



Informing the National Strategy for Alzheimer's Disease and other Dementias

NATIONAL SURVEY FINDINGS

Bill C-233: An Act respecting a national strategy for Alzheimer's disease and other dementias



CHCA's consultative role

What is needed to make HOME CARE BETTER for people living with dementia and SUPPORT THEIR CARERS who play such a vital role?

- Member of the Dementia Conference Planning Committee
- Online surveys – home care providers & caregivers

Findings of Home Care Providers Survey

There are significant gaps in the quality and quantity of home support services enabling people with dementia to live well and safely in their own homes.

245
respondents
from a variety of
positions:

Policy and
program
planners

Health
administrators

Frontline care
providers

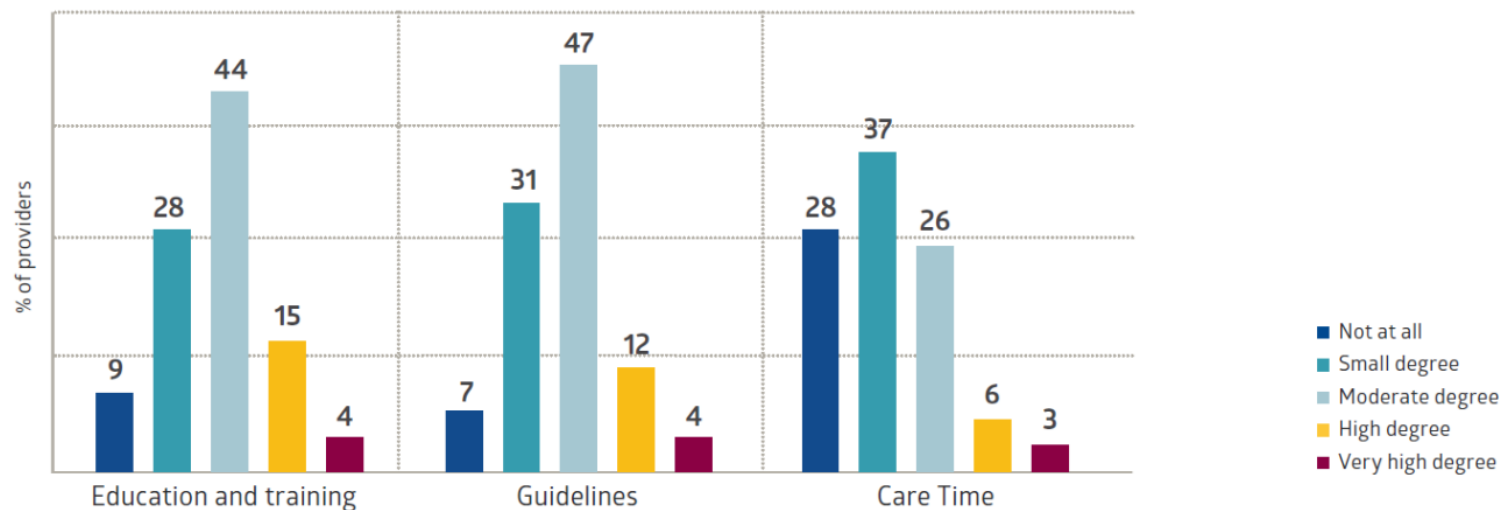
Findings of Home Care Providers Survey

Significant gaps in dementia care in the home

- Education and training
- Practice guidelines
- Care time

- 78% reported a 'high' to 'very high' degree of **challenge** in providing dementia care
- 9% felt **adequately prepared** to respond effectively to an individual's behavior changes and ensuring safety in the home

