

Concept Letter

Alzheimer's Awareness and Caregiver Education Initiative

A Cross-National Canada–Trinidad & Tobago Collaboration

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Executive Summary

This concept letter proposes a cross-national Alzheimer's awareness and caregiver education initiative grounded in lived experience, clinical practice, and doctoral research. Drawing on findings from Canada, the United States, and Trinidad and Tobago, the initiative responds to a consistent, evidence-based gap in caregiver supports across jurisdictions.

Doctoral research and professional practice demonstrate that caregivers, particularly sandwich generation caregivers, experience parallel challenges regardless of country, including burnout, emotional exhaustion, role overload, and insufficient formal supports. These outcomes are shaped by intersecting factors such as gender, age, migration history, employment demands, and cultural expectations around family caregiving.

This initiative positions Alzheimer's awareness and caregiver education as a shared concern between Canada and Trinidad and Tobago, offering an opportunity for collaborative, culturally responsive approaches that strengthen caregiver capacity while reducing long-term system strain.

This document is intended as a discussion-starter to explore alignment, interest, and potential next steps.

Background and Context

I am a dual Canadian–Trinidadian citizen who spent my formative years in Trinidad, attending Dunross Preparatory School and Holy Name Convent. During this time, my father was seconded from the Canadian government and later employed by the Government of Trinidad and Tobago in senior aviation

leadership roles. My mother was a registered nurse who practiced in both Trinidad and Canada.

At age 57, my mother was diagnosed with Alzheimer's disease. Following the sudden death of my father in 2001, she came to live with me in Brampton, Ontario, at which point I became a full-time sandwich generation caregiver while raising a young child and maintaining professional responsibilities. This caregiving role continued for many years and profoundly shaped my academic, clinical, and advocacy work.

Since 2018, I have served as Co-Chair of the Older Adult and Caregiver Committee with Age Well. I have spoken at national and international conferences on Alzheimer's disease, dementia care, and living with the disease, and have authored peer-reviewed medical journal articles. I am also the author of multiple books on caregiving, dementia, and emotional health, including titles from the What They Forget to Tell You series. This initiative emerges at the intersection of personal history, professional training, and long-standing engagement in aging and dementia care.

Research Foundation and Methodological Rigor

This initiative is informed by my doctoral dissertation: Longitudinal Effects of Sandwich Generation Caregivers of Alzheimer's Disease Parents in Palliative Care.

The study employed a phenomenological methodology examining lived caregiving experiences over time. Participants were drawn from Canada, the United States, and Trinidad and Tobago. Despite differences in healthcare systems, geography, and service availability, the outcomes were consistent across jurisdictions.

Caregivers reported sustained emotional strain, identity disruption, limited access to caregiver-specific education, and insufficient formal supports, particularly in relation to dementia and Alzheimer's disease. These findings reinforce that caregiver distress is not country-specific, but systemic.

This research foundation aligns with international dementia and caregiver literature and reflects the same evidence base used in the development of the FORUS caregiver education framework.

Intersectional Caregiving Realities

Caregiving does not occur in isolation. Research and practice consistently show that caregiver burden is shaped by intersecting social and structural factors, including gender, age, migration history, employment demands, and cultural expectations around family responsibility.

Sandwich generation caregivers, many of whom are women balancing paid work, parenting, and elder care, experience compounded strain that often remains invisible within formal healthcare systems. These intersectional realities are present in both Canada and Trinidad and Tobago, despite differences in policy and service frameworks.

Recognising these intersections is essential for designing Alzheimer's awareness and caregiver education initiatives that are effective, humane, and sustainable.

Rationale for a Cross-National Initiative

The consistency of caregiver outcomes across Canada, the United States, and Trinidad and Tobago points to a shared challenge rather than isolated national issues. While system-level responses differ, the lived realities of caregivers remain strikingly similar.

Both Canada and Trinidad and Tobago face growing aging populations, increasing reliance on unpaid family caregiving, and limited caregiver-specific education and emotional supports. This convergence creates a natural opportunity for collaboration grounded in mutual learning rather than one-directional knowledge transfer.

Alzheimer's awareness and caregiver education represent a meaningful and practical entry point for such collaboration.

Concept Overview

The proposed initiative would focus on Alzheimer's awareness and caregiver education through a structured, accessible framework that may include:

- Education on dementia and Alzheimer's disease progression
- Understanding behavioural and emotional changes
- Communication and de-escalation strategies
- Caregiver burnout prevention and emotional regulation
- Anticipatory grief and long-term caregiving impact

- Supporting caregivers without pathologising or moralising their experience

Content can be adapted for family caregivers, healthcare and community workers, faith-based organisations, and public awareness settings. Delivery could be online, in person, or hybrid, depending on stakeholder interest and feasibility.

Purpose of This Concept Letter

This letter is intended to explore alignment and interest and to open a dialogue about whether a culturally responsive Alzheimer's awareness and caregiver education initiative could be meaningful and useful within the Trinidad and Tobago context, in partnership with Canadian stakeholders.

I welcome the opportunity to discuss this concept further and to collaboratively determine appropriate scope, partnerships, and next steps.

References

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Leid, C. Alzheimer's – What They Forget to Tell You: A Personal Journey.

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Additional titles in the What They Forget to Tell You series and related schema therapy-informed works on emotional health and caregiving.

World Health Organization. Dementia Fact Sheet and Global Action Plan on the Public Health Response to Dementia.

Public Health Agency of Canada. Dementia in Canada: National Strategy and Caregiver Impact Reports.

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