



Dementia
Advocacy
Canada

Voices of Lived Experience

Survey Report
June 2019

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Overview

People living with dementia and care partners from across the country want to have an active and respected role in decisions about policies and programs that impact their lives. Together they recognize their value as a distinct and separate group who, by working together, can amplify the voices of people with lived experience in Canada.

Dementia Advocacy Canada (DAC) was founded in 2019 (as a continuation of conversations that began in May 2018 at the National Dementia Conference) to provide a conduit for the voices of those with lived experience to be heard.

Over several months of discussion, three advocacy priorities emerged:

-  System navigation from diagnosis to end of life.
-  National requirements for regulation of Personal Support Workers and Health Care Aides to ensure minimum standards for education and training
-  Rehabilitation to help people living with dementia to live as well as possible.

Our vision is for people living with dementia, their families and care partners, to live in balanced partnership in the community.



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Voices of Lived Experience

Executive Summary

Dementia Advocacy Canada designed an online survey in Spring 2019 to confirm their priorities aligned with those of Canadians living with dementia and care partners. People from all regions in Canada who are/were care partners or are living with dementia were invited to participate, capturing a wide range of perspectives.

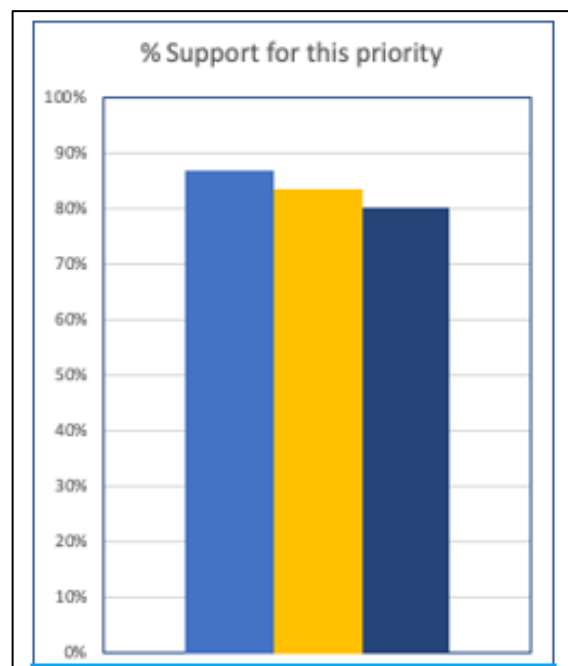
PRIORITIES

Over 80% of respondents agreed with all three of these priorities. This strong support confirms our work to date and provides us with a mandate to move forward.

- System navigators are assigned upon diagnosis and remain through to end of life
- National requirements for regulation of Personal Support Workers and Health Care Aides to ensure minimum standards for education and training
- Rehabilitation to live as well as possible with a dementia diagnosis

Survey respondents were asked to provide additional suggestions for advocacy. The aggregated responses, in order of the most frequently mentioned, include:

- Support for caregivers (e.g. training, financial support, respite and improvements to Home Care) (18)
- Physician education (7)
- Improvements to long-term care (5)
- Research (5)
- Medical Assistance in dying (MAiD) legislation (3)
- Young onset support (2)
- Access to services in rural areas (2)
- Advocacy/Awareness (2)



RESPONDENTS

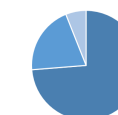
90 surveys were completed.
Of these respondents:



66% women, 34% men



9 provinces and 1 territory are represented



- 73% are care partners and/or have a family member with dementia
- 20% are living with dementia
- 6% have a diagnosis of MCI (mild cognitive impairment)

Background

There is an urgency to address dementia as a health crisis:

According to the Canadian Institute of Health Information (CIHI) Report: Dementia in Canada (2018) more than 402,000 Canadians aged 65 and older are living with diagnosed dementia. An additional 16,000 Canadians under the age of 65 are living with young onset dementia. Approximately 76,000 new cases of dementia are diagnosed in Canada every year. The Canadian Academy of Health Sciences (CAHS) (2019) states that in addition to dementia's personal toll, it also poses a challenge for our health and social care system. Estimated total health care system costs for persons with dementia are projected to reach \$16.6 billion by 2031.

Approximately 76,000 new cases of dementia are diagnosed in Canada every year.

Estimated total costs for persons with dementia are expected to increase to \$16.6 billion by 2031.

The cost (human and financial) to Canada's caregivers:

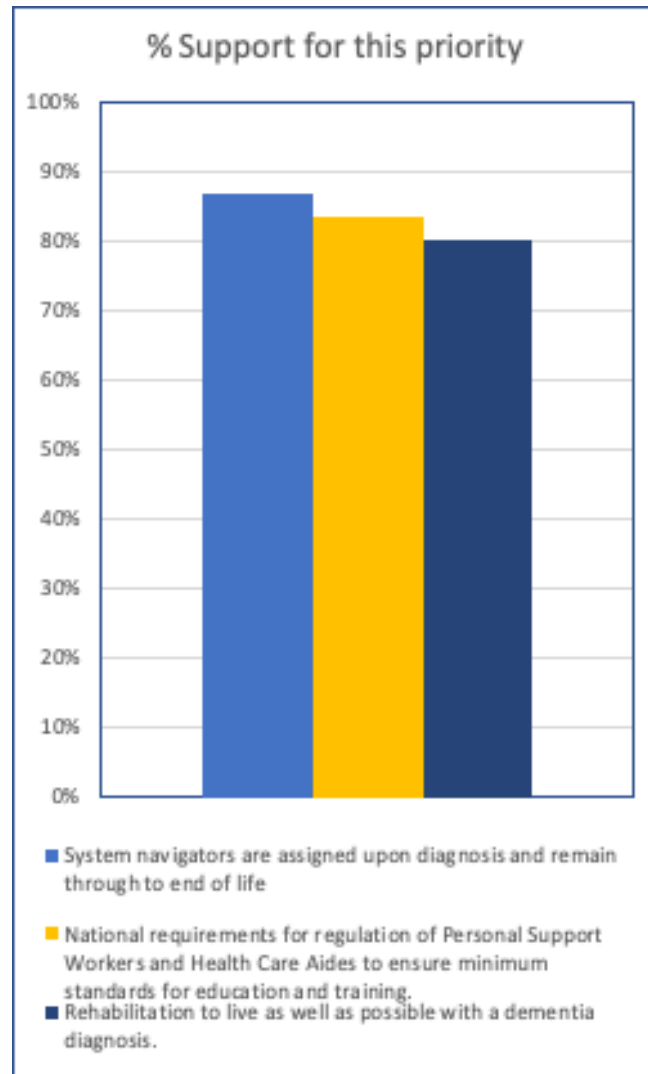
CIHI (2018) states that unpaid caregivers of older adults with dementia spend an average of 26 hours a week providing care, compared with 17 hours for caregivers of other older adults.

Of greater concern, almost twice as many caregivers of older adults with dementia exhibit symptoms of distress, such as anger, depression or feeling unable to continue (45% versus 26%).

According to the CAHS (2019) it is critical that caregivers be supported in their caring roles. Certain interventions (i.e., education, training, counselling, supportive workplace) may help preserve resiliency and may help sustain or increase their availability as caregivers.

*Persons living with dementia and care partners have valuable insights.
The time to be heard is **NOW**.*

Survey Results Provide a Mandate to Move Forward



Support and Survey Comments:

Over 80% of all respondents agreed with the three priorities (“this is a priority for me” or “this is an important issue”) with the most people agreeing that system navigators be assigned upon diagnosis (87%) followed by Support Worker requirements (83%) and Rehabilitation (80%).

Other issues raised by respondents (in order of frequency):

- Support for caregivers (e.g. training, financial support, respite and improvements to Home Care) (18)
- Physician education (7)
- Improvements to long-term care (5)
- Research (5)
- Medical Assistance in dying (MAiD) legislation (3)
- Young onset support (2)
- Access to services in rural areas (2)
- Advocacy/Awareness (2)

“An amendment to Bill C14 to legalize Advance Requests for MAiD for those with Dementia who had indicated this right to choose.”

“Education and emotional support for persons living with dementia and caregivers in rural and remote areas”

“How to get support if your family doctor will not follow through on possible dementia diagnosis assessment from Alzheimer's clinic results.”

“Workplace issues for family caregivers - I took early retirement to care for both parents while other family members never missed a day of work.”

Additional Survey Comments

“The health care system should be more flexible, so that an individual with a dementia diagnosis is supported to gradually spend part of their time at a long-term care facility as part of a slow transition, i.e. 2-3 days a week at LTC to start, then 4-5 days and so forth.”

“National requirements for minimum amount of PSW/HCA hours assigned to residents of long term care homes, particularly those with advanced dementia.”



“We have insurance but it scares me how much I'm hearing a facility will cost when the time comes. We would not be able to afford it I'm afraid. I understand from others that be prepared to sell your home. The financial impact will be terrific.”

“Caregiver allowance if one has to stay home to take care of someone.”

The Voices of Lived Experience Need to Be Heard

Dementia Advocacy Canada's priorities align with the recommendations made by national authoritative public, private, non profit, and academic sectors.

In 2019, the Canadian Academy of Health Sciences (CAHS) was tasked "to provide an evidence-informed and authoritative assessment on the state of knowledge to help advance federal priorities under the National Strategy for Alzheimer's Disease and Other Dementias Act." Their conclusions support the advocacy priorities identified by Dementia Advocacy Canada:

- improve system navigation
- implement training standards for people working in the dementia field
- support for people living with dementia and their care partners to remain in their community as long as possible.

CAHS also recognizes that people living with a dementia diagnosis and care partners should have an opportunity to engage in policy discussions that affect their lives.

The Voices of Lived Experience need to be heard



Dementia Advocacy Canada (DAC) offers a forum for conversations across the country and as such, DAC is poised to provide a voice for those impacted by dementia in Canada.

Survey Priorities and DAC's Recommendations

The lack of coordination & the difficulty navigating a fragmented system

According to the CAHS Report (2019):

- Healthcare for persons with dementia, is often piecemeal, fragmented and uncoordinated, and it can be difficult to tell who, if anyone, is in charge.
- There is often a lack of continuity in healthcare systems for persons living with dementia, with little integration or communication between different teams and specialties
- There are limited community-based supports and, when they are available, they are often difficult to access in a timely manner, the emergency room is most often the default resource for caregivers seeking support
- Gaps in continuity and poor communication between care settings may cause re-hospitalizations and death.
- Persons living with dementia and their caregivers experience limited access to health and social care for multiple reasons. Many people are uncertain about where to go for assistance and can experience delays in getting the health care supports they need.

Dementia is a complex condition presenting unique and constantly changing challenges for those living with it and their care partners. A single point of contact will help identify a clear pathway to appropriate and timely supports and services.



Dementia Advocacy Canada recommends a system navigator be assigned from diagnosis through to end of life to help with care coordination and connect individuals living with dementia and their families to the programs and support they need, when they need it.

“ Living with dementia involves a continuous process of coping with various challenges in daily living, however, the process of effectively managing these challenges is one of the ways to improve the quality of life of people with dementia and their family members.”

Survey Respondent

Survey Priorities and DAC's Recommendations

The deficit in dementia care training

According to the CAHS 2019 Report “Improving the Quality of Life and Care of Persons Living with Dementia and their Caregivers:

- International evidence shows that the proportion of health and social care providers receiving training in dementia care is low and that the training provided is of variable quality
- There are limited standards for direct care providers across provinces.
- Further training must focus on helping providers at all levels implement person-centered interventions and approaches to enhance the wellbeing and quality of life of persons with dementia at all stages.

The Senate Report on Dementia in Canada (2016) recognized the need for a collaborative approach (government, regulatory bodies and educational institutions) to address health human resource capacity, training and education.

It is imperative that those being cared for and those relying on such care have confidence in those providing this care. Care should be of the highest quality addressing physical, psychological and social needs, At all times, the person living with dementia must be treated with compassion, dignity and respect.



Dementia Advocacy Canada recommends regulation of Personal Support Workers and Health Care Aides and the establishment of a national framework with standards of excellence and core competencies. This will enable educational institutions and employers to develop appropriate continuing education programs and performance expectations of staff who provide dementia care and services across all settings

“This is going to become an even bigger issue and important to set up standards for care now and help people live to their fullest capacity as long as possible.”

Survey Respondent

Survey Priorities and DAC's Recommendations

Individuals living with dementia can benefit significantly from rehabilitation

Canada was the first member country to recognize dementia as a disability at the United Nations Convention on Rights of Persons with Disabilities (2017) and yet little action has been taken to acknowledge this important declaration.

There are some in the medical community who dismiss rehabilitation for people living with dementia as a waste of resources. However, international advocate Kate Swaffer (2015) reports positive results from her intensive therapy routine that includes walking, Pilates, speech therapy, meditation and learning new information on topics of interest to her.

For those who raise concerns about the costs Clare (2017) posits that these costs “might be offset by preventing difficulties, limiting the costs of managing distressing symptoms, and delaying institutionalization.”

People can live for many years after a dementia diagnosis. Dementia Advocacy Canada strongly believes in the rights of people living with dementia to access multidisciplinary rehabilitation immediately following a diagnosis in order to maintain independence as long as possible and remain active members in community.



Dementia Advocacy Canada (DAC) recommends the creation of national guidelines for a strengths-based rehabilitation program. DAC calls upon the Government of Canada to introduce/adopt measures that reflect Canada's recognition of these rights.

The focus needs to be “maintaining function for as long as possible, regaining lost function where there is potential to do so and adapting to lost function that cannot be regained”

Poules et al, (2017)

Who Responded

The survey was available on-line across Canada for one month. Surveys were completed from most areas in Canada, male and females were represented, there was a range of ages and it includes responses people living with dementia.

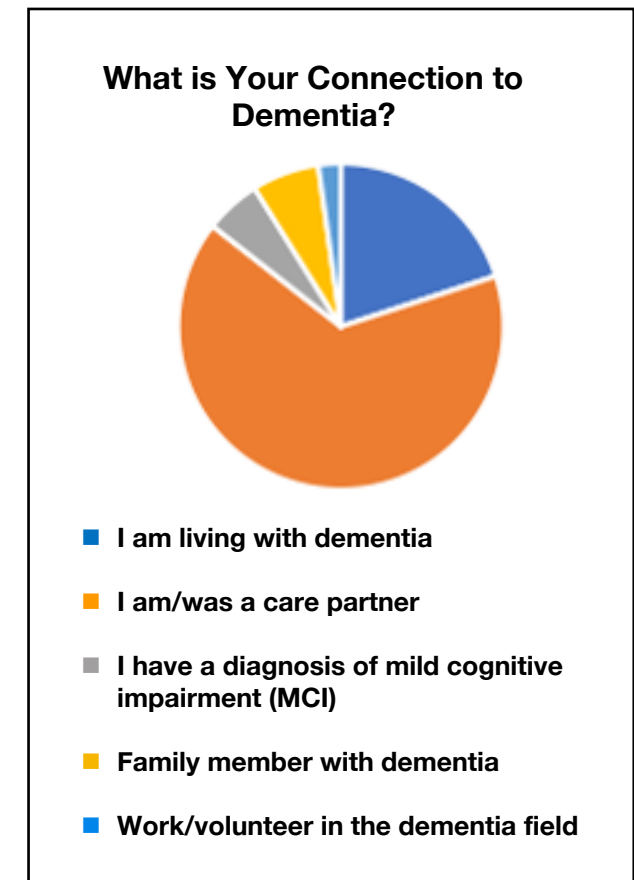
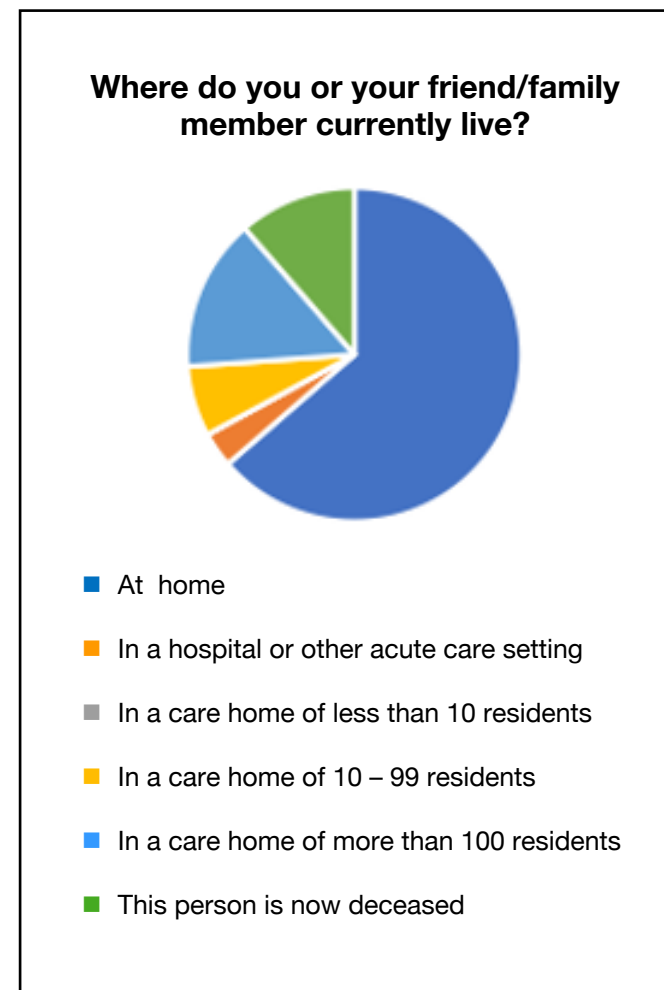
Responses from people living with dementia:

With only one exception, all of the people who indicated they had a dementia diagnosis live at home. The gender split was equal, and the age distribution was consistent with the other respondents. 55% of respondents were diagnosed between 1 and 5 years ago and 28% were diagnosed between 5 and 10 years ago.

Responses from Care Partners:

67% of the respondents identified themselves as care partners. The gender distribution was unequal: 83% female and 17% male. The age and geographic distribution were consistent with the other respondents. 57% indicated that the person they care for lives at home with the 43% living in long-term care.

The results from the survey were consistent across gender, age, geographic location, diagnosis status, date and perspective (e.g. care partner vs person with a diagnosis). This provides a strong base for moving forward with DAC's advocacy priorities.



Conclusions and Summary

Dementia is a health crisis in Canada. The social, human and financial costs will overwhelm our society and our healthcare system if we don't take action NOW.

There is no easy solution to dementia and a one-size-fits-all approach does not work. While there are common symptoms, each person with dementia has a unique set of variables determined by their specific genetics, lifestyle and personal experiences including the availability and ability of family members to provide support.

We must eliminate silos and find effective ways to work together. We must find a way to allocate resources more effectively so that Canadians impacted by dementia can access supports and services they need when needed.

Dementia is bigger than Alzheimer Societies, bigger than government and bigger than health care. People living with dementia and care partners want to have an active and respected role in decisions about policy, program development, services and research. It is imperative we all work together to find solutions.



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Recommendations by Dementia Advocacy Canada:

- ⚙️ System navigation from diagnosis to end of life.
- ⚙️ Regulation of Health Care Aides (HCA) or a Personal Support Workers (PSW), to ensure compliance with a newly developed framework of core competencies and standards of excellence in service delivery. Includes minimum standards of education and training.
- ⚙️ Rehabilitation to help people living with dementia to live as well as possible.

About Dementia Advocacy Canada

We are a grassroots group of people living with dementia and care partners. We want to influence policy, inform program development and improve access to support and services across Canada.

We want to have an active & respected role in decisions about all programs and policies that impact our lives.

Join us and help shape an inclusive Canada.

www.dementiacanada.com

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