

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

NATIONAL SURVEY FINDINGS

MAY 2018



Canadian Home Care
Association
canadienne de soins
et services à domicile

Advancing Excellence in Home Care

ABOUT THIS REPORT

One of the fastest growing patient populations receiving home care services is individuals living with Alzheimer's disease and other dementias. These progressive and degenerative conditions not only have a tremendous impact on the person with dementia, but also places great demand on their carers,¹ health care service providers and the health system at large.

The Canadian Home Care Association (CHCA) conducted online surveys throughout January 2018, Alzheimer's Awareness Month, targeting home care service providers and carers. The objective of the surveys was to gain a better understanding of what is needed to make home care better for people living with dementia and support their carers who play such a vital role. In recognition of existing provincial and territorial dementia strategies, survey questions were developed to reaffirm and build on common elements across the country.

This report summarizes the feedback from the surveys and has been used to inform the federal government in its advancement of Bill C-233, an Act respecting a national strategy for Alzheimer's disease and other dementias. The Act directs the federal Minister of Health to develop and implement a comprehensive national strategy for the care of people living with Alzheimer's disease or other forms of dementias, as well as their families and caregivers.

¹ Carers are family members, neighbours and friends who take on an unpaid caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness. Carers are also known as caregivers or family caregivers.

SPECIAL RECOGNITION

Thank you to members and partners of the Canadian Home Care Association and Carers Canada for sharing the surveys with your staff, carers and networks. To all our respondents, we appreciate the time you have taken from your busy schedule to share your experience and expertise in caring for individuals living with Alzheimer's and other dementias. Lastly, a very sincere thank you to David Daghli, P.Eng., Ph.D., for analyzing the survey results.

HIGHLIGHTS

People living with dementia are likely to have complex needs, compounded by a range of co-morbidities, which make challenges of caregiving significant.

Enhancing support for carers is identified as a top priority under all key themes in creating better home care.

Carers are a vital part of the health care team and yet their involvement, input and engagement in health care planning is not consistent.

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.

Home care support, care coordination and future planning are among the services carers rated as "very" or "somewhat" dissatisfying.

FINDINGS OF HOME CARE PROVIDERS SURVEY

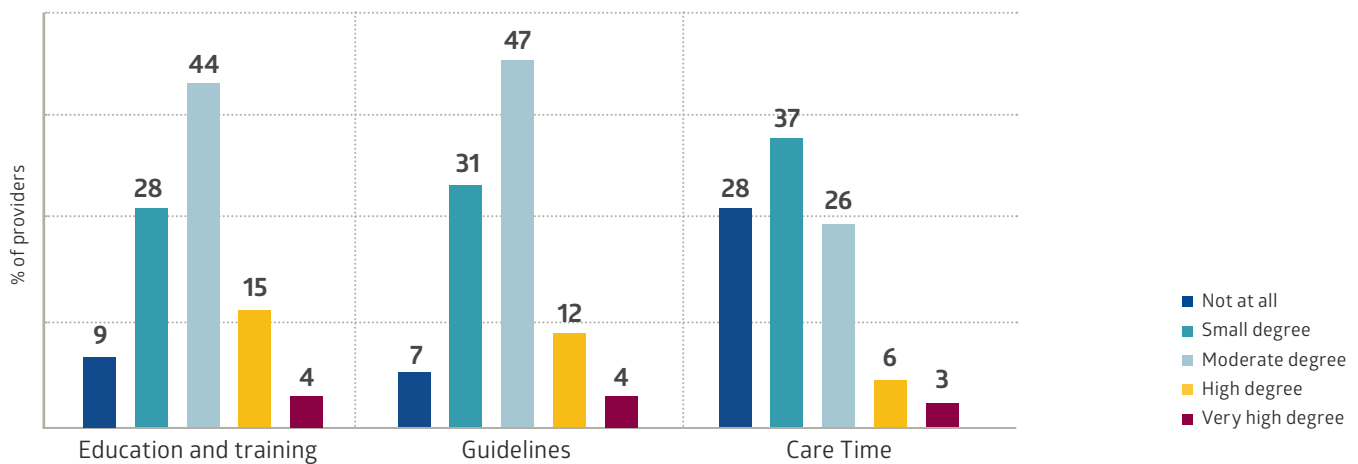
People living with dementia want to live well and independently in their own homes and participate in their community for as long as possible. A total of 245 home care providers from a variety of positions (i.e. policy and program planners, health administrators and front line care providers) across Canada shared their experiences and provided input on key strategies to enhance care in the home for people living with dementia.

