# Policy Brief

## What Should Dementia Care Look Like Moving Forward? Perspectives of Caregivers, Academia, and Healthcare professionals.

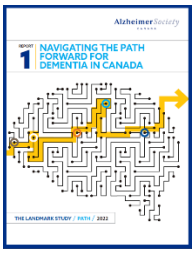
### Target Audience

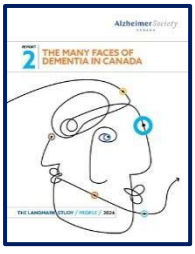
The Ontario Ministry of Senior and Accessibility and Ministry of Health and Long-term Care.

### The Problem

Over 400 Canadians experience the onset of dementia every day. As a nation, we are witnessing exponential growth of the cognitive disorder, with cases expected to almost double from 2025 to 1.7 million by 2050.

Accordingly, the consequences on the healthcare system are vast, with caregivers at the core of this impact. With the appropriate steps, we can work towards mitigating these effects effectively by reducing the repercussions and caregiving hours. However, the question remains: ***How***?




The Alzheimer's Society of Canada put forward two reports to help answer this question, with an emphasis on the roles of healthcare systems, governments, and researchers.

### The Action

Notably, the management of dementia is not one-size-fits-all, and a **closer look at community consultations can help provide a more targeted plan for the province**.

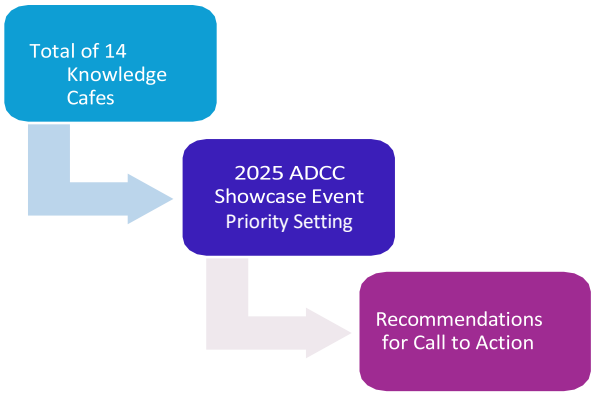

### EXECUTIVE SUMMARY

- Priorities and action in dementia care require a targeted approach.
- Knowledge cafes (discussions) conducted with 88 caregivers, faculty, and healthcare professionals.
- Results presented and deliberated at 2025 Advancement for Dementia Care Centre (ADCC) Showcase Event in Durham Region, Ontario.
- Input from community partners and healthcare professionals indicated that changes are required on education, community, and institutional levels.
- Recommendations revolve around raising awareness about dementia, recognizing differences among cultures, and support with navigating health systems and resources, as well as improved care coordination of services and programming.

## The Approach

With the funding support from the Canadian Institute of Health Research (CIHR) Planning & Dissemination Grant, Dr. Winnie Sun and Dr. Amer Burhan, in collaboration with ADCC team conducted a community-based participatory research to gather opinions on the future directions in dementia care. Knowledge cafes* with caregivers, faculty, healthcare professionals (HCP) highlighted the gaps and opportunities to advance dementia care.

Results were presented at the annual Advancement for Dementia Care Centre (ADCC) Showcase event in the Durham Region to establish consensus building in key priorities and areas of focus with recommendations for action.




## What We Heard From Caregivers

***Challenging The Assumptions Through Understanding Personhood***

*"Increased dialogue about dementia in the same way that cancer and stroke diagnoses are discussed, as a diagnosis that should be taken care of rather than being seen as an annoyance."*

*"It's vital to give culturally sensitive care, especially in people with dementia who demonstrate regression in their mental capacity. They will be more receptive and familiar with habits and practices that they partook over the course of their lives, rather than the strict rules or unfamiliar approaches/environment in a hospital or long-term care facility."*

## What We Heard from Academia

***Understanding The Current Landscape Of Dementia And Its Challenges***

*"Trying to get respite care… you have to book 3–4 months in advance. Then you have to choose from a list of homes… and ending up giving up and say forget it."*

*"It's challenging to see your loved one being really disintegrate… They deserved to have a peaceful retirement."*

*"Life expectancy for men in some Oshawa neighborhoods is 10 years below the national average… Dementia care needs are not one-size-fits-all."*