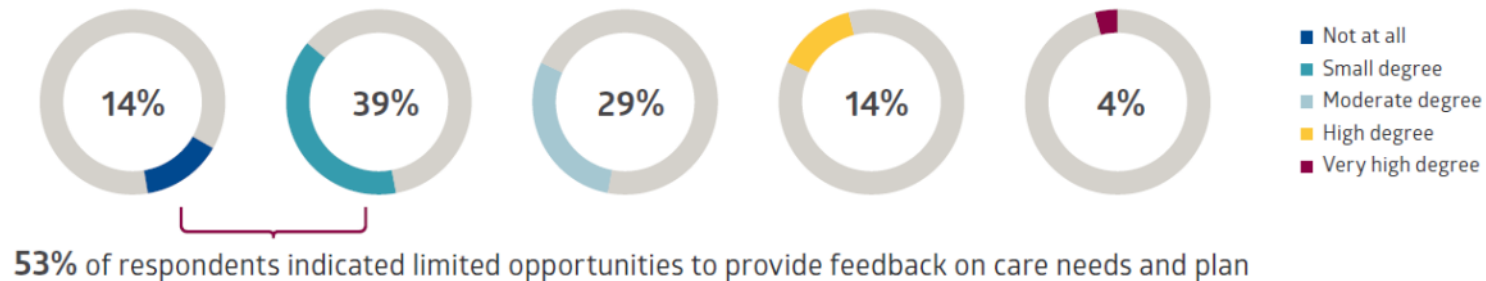
Perceived availability of education, guidelines and care time



Findings of Home Care Providers Survey

Significant gaps in dementia care in the home

- Limited opportunities for para-professionals (e.g. Personal Support Workers) to provide feedback on care needs and plan



Findings of Home Care Providers Survey

Key strategies to enhance care in the home for people living with dementia

Three overarching themes:

- **Reduce risk and provide early intervention** for individuals living with dementia to delay decline, prevent crisis and postpone transition to long-term care placement
- **Provide high quality person-centred dementia care** and support to enhance care in the home
- **Enhance system capacity** to support accessible home care for individuals living with dementia.

Findings of Home Care Providers Survey

Key strategies to enhance care in the home for people living with dementia

Reduce risk and provide early intervention

Provide high quality person-centred dementia care

Enhance system capacity

PRIORITY ACTIONS	PRIORITY ACTIONS	PRIORITY ACTIONS
<ol style="list-style-type: none">1. Expansion of community support programs (e.g. First Link) which provide early referrals for people with dementia and their families.2. Access to patient and caregiver resources on managing the condition and daily lives (including abuse prevention information).3. Advance care planning to support people with mild cognitive impairment and their families to plan for future personal and health care decisions.4. An assessment approach specific for home care providers to support early identification of dementia.	<ol style="list-style-type: none">1. Increase respite and support for carers (i.e. better funding for family care support, easier access and navigation, whole family education).2. Practice guidelines, tools and resources for frontline home care providers (professionals and para-professional) to assist with the behavioural symptoms of dementia.3. Specialized care coordinators linked to a health care team that includes family physicians, carers, home and community health services.4. Identification of core competencies for frontline home care providers and incorporation of these into interdisciplinary dementia education and training opportunities.5. Use of assistive technology to help individuals living with dementia maintain safety and independence.	<ol style="list-style-type: none">1. A greater range of dementia specific services available in the community.2. Integrated strategies with hospitals and emergency departments to address the needs of people living with dementia and their caregivers.3. Evidence-informed measures of quality dementia care in the home setting.4. Enhance information sharing across jurisdictions and regions on best practices.5. Targeted research to improve outcomes for people living with dementia and their families in the home.

Findings of Carers Survey

116 caregivers from across Canada

“ I was all alone and did not know what questions to ask...”

“ If folks were made aware at the early onset of the disease or before, they might be able to come up with better planning. We did not plan, I coped.”

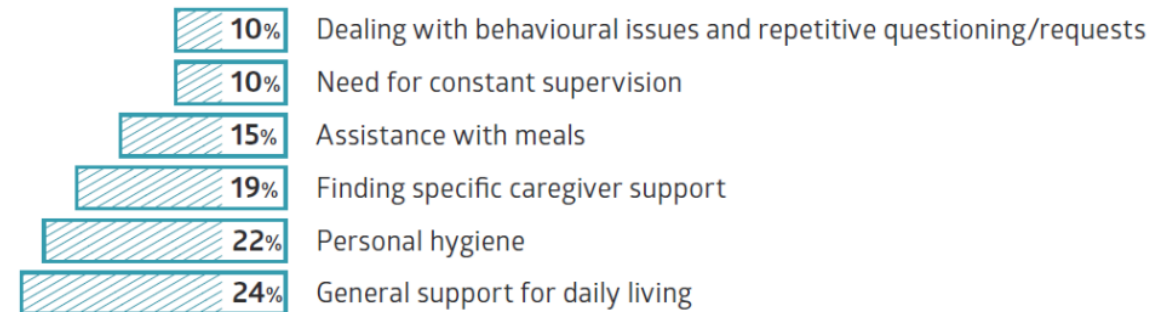
“ The biggest gap and challenge is skilled, trained and competent staff who are able to perform these tasks. Often staff were not the right "fit" to care for individuals with dementia care needs. This is complex care requiring skill in order to maintain the dignity of these special individuals.”