Significant gaps in dementia care in the home

Majority of respondents (78%) reported a 'high' to 'very high' degree of challenge in caring for people living with dementia. Only 9% of respondents felt adequately prepared to respond effectively to an individual's behaviour changes and ensuring safety in the home. Challenges that may contribute to this include:

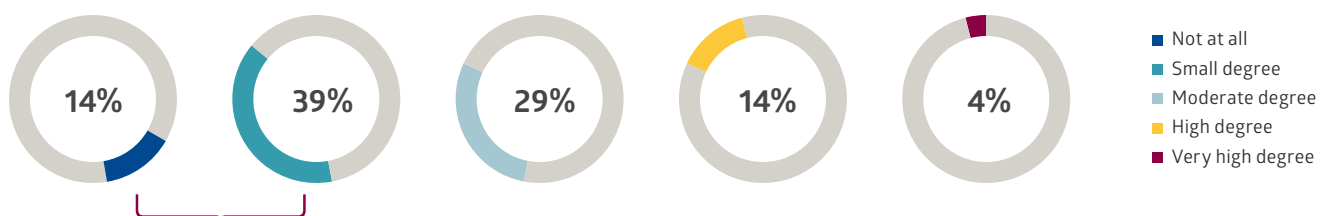
- lack of education and training specific to dementia;
- limited practice guidelines for dementia care in the home; and
- lack of time during each visit to address all the needs of patients and their caregivers.

Perceived availability of education, guidelines and care time



As a provider who spends the greatest amount of time with the patient, para-professionals (e.g. Personal Support Workers) are often the first professional to notice changes in the patient's condition or situation. This includes being aware of the safety of their patients so they can stay in their home for as long as possible. However, through the survey, it was identified that there are varying opportunities or mechanisms for para-professionals to provide feedback on the patient's care needs and plan.

Perceived opportunities to provide feedback



53% of respondents indicated limited opportunities to provide feedback on care needs and plan

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

Respondents prioritized key strategies that emerged from common elements found across existing provincial and territorial dementia strategies. The strategies were grouped into three overarching themes.

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

Research priorities to support evidence-informed dementia care in the home and community setting

Respondents were asked 'Looking ahead, what research areas for dementia care in the home and community setting should be given a priority?' There were 140 individual responses captured from the survey with the following predominant themes:



Awareness of and support for carers: role as a care partner, support services, system navigation, caregiver education and training, respite options and financial.



Education and training for health care professionals: best practice guidelines, behaviour management strategies and communication tools.



Early diagnosis and management of care: risk reduction, early assessment and interventions, progression and future planning.



Culturally sensitive dementia care: community social engagement programs, rural dementia care, approaches for Indigenous communities, dementia-friendly communities and safety measures.