*"Sometimes designing for dementia care programs means going back to basics—just need a set of simple, clear buttons."*

*"Smaller home-like environments are what older adults need—not the mega warehouses being built that are not meeting their real needs.*

***Knowledge Cafes**: Open dialogue and discussions with community members, driven by a participatory approach.

## What We Heard From HCP

***Care Fragmentation And Shortage Of Resources***

*"In-home respite just isn't out there… and the caregiver relief support is fragmented, we're focusing on that, but we don't have the staff to do it."*

***Need For Educational Preparation***

*"People always think that dementia is so scary… letting people know that with the right support… they can continue to thrive."*

*"One of the most important things we can do is embed dementia education into colleges and university curricula. Right now, most courses on seniors focus on frailty or death and dying. But that's not the whole picture."*

*"Newer staff sometimes panic when someone gets agitated. They don't know it's just part of the disease process."*

***Respect For Cultural Diversity***

*"We started using songs in someone's first language and suddenly they were smiling, engaged—it brought them back."*

*"We need cultural corners—spaces that reflect different traditions, languages, even festivals."*

***Transforming Care Through Innovations***

*"I love those dementia villages… I really wish we could have a ton of those, and I really wish they didn't cost $10,000."*

*"I'd love more innovative tech app that lets us log responsive behaviors in real time."*

## Priorities

1) Addressing systemic gaps in promoting navigation of services and resources for better care coordination and support

2) Cultivating community-based care to promote aging-in-place

3) Catalyzing innovations in caregiver respite and education

4) Overcoming fragmented and crisis-driven, reactive care systems

5) Strengthening competency-based training and micro-credentialing in dementia care

6) Advancing quality-of-life metrics and dementia care prevention

7) Providing adequate training in managing responsive behaviors & multi-modality approaches to dementia care

8) Strengthening community-based dementia care through proactive, coordinated, and integrated approaches

9) New strategies/interventions to advancing management of behavioral symptoms with practical training

10) Mitigating staffing and systemic issues to build stronger workforce capacity

11) Promoting integrated caregiving support through centralized community services, with engagement from family, and frontline professionals

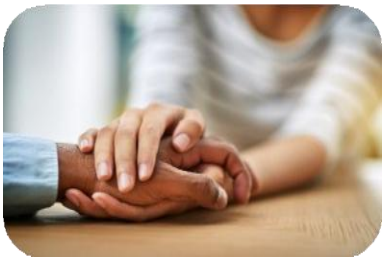
12) Destigmatizing dementia through raising awareness, education and open dialogue

## Recommendations For the Ministries

1) Advance National Strategy in Dementia Care through Interdisciplinary Collaboration and Partnership
2) Invest in Strengthening a Comprehensive Dementia Care Education
3) Explore Technology-Enabled Care Solutions to Facilitate Caregiving, Dementia Prevention and Management
4) Connect People with Resources And Navigators to Encourage Service Uptake
5) Implement and Sustain What We Know and Already Have to Establish Proactive Care Delivery and Coordination
6) Develop Strategic Partnerships that Support Joint Efforts in Advancing Dementia Care Innovations and Therapeutics
7) Address Care Provider Shortages through Workforce Retention Program
8) Consolidate Interdisciplinary Coordination In Policy, 80/20 Rule (Benefits 80% of People)
9) Strengthen Community Based Dementia Care: Grass Root Initiatives
10) Integrate Complementary Approach of Both Pharmacological and Non-Pharmacological Interventions to Maximize Outcomes of Care

## Implications

By implementing these recommendations, we can work towards a more unified approach to dementia care that connects, not divides.



Together, we can advance person-centered dementia care that embraces equity, diversity and inclusion, while addressing the care burden on caregivers as well as building workforce capacity that promotes dementia-friendly community across the care continuum.


## Acknowledgements

We would like to acknowledge the valuable contributions from team members, partners, and advisors from Ontario Tech University, Advancement for Dementia Care Centre (ADCC), Ontario Shores Centre for Mental Health Sciences, Alzheimer's Society of Durham Region, Durham Region Long-Term Care, Oshawa Senior Community Centre 55+ (OSCC), Geriatric Assessment Intervention Network (GAIN) and Senior Care Network.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