



A
Dementia
STRATEGY
FOR CANADA

Together We Aspire

IN BRIEF



Public Health
Agency of Canada

Agence de la santé
publique du Canada

Canada 

EXECUTIVE SUMMARY

Canada's first national dementia strategy sets out a vision for the future and identifies common principles and national objectives to help guide actions by all levels of government, non-government organizations, communities, families and individuals. It places people living with dementia and the family and friends who provide care to them at its centre.

This strategy would not have been possible without the valuable input received from people living with dementia, family/friend caregivers and other stakeholders at the **National Dementia Conference: Inspiring and Informing a National Dementia Strategy for Canada**, at regional roundtables, and expert advice received through commissioned reports and written submissions. It also reflects the guidance of members of the Ministerial Advisory Board on Dementia, provincial and territorial government officials, and officials from federal government organizations.

The vision for this strategy is bold and reflects the aspirations of those who shared their priorities for Canadian efforts. The strategy has a broad scope through its three national objectives: **prevent dementia; advance therapies and find a cure; and improve the quality of life of people living with dementia and caregivers**. Areas of focus are set out for each of these objectives.

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Five principles set out values to guide activities taken in support of the strategy: prioritizing **quality of life** for people living with dementia and caregivers; respecting and valuing **diversity** to ensure an inclusive approach, with a focus on those most at risk or with distinct needs; respecting **human rights** of people living with dementia to support their autonomy and dignity; being **evidence-informed**, through a broad approach to gathering and sharing the best available knowledge and data; and remaining **results-focused** to ensure tracking of progress and evaluation.

The strategy identifies five pillars that are essential for implementation. **Collaboration** with other governments, researchers, those living with dementia and many others will help us make progress. Through **research and innovation**, we will address knowledge gaps and develop therapies that will improve the quality of life of people with dementia and caregivers, and move towards a cure. Enhanced **surveillance and data** will help us to understand the scope of dementia in Canada, and focus our efforts and resources where they are most needed and will be most effective. The development of culturally appropriate and culturally safe **information resources** on dementia will help care providers to provide quality care and will help all Canadians to better understand dementia. Finally, a **skilled workforce** will support dementia research efforts and provide evidence-informed care, which will improve the quality of life of people living with dementia and caregivers.

The strategy recognizes groups at higher risk of dementia as well as those who face barriers to equitable care. These groups include but are not limited to Indigenous peoples, individuals with intellectual disabilities, individuals with existing health issues that are known to increase the risk of developing dementia, older adults, women, ethnic and cultural minority communities, LGBTQ2 individuals, official language minority communities, rural and remote communities, and those with young onset dementia.



A DEMENTIA STRATEGY FOR CANADA

Together We Aspire

Vision

A Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood, and effectively treated.

Principles

- Quality of life
- Diversity
- Human rights
- Evidence-informed
- Results-focused

National Objectives

Areas of Focus



Prevent dementia

1. Advance research to identify and assess modifiable risk and protective factors
2. Build the evidence base to inform and promote the adoption of effective interventions
3. Expand awareness of modifiable risk and protective factors and effective interventions
4. Support measures that increase the contribution of social and built environments to healthy living and adoption of healthy living behaviours



Advance therapies and find a cure

1. Establish and review strategic dementia research priorities for Canada
2. Increase dementia research
3. Develop innovative and effective therapeutic approaches
4. Engage people living with dementia and caregivers in the development of therapies
5. Increase adoption of research findings that support the strategy, including in clinical practice and through community supports



Improve the quality of life of people living with dementia and caregivers

1. Eliminate stigma and promote measures that create supportive and safe dementia-inclusive communities
2. Promote and enable early diagnosis to support planning and action that maximizes quality of life
3. Address the importance of access to quality care, from diagnosis through end of life
4. Build the capacity of care providers, including through improved access to and adoption of evidence-based and culturally appropriate guidelines for standards of care
5. Improve support for family/friend caregivers, including through access to resources and supports

Pillars

Collaboration • Research and innovation • Surveillance and data • Information resources • Skilled workforce

INTRODUCTION

Dementia has a significant and growing impact on Canadians. In 2015–16, more than 419,000 Canadians aged 65 years and older were living with diagnosed dementia. As this number does not include those under age 65 who have diagnosed dementia nor those who have not been diagnosed, the true picture of dementia in Canada may be larger.