PROVINCIAL DEMENTIA STRATEGY AND ACTION PLAN

- **Nova Scotia's dementia strategy, Towards Understanding (2016)**, focuses on ensuring access to timely, accurate diagnosis, more public education and awareness, better supports for families and caregivers, and enhancing the health system to provide coordinated dementia care.
- Quebec's Action Plan, **Meeting the Challenge of Alzheimer's Disease and Related Disorders: A Vision Focused on the Individual, Humanism, and Excellence (2009)**, proposes seven priority actions, with 24 recommendations on a number of cross-cutting themes, including: caregivers, behavioural and psychological symptoms of dementia (BPSD), alternative living arrangements, development and support of medical practice, ethical issues, and research and innovation.
- The Ontario Ministry of Health and Long-Term Care has developed a discussion paper, **Developing Ontario's Dementia Strategy (2016)**, to engage Ontarians in a conversation about how to improve access to quality care for people living with dementia and support those who care for them.
- **Manitoba's Framework for Alzheimer's Disease and Other Dementias (2014)** sets a five year roadmap in five key areas, which includes raising awareness and understanding; early recognition, initial assessment and diagnosis; management, care and support; end-of-life care; and research and evaluation.
- **Alberta Dementia Strategy and Action Plan (2017)** outlines the steps that government, in collaboration with community organizations, care providers and individuals living with dementia and their caregivers, can take to raise awareness of dementia and support all Albertans living with dementia. The strategy focuses on brain health, timely diagnosis, accessible services as well as providing supports for families from the onset of dementia through to end of life.
- **The Provincial Dementia Action Plan for British Columbia (2012)** provides a common road map to continue building on investments in clinical innovations and new approaches to service delivery actively underway across the province.

FINDINGS OF CARERS SURVEY

Carers are a vital determinant to positive outcomes for people living with dementia. Their valuable role is reinforced through the home care providers survey where supporting caregivers was identified as a key priority in all three themes in creating better home care for people living with dementia.

As a subset of the CHCA's dementia surveys, we conducted a carer dementia survey to capture a more in-depth profile on the unique needs of supporting caregivers in the home. If carers are to continue providing care to this growing population, adequate supports are needed not only to assist them in their role but also to ensure their quality of life. The survey received completed data from 116 carers from across Canada. In this survey, the term "carer" is referred to a person who takes on an unpaid care role to support someone living with Alzheimer's disease and other dementias. Carer is also referred to as caregiver or family caregiver.

Caring is complex

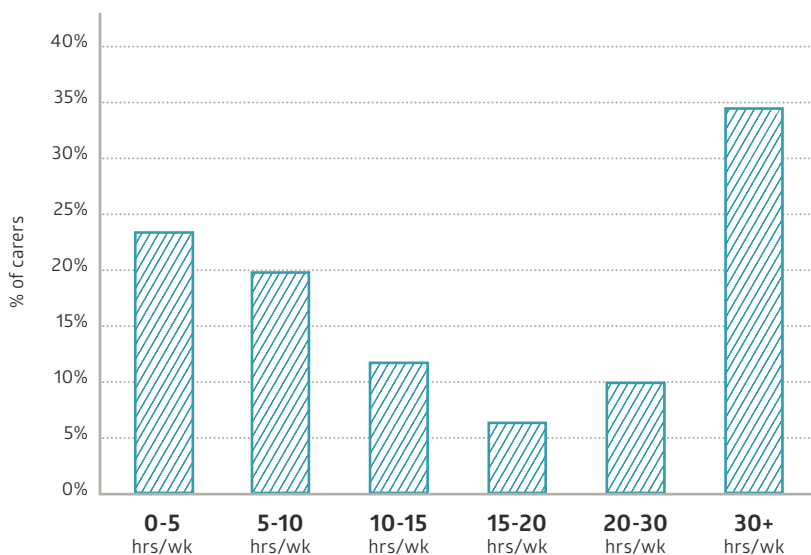
People living with dementia often have other medical conditions which could increase their need for assistance and make caring for them more complex. The top 5 reported conditions are:

- Skeletal Conditions—e.g. Arthritis, limited mobility
- Heart Conditions—e.g. Atrial Fibrillation, Congestive Heart Failure
- Glandular Conditions—e.g. Diabetes, Hypothyroidism
- Blood or Circulation Conditions—e.g. Hypertension, High Cholesterol
- Nervous System Disorders—e.g. Stroke, Parkinson's Disease

66% of people living with dementia also have other health condition(s).

