live with dementia. Participants suggest medical students and those treating dementia spend time with people living with the condition and their care partners to gain a more fulsome appreciation of their reality.

A Clear Pathway

Provide people impacted by mild cognitive impairment/mild dementia with a standard, stepwise path forward. Bolster understanding of what comes next, what are the intervention moments, where to seek information and resources describing some of the scenarios that may unfold as the disease progresses and how care may take shape. Diminish trial and error across the current haphazard, unpredictable, and disjointed dementia journey.

> **"A friend who has had the disease longer than me, is now at the stage where he cannot recognize anyone but his wife... is that something that will come to all of us in the end or just among the range of possibilities? It was described to me as a general decline, but I want to be more aware of the stages of disease, what is to come, what does progression look like."**

Receiving the News of a Dementia Diagnosis

People with lived experience ask that others receive their news of a mild dementia diagnosis with empathy, compassion, curiosity, and pragmatism. Surfacing the notion of coaching Canadians on how to genuinely engage friends, family, and co-workers on the topic, particularly when first being told of an individual's diagnosis. Participants shared stories of how friends and family responded to their disclosure, and agreed saying "but you look so good, you can't have dementia, you don't act like you have dementia" is not helpful. Members described that responses and feedback *'are funny, you have to be prepared to get inappropriate reactions."* It became apparent that the needs and feelings of people living with dementia when telling people of their diagnosis are going underrecognized and unaddressed by healthcare professionals, family, and friends. Perhaps the most comforting responses arise from empathetically acknowledging the condition and expressing compassionate curiosity, *'how can we help?'*

> **"I told some family straight away, another sister I have not said anything to yet, I keep putting it off. I rang up a guy I went to university with who said I am so sorry to hear, how can we help? That was helpful."**

For one woman, she found *"telling people gave me the freedom to be who I am"* reinforcing her autonomy. She emphasized that she would keep telling her story to bring about change to ensure the next generation is embraced by a community of informed support.

CONCLUSION

Empathy, Independence, and Community: Navigating the Way Forward

This report, rich with insights and personal stories, offers a window into the multifaceted world of those living with dementia. Our journey through these pages reveals several key takeaways that are vital for shaping a more inclusive and supportive society.

1. **Embracing Different but Meaningful Lives:** Persons living with dementia often find vibrant quality and thriving in everyday moments. There's a prevailing belief that life with dementia, while different, can still be deeply meaningful. This perspective challenges us to rethink how we, as a society, view and interact with persons living with dementia.
2. **The Dichotomy of Persona and Understanding:** People living with dementia grapple with a delicate balance between protecting their personhood and desiring deeper empathy from healthcare providers, workplaces, and social networks. This dichotomy calls for enhanced awareness and education about dementia, promoting a more empathetic and informed approach in all sectors.
3. **Independence and Community Support:** The report highlights the pride those living with dementia take in their ability to live independently, yet interdependently, acknowledging the importance of community support. This insight emphasizes the need for accessible community resources that foster autonomy while offering necessary assistance.
4. **Addressing the Fear of Loss:** A significant barrier to early diagnosis and treatment is the fear of what might be lost—employment, autonomy, relationships. Understanding and addressing these fears are crucial steps toward encouraging timely medical intervention and support.

As we move forward, these insights offer a roadmap for CanAge, its partners, and the broader community. Together, we can advocate for policies and practices that not only recognize the challenges faced by persons living with dementia, but also celebrate their strengths and contributions. By fostering an environment of empathy, support, and respect, we can ensure that our friends and loved ones live not just longer but better lives.