The need to address dementia in Canada was emphasized with the passing of the *National Strategy for Alzheimer's Disease and Other Dementias Act* (the Act) in June 2017. This Act requires the federal Minister of Health to develop a national dementia strategy informed by a national conference and create a Ministerial Advisory Board.

The **National Dementia Conference: Inspiring and Informing a National Dementia Strategy for Canada** was held in May 2018 and brought together a diverse group of Canadians to identify and discuss challenges related to dementia, identify opportunities for collaboration and action, and share ideas for a national strategy. Participants at the conference included people living with dementia, caregivers, advocacy groups, health professionals, researchers and representatives from provincial and territorial governments.

Additional input for the strategy was gathered at six roundtables held across Canada as well as through commissioned reports and written submissions. The strategy also includes guidance received from the Ministerial Advisory Board on Dementia, and gathered from ongoing engagement with provincial and territorial governments and other federal organizations.

What is dementia?

Dementia is an umbrella term used to describe a set of symptoms affecting brain function that are caused by neurodegenerative and vascular diseases or injuries. It is characterized by a decline in cognitive abilities. These abilities include: memory; awareness of person, place, and time; language, basic math skills; judgement; and planning. Dementia can also affect mood and behaviour.

As a chronic and progressive condition, dementia can significantly interfere with the ability to maintain activities of daily living, such as eating, bathing, toileting and dressing.¹

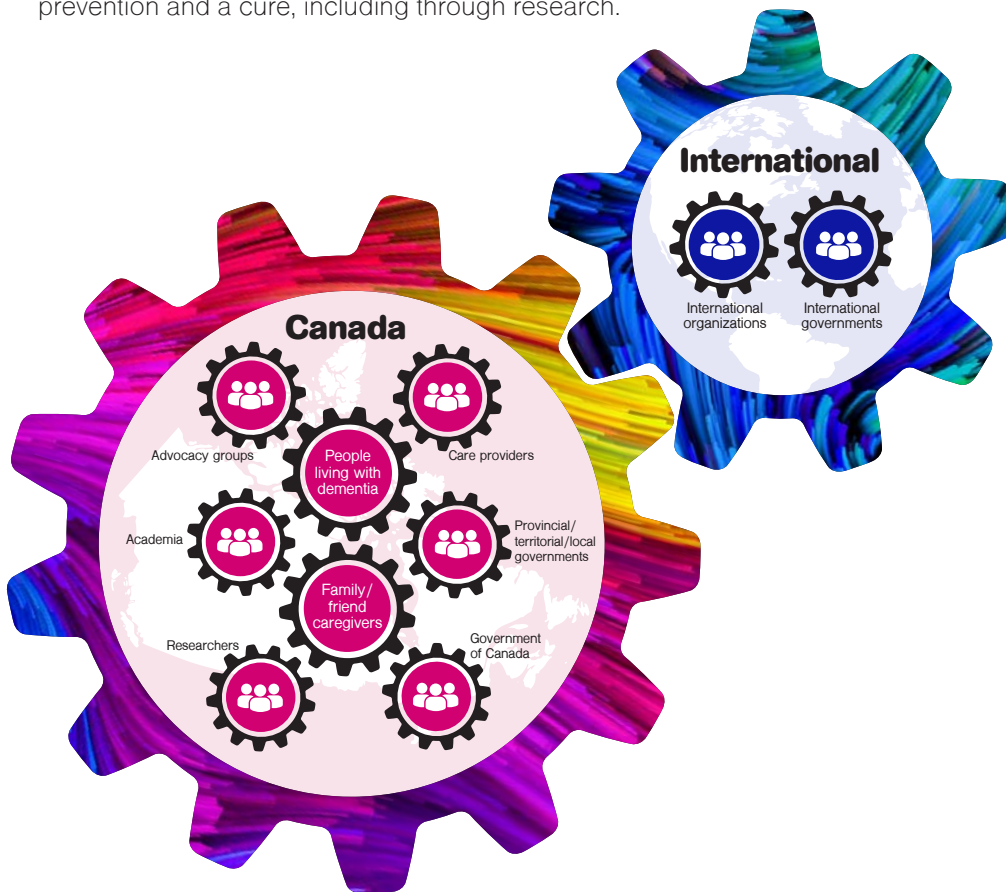
Alzheimer's disease, vascular disease and other types of disease all contribute to dementia. Other common types of dementia include Lewy body dementia, frontotemporal dementia and mixed dementias. In rare instances, dementia may be linked to infectious diseases, including Creutzfeldt–Jakob disease.