Findings of Carers Survey

Caring is complex

- 66% of people living with dementia also has other health condition(s).
- 79% of caregivers find caregiving 'somewhat' or 'very' challenging.

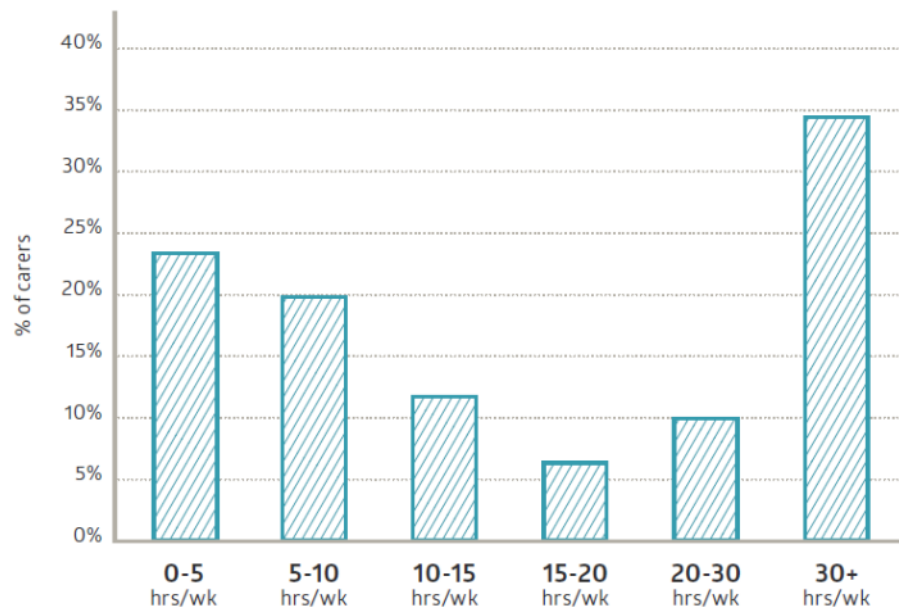
Tasks carers felt they needed help with



“ Getting my sister to eat, hearing the same thing over and over... this is a part of the disease, but every 5 minutes can be taxing. Some days everything can be difficult, other days are wonderful. ”

Findings of Carers Survey

Caring is complex



Caregivers provide up to 30 hours/week

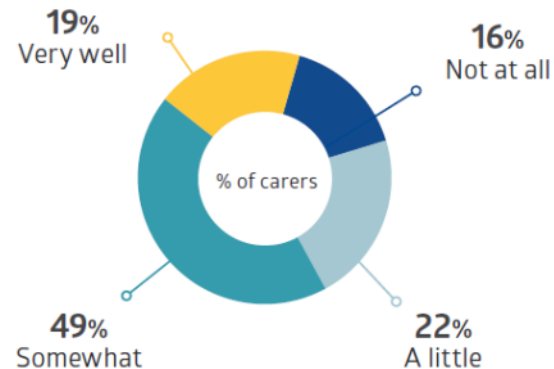
“ I am 55 and find working full-time, parenting for my own children, doing volunteer work, and caring for a parent very overwhelming at times.”

Findings of Carers Survey

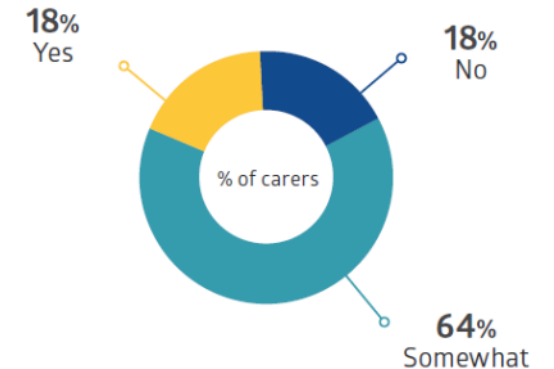
Caring is complex

Less than 20% of carers felt 'very well' prepared for and/or able to adequately respond to the changing care needs.