Amount of care

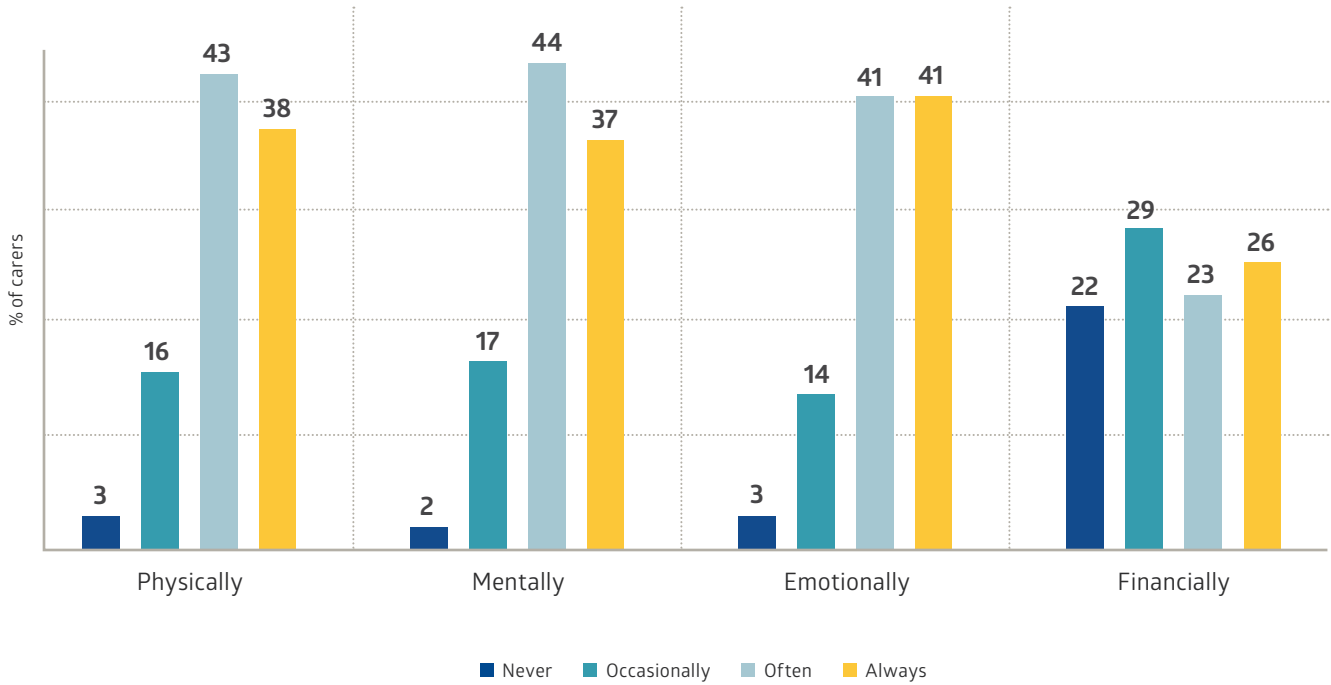
On average, carers spend 20 hours/week supporting a person with dementia, with 34% of carers providing more than 30 hours/week.



“ 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.”

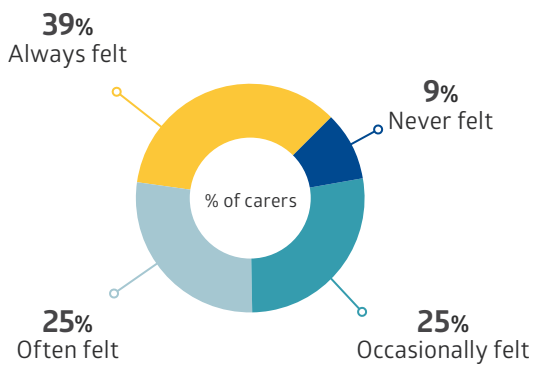
Although for many individuals there is personal satisfaction derived from caring, caregiving demands can also be detrimental physically, mentally, emotionally and financially. More than half of carers felt they had no time for themselves and had to neglect their own health because of caregiving responsibilities.

Impact of caring on carers' health and well-being

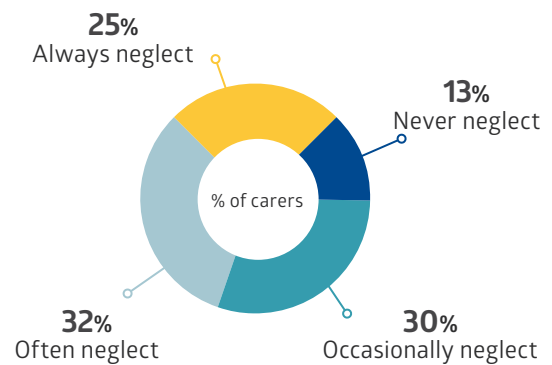


“If my husband’s situation remains more or less as it is now, I can manage it. Assuming my health stays satisfactory. If either one of us deteriorates, who knows.”

Have you felt like you have no time for yourself?



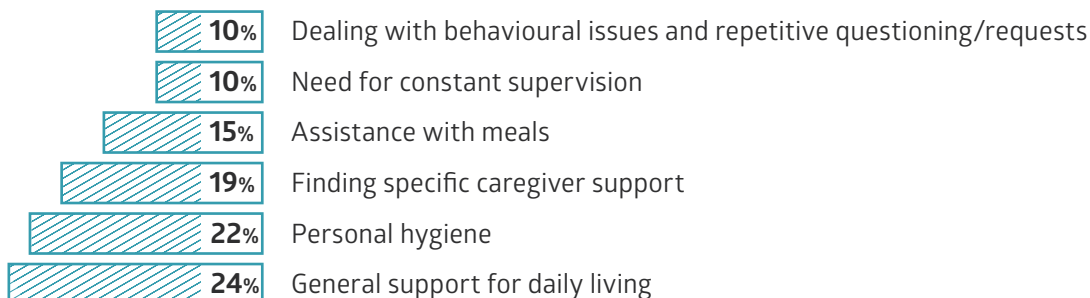
Has caregiving made you neglect your own health?



Challenges of caregiving

Seventy-nine percent (79%) of caregivers felt that it is either somewhat or very difficult for them to help with daily activities and care for someone with dementia.

Tasks carers felt they needed help with

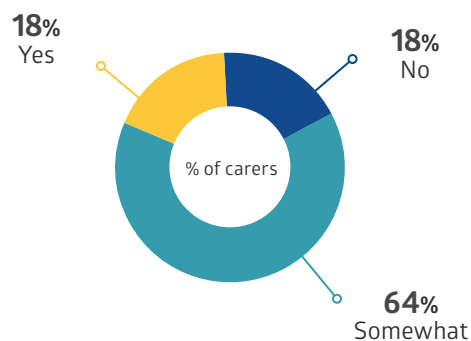
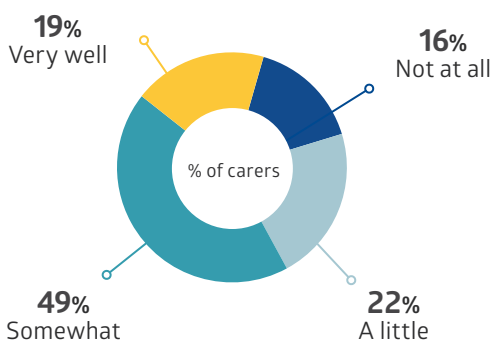


“ Getting my sister to eat, hearing the same thing over and over... this is a part of the disease, but every 5 minutes can be taxing. Some days everything can be difficult, other days are wonderful. ”

Preparing for and responding to changing care needs

Only 19% of carers felt 'very well-prepared' in responding to behaviour symptoms associated with dementia, 44% felt they are 'somewhat prepared', 22% felt a 'little prepared' and 16% did not feel prepared at all.

Only 18% of caregivers felt that they are able to anticipate and adequately respond to the changing needs of a person they care for, 64% felt they are 'somewhat' able to and 18% felt they were not able to.



When asked to further comment on their responses, the sudden and rapid changes in the care recipient's condition and behaviours were shared as major reasons by those who felt unprepared. 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.

Access and quality of supports for carers varies widely

Although carers are vital members of the health care team, their involvement, input and engagement in health care planning is not consistent. While the majority of carers (61%) were ‘often’ or ‘always’ involved in decisions about the individual’s care plan, 10% of carers indicated that they were ‘never’ involved. Only 29% of carers were ‘always’ given the opportunity to ask questions regarding the condition, how it will progress and/or recommended treatments. Similarly, 29% felt they were ‘always’ given options to ensure decisions made respect the person’s wishes, values and needs. When asked whether health care provider(s) support them in maintaining their own well-being while being a caregiver, 60% of carers reported ‘never’ or ‘occasionally’.

	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%	

“ Keeping my mom active and engaged in activities is a constant need and impossible to do when working. Home support is not able to provide enough care to support this need of stimulation and being involved in something other than watching TV. ”

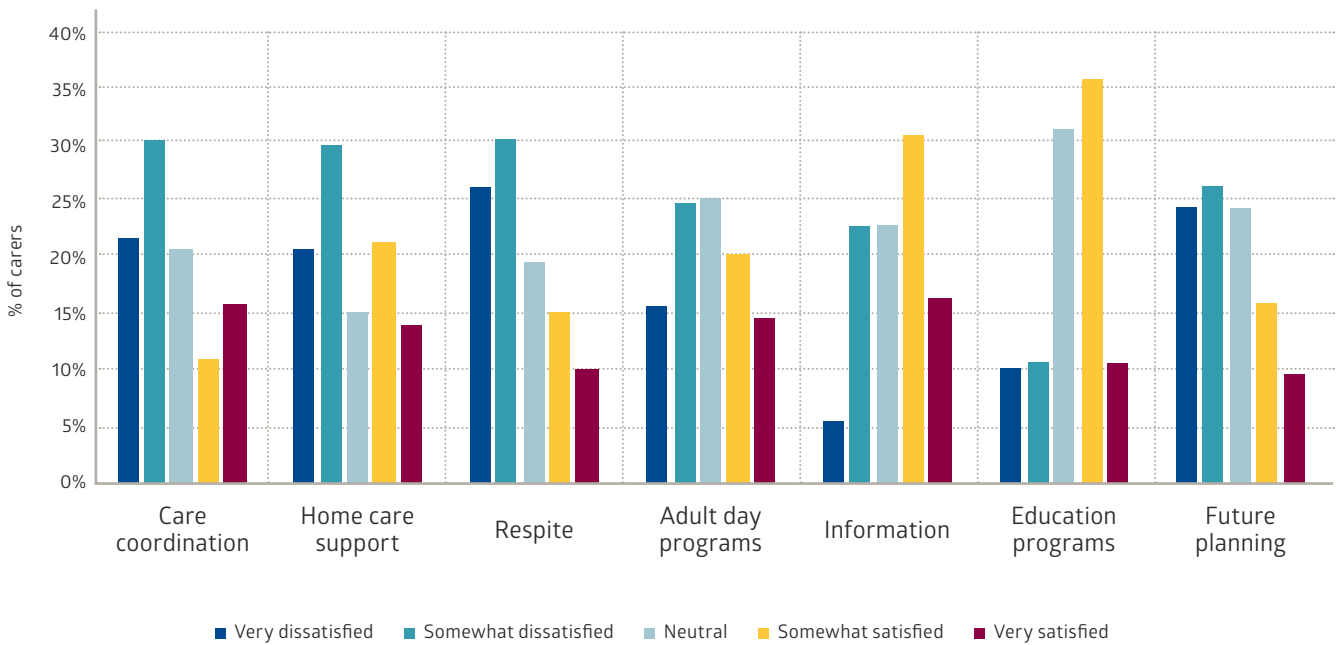
“ The biggest gap and challenge is skilled, trained and competent staff who are able to perform these tasks. Often staff were not the right "fit" to care for individuals with dementia care needs. This is complex care requiring skill in order to maintain the dignity of these special individuals. ”

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

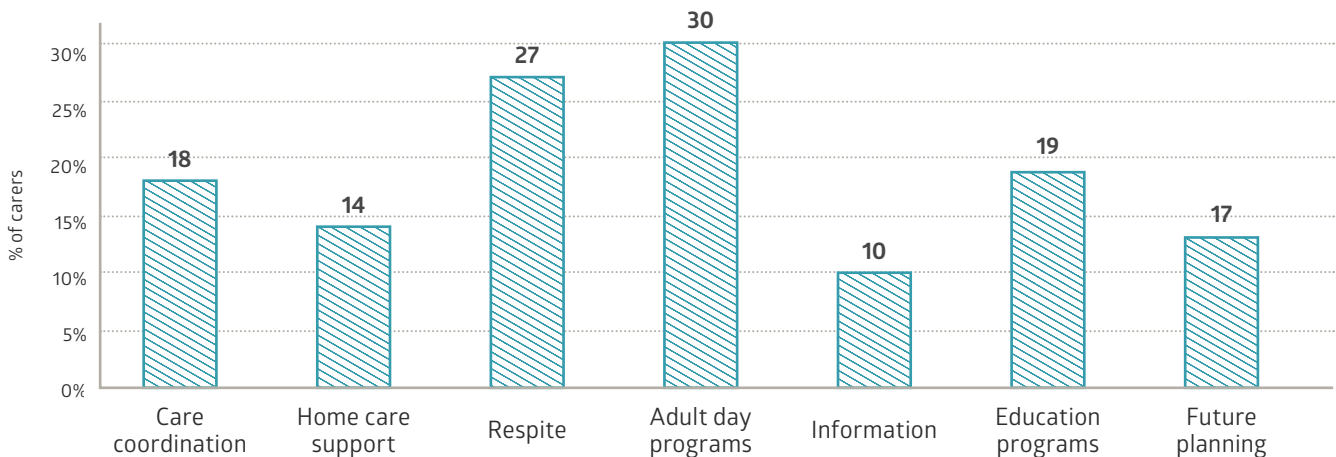
Carers may not know when they need extra supports, or how to access or use available resources. Through the survey, 30% of carers indicated they have never accessed adult day programs, 27% reported they have never accessed formal respite programs and 19% of carers have never attended education programs.

Those who access services reported great variance on the accessibility and quality of resources or information available. On average, carers are 'somewhat satisfied' with the quality and accessibility of information, education programs and adult day programs. Services that carers rated as 'very dissatisfied' or 'somewhat dissatisfied' are home care support (43%), care coordination (44%) and future planning (42%).

Carers' assessment of available supports



Percentage of carers who have never accessed supports



Carers need a range of supports

It is evident that a carer's role is active, intense and can present significant risk to the caregiver's well-being. Carers need a range of supports to balance their caring responsibilities and have a good quality of life alongside caring. Carers were asked for comments, reflecting on what helped them and what supports are needed. There were 79 remarks recorded with the following overarching themes:

- Provide more **home care** (professional care, 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




CONCLUSION

Addressing the overwhelming scale, impact and cost of dementia must take into account Canadians' strong desire to age at home. Home care service providers and carers provide a range of vital care and support services to enable people with dementia to live well in their own home. By sharing their experiences and expertise, over 350 home care providers and carers shed light on key challenges and opportunities to ensure people living with dementia can continue to remain active, engaged, healthy and safe in their community for as long as possible.

“ 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 Canadian Home Care Association (CHCA), incorporated in 1990, is a national not-for-profit membership association representing home care stakeholders from governments, health authorities, local health integration networks, service providers, and equipment and technology companies. The CHCA advances excellence in home care through leadership, awareness, advocacy and knowledge.

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