¹ World Health Organization. Current and future long-term care needs. 2002; www.who.int/chp/knowledge/publications/ltc_needs.pdf

VISION

A Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood, and effectively treated.

Achieving the best quality of life for people living with dementia and caregivers is at the centre of this strategy. The vision prioritizes the need to support and value people living with dementia to make it easier for them to live well for as long as possible, to deepen the understanding of dementia and to raise awareness of dementia and stigmatizing behaviours. It also recognizes the importance of improving therapies and investing in efforts towards prevention and a cure, including through research.



The strategy sets out three national objectives including areas of focus. It builds on existing dementia efforts, including provincial and territorial initiatives and federal investments. There are also five principles which inform the strategy and five cross-cutting pillars which are essential for implementation. The implementation of this strategy also relies on collaboration toward common goals across federal, provincial, territorial and local governments, as well as with many other organizations and individuals.

FIVE PRINCIPLES

Five principles set out values to direct and guide action on dementia in Canada. These principles are intended to inform all elements of the strategy including when evaluating options for policies and programs that have a direct impact on dementia-related issues. This strategy calls on all governments in Canada and other stakeholders to consider and support these principles through their own work on dementia.

Prioritizing quality of life: Actions taken to implement the strategy prioritize the wellbeing of people living with dementia and caregivers. Quality of life includes living well for as long as possible, access to quality care and supports, and supportive communities.

Respect and value diversity: Initiatives undertaken by all partners are inclusive, with special consideration of those most at risk of developing dementia and those who face barriers to equitable care. Respecting and valuing diversity also includes a focus on distinct Indigenous needs and community involvement.

Respect human rights: Actions taken under the strategy will respect the human rights of those living with dementia, and reflect and reinforce Canada's domestic and international commitments to human rights. A human rights lens is one of inclusion and health equity, respect for choice, hearing the voice of those living with dementia, and consideration of caregiver perspectives.

Evidence-informed: All partners will use evidence to make decisions and take a broad approach to gathering and sharing the best available knowledge and data about dementia. Evidence-informed considers best evidence, all forms of knowledge, working together to build evidence and knowledge, and informed decision-making.

Results-focused: Partners focus on outcomes in implementing the strategy and tracking progress, including evaluating and adjusting actions as needed. Results-focused includes initiatives that support reporting, enabling evaluation, measurement, accountability and flexibility to evolve.

THREE NATIONAL OBJECTIVES



Prevent
dementia



Advance therapies
and find a cure



Improve the quality
of life of people living
with dementia and
caregivers



Prevent dementia

This national objective focuses on helping us better understand how dementia can be prevented and ensuring more Canadians are aware of actions they can take that may reduce the risk of developing dementia or that may delay its onset.

This strategy is for everyone living in Canada, whether or not they are currently impacted by dementia. There is growing scientific evidence that healthy living from an early age may prevent dementia and delay its onset.

Research has shown a relationship between dementia and lifestyle behaviours that lead to chronic conditions like type 2 diabetes, heart disease and high blood pressure, as well as with behaviours like smoking and harmful alcohol use. Evidence also suggests that higher levels of education may improve the brain's ability to resist, offset and cope with damage and decline. In order to build a foundation for preventing dementia, it is necessary to better understand these and other factors that are linked to an increased risk of developing dementia.