Sense of 'preparedness' in responding to behaviour changes



Sense of ability to respond to changing care needs



A trusted support system, previous experiences, and self-education are among the reasons shared by respondents who felt very well or somewhat prepared in responding to behaviour changes.

Findings of Carers Survey

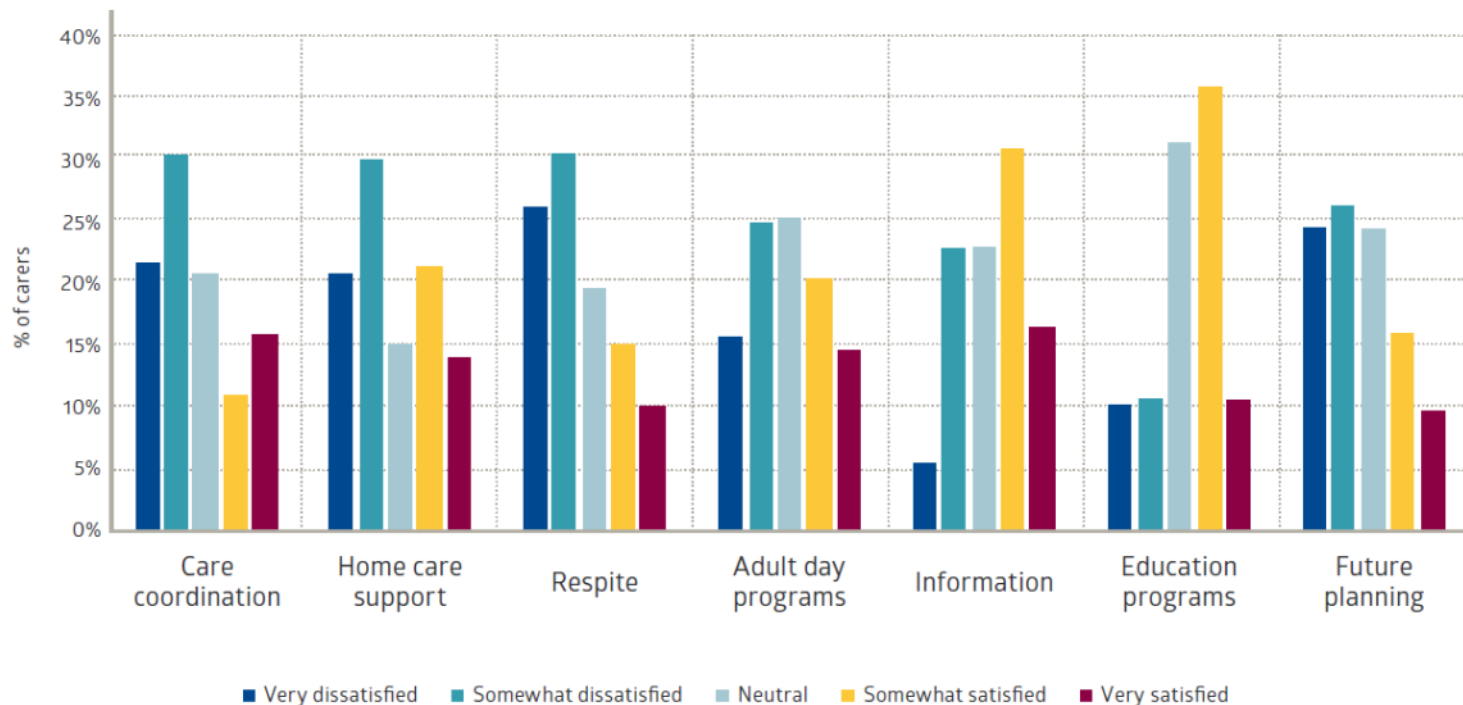
Access and quality of supports for carers varies widely

	ALWAYS	OFTEN	OCCASIONALLY	NEVER
Received support to maintain own well-being	17%	23%	33%	27%
			60%	
Given options to ensure decision made is patient-centred	29%	30%	30%	10%
			40%	
Provided opportunity to ask questions	29%	33%	28%	10%
			38%	
Involved in care planning	30%	31%	32%	7%
			30%	

Findings of Carers Survey

Access and quality of supports for carers varies widely

Carers' assessment of available supports



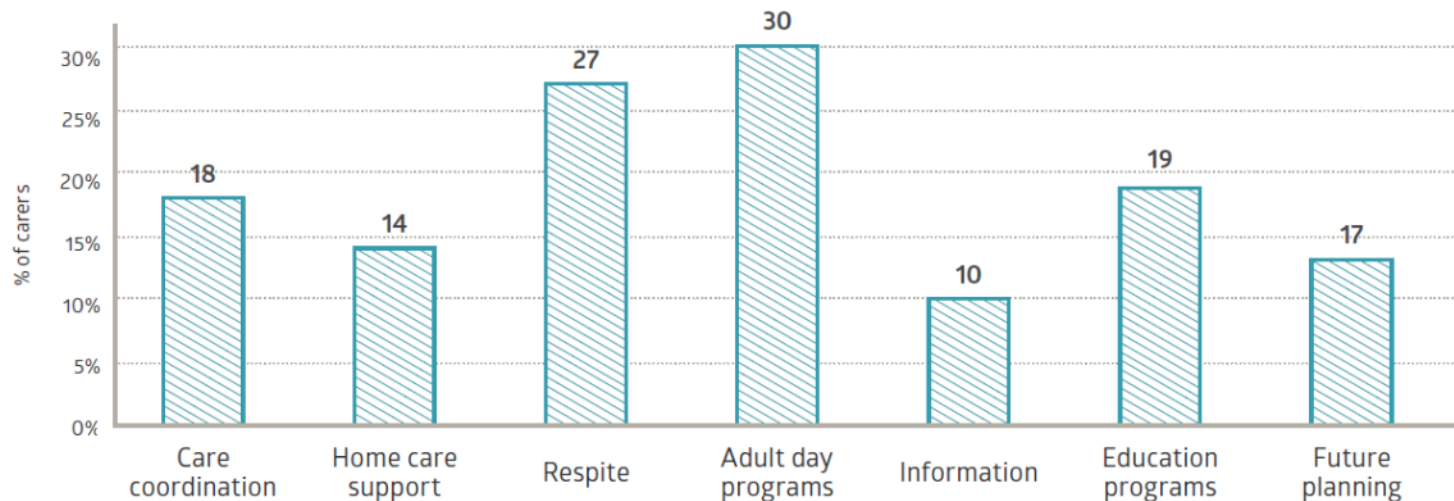
Top 3 services that carers rated as 'very' or 'somewhat' **dissatisfied**:

- Home care supports
- care coordination
- future planning

Findings of Carers Survey

Access and quality of supports for carers varies widely

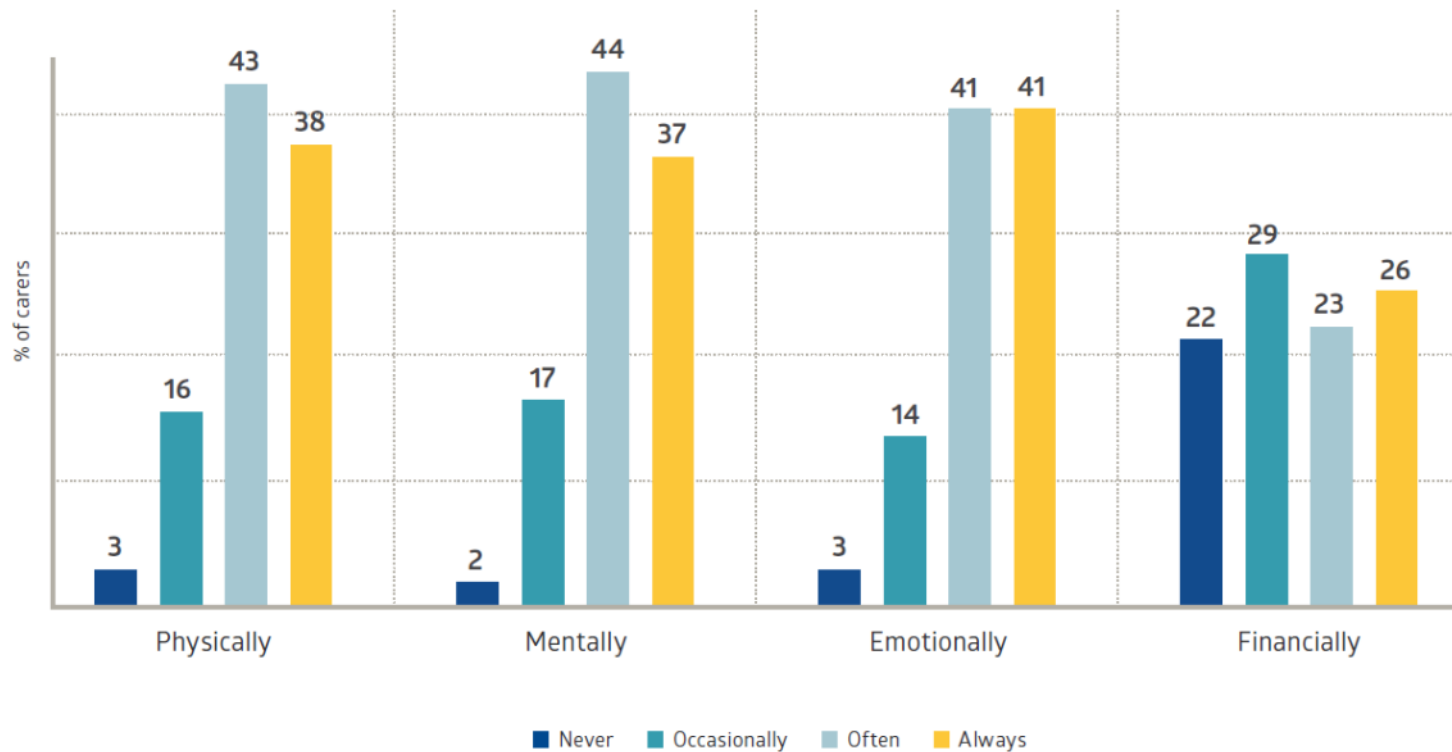
Percentage of carers who have never accessed supports



Carers may not know when they need extra supports, or how to access or use available resources.

Findings of Carers Survey

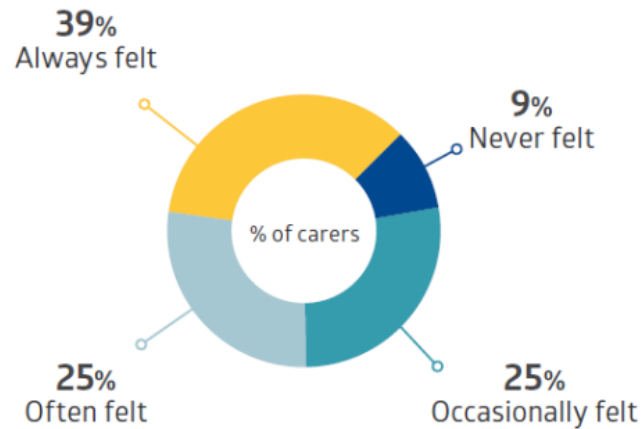
Impact of caring on carers' health and well-being



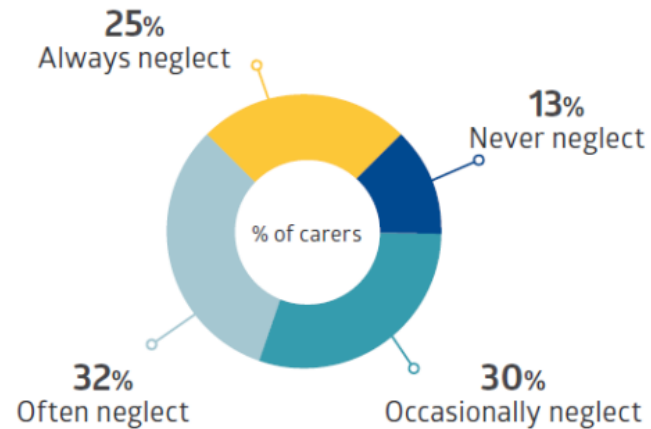
Findings of Carers Survey

Impact of caring on carers' health and well-being

Have you felt like you have no time for yourself?



Has caregiving made you neglect your own health?



Findings of Carers Survey

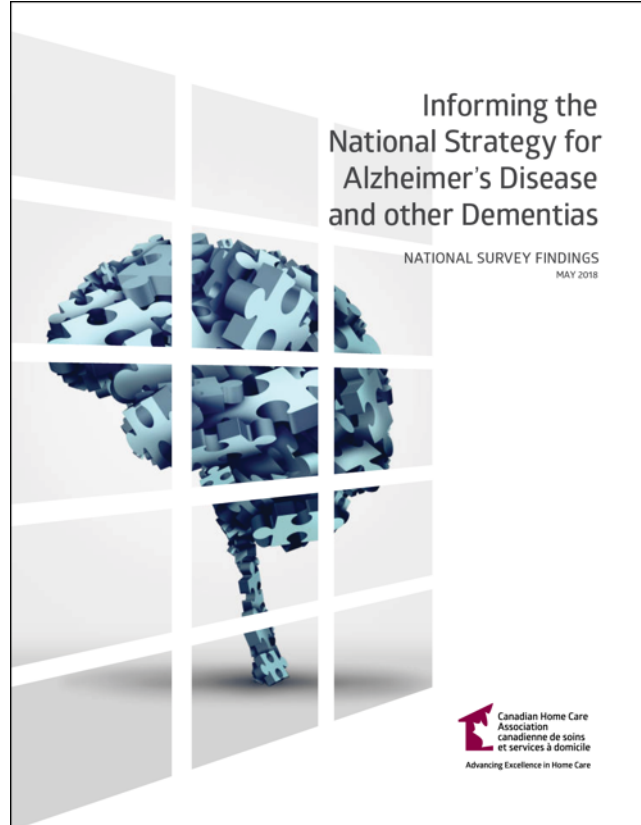
Carers' reported need for supports

- Provide more **home care** (professional , respite and support services)
- Create **support groups** (peer to peer, organizations)
- Easier way to **access care** (in the home)
- Better **coordination** of services
- **Information** to better understand dementia and early diagnosis

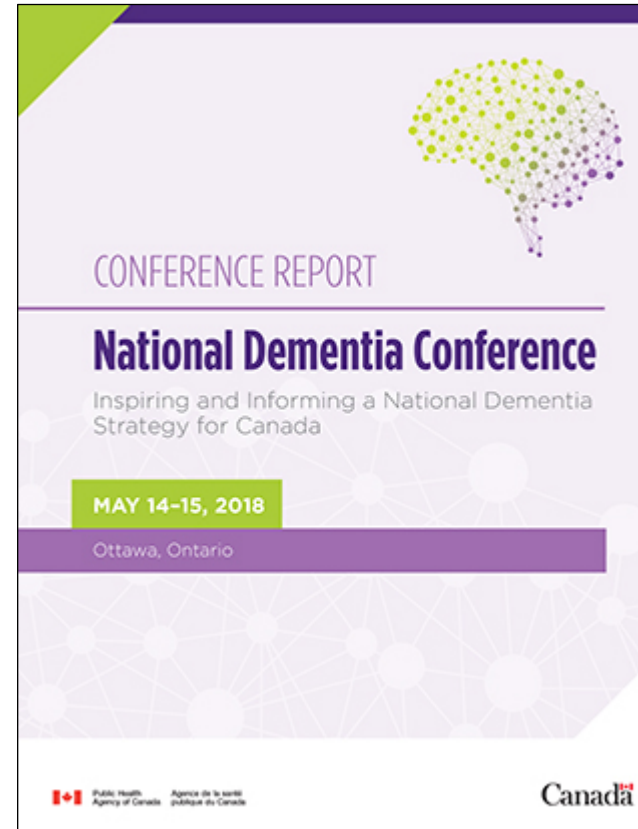
Summary

- Targeted education, training and practice guidelines for front line home care professionals are needed to support dementia care
- Enhancing support for carers is identified as a top priority under all key themes in creating better home care.
- Although supports are available, carers may not be aware or know how to access them.
- Progress has been made – but quality and availability of support services are not consistent to enable people with dementia to live well and safely in their home.

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www.cdnhomecare.ca



<https://www.canada.ca/en/services/health/publications/diseases-conditions/national-dementia-conference-report.html>