Beyond understanding which health conditions, behaviours, and situations increase the risk of developing dementia, it is also important to understand the most effective actions that can be taken to prevent dementia. For example, interventions that address a number of factors at the same time could potentially be a better way to reduce the risk of developing dementia. Building the evidence base about effective interventions is an essential step in increasing the success of prevention efforts.

As we learn more about interventions that are most effective in reducing risk, sharing this knowledge broadly, in a way that is culturally appropriate, will be important. By increasing awareness among both care providers and the general population, Canadians will be more informed about what they can do to reduce their risk of developing dementia.

While it is important that people are aware of risk and protective factors, this knowledge alone cannot prevent or delay the onset of dementia. People must also be supported by their environments—the people, places and social contexts that impact their daily lives. These environments, if appropriately designed, can make it easier to adopt healthy living behaviours and can reduce social isolation which may reduce the risk of developing dementia.



Advance therapies and find a cure

Canadian researchers are actively collaborating domestically and internationally to further knowledge on dementia. However, much more work remains to be done to enhance our understanding of dementia and its root causes, and to use that knowledge to develop effective therapies and find a cure.

Efforts to support an inclusive approach to the selection of dementia research priorities are necessary. Reviewing research priorities regularly with diverse stakeholders and populations, including people living with dementia and caregivers, will help to ensure that gaps in knowledge are addressed and that research includes a focus on issues that impact those living with dementia and those who provide care.

Increasing dementia research that explores biomedical, clinical, health systems and population health is critical for the advancement of our understanding of dementia and our ability to treat and manage it. Biomedical research aims to understand at the cellular level what changes are occurring in the brain and why. Clinical research examines the safety and effectiveness of medications, devices, tools for diagnosis and therapies. Health systems research examines how people access health services, health professionals, care costs and health outcomes. Population health research aims to examine the health of an entire population by understanding how social, cultural, environmental, occupational and economic factors can influence health status.

The development of innovative approaches to therapies across all stages of dementia, from before symptoms appear to early and advanced symptoms, will be encouraged. Types of innovation could include new technologies, along with social and biomedical innovations such as assistive technologies, individualized cognitive training, drug and non-drug therapies.

For research on dementia therapies to be effective and culturally appropriate, people living with dementia as well as their families and caregivers must be meaningfully involved in the research process. Their voluntary participation is a vital contribution to understanding which therapies are effective.

To share research results, researchers typically publish findings in academic journals so that other researchers can consider this new evidence. However, more can be done to share this information broadly and in a timely fashion so as to quickly turn research findings about dementia therapies into relevant information that can be adopted in clinical, community and family settings.



Improve the quality of life of people living with dementia and caregivers

Improving the quality of life of those living with dementia and caregivers is the motivation for the national dementia strategy.

Stigmatization and discrimination sometimes occur within the health system and in the community where they can create barriers to diagnosis, treatment and care which can greatly impact quality of life. Creating supportive, safe and inclusive communities across Canada for people living with dementia and caregivers is essential to maximizing the quality of life of people living with dementia. In dementia-inclusive communities, the participation and contribution of people living with dementia is encouraged, supported and valued, and the care and support provided within the community is culturally safe, culturally appropriate and mindful of diversity.

Training and effective diagnosis tools are necessary so that primary care practitioners have greater confidence in diagnosing dementia early. Through early diagnosis, therapies, services and supports can be accessed earlier, which can help reduce the severity of symptoms, and individuals and their friends and family members can prepare for the future.

Information on dementia services and supports is not always easy to find, access or coordinate. People living with dementia and caregivers would benefit from easier access to care and supports available in their community. Effective care coordination that respects the rights of those with dementia to make their own decisions and includes access to palliative care supports quality of life.

Delivering quality dementia care requires a wide range of appropriately trained care providers to meet the varying needs of people living with dementia and caregivers. Challenging working conditions and a lack of training can lead to burnout and high turnover rates for care providers. Increasing the capacity of care providers and providing better access to evidence-informed guidelines for standards of care and best practices can improve the quality of care provided.

Family members and friends who provide care to people living with dementia experience high levels of stress, are at higher risk of injury and depression and are particularly susceptible to financial and employment difficulties. Ensuring that caregivers have the supports and information they need can reduce this stress and improve the quality of life of the person with dementia for whom they are caring.

FIVE PILLARS

Five cross-cutting pillars are essential for effective implementation of this strategy.

COLLABORATION

The implementation of the strategy depends on continued collaboration on dementia, including with people living with dementia, caregivers and communities. All governments in Canada and many stakeholders, including care providers, community and social service organizations, researchers and advocacy groups, have a role to play in contributing to the achievement of the strategy's objectives.

RESEARCH AND INNOVATION

Canada remains committed to supporting research focused on prevention, therapies, quality of life of those living with dementia and caregivers and, ultimately, a cure. Canada will continue to conduct research, develop innovations, evaluate research findings and promote adoption of the most effective approaches as best practices across the country.

SURVEILLANCE AND DATA

Optimizing dementia surveillance will provide a more accurate picture of the impact of dementia in Canada. This will give us greater insight into groups within the general population that are more impacted and more at risk, and will support better identification of their health needs and those of caregivers.

INFORMATION RESOURCES

Valuable information and best practices on dementia exist in Canada and around the world. Efforts to improve access and enhance information resources will broaden awareness and understanding of dementia and support greater health equity. Innovative ways to improve access to information resources will be explored.

SKILLED WORKFORCE

Canada's dementia workforce is diverse. It includes researchers who are seeking to understand the causes of dementia, exploring the development of therapies and seeking a cure, as well as health professionals and other care providers who interact with people living with dementia and caregivers. Having a workforce that is well trained and equipped to pursue dementia research and provide quality dementia care is essential.

FOCUS ON THOSE AT HIGHER RISK OF DEVELOPING DEMENTIA AND THOSE FACING BARRIERS TO EQUITABLE CARE

Indigenous peoples face barriers to culturally safe and culturally appropriate treatment and care and many have to leave their communities for care. As well, evidence suggests that the proportion of the population living with dementia is increasing more rapidly among First Nations populations compared to the general Canadian population and that dementia onset may be occurring earlier. For those with **intellectual disabilities**, traditional dementia assessment tools are often ineffective and care providers are sometimes not trained in supporting those individuals with intellectual disabilities who also have dementia. Studies suggest that 50–70% of adults with Down Syndrome over the age of 60 are likely to develop dementia.

Older adults and **women**, as well as **those who have existing health issues** (e.g. mid-life hearing loss, those who have had a stroke or heart failure) and those who engage in **behaviours** known to be risk factors, such as physical inactivity and smoking, are at higher risk of developing dementia.

Those who are **lesbian, gay, bisexual, transgender, queer, and two-spirit** and those in **ethnic and cultural minority communities** often face discrimination and stigma which can lead to barriers to care. Those with **young onset dementia** often lack supports and services that are appropriate for their age and those in **rural and remote communities** lack supports and services that are nearby, often requiring travelling long distances for care. Those in **official language minority communities** can face difficulty in getting services and support in their first language. These groups may also experience delays in diagnosis due to these barriers.

Further research is required to determine if there are other populations at higher risk of developing dementia or that are facing barriers to equitable care.



TARGETED INVESTMENTS THAT WILL BE LEVERAGED WITH PARTNERS

The Canadian Institutes of Health Research (CIHR), Canada's federal funding agency for health research, invested close to \$200 million in dementia-related research between 2013 and 2018. The [CIHR Dementia Research Strategy](#) supports research on the latest preventive, diagnostic and treatment approaches to Alzheimer's disease and other neurodegenerative diseases causing dementia. CIHR continues to support dementia research annually through both its open and strategic research funding programs.

In 2018, PHAC launched the [Dementia Community Investment](#), a \$4 million per year ongoing investment. This investment provides funding for community-based projects that: optimize the wellbeing of people living with dementia and/or caregivers; increase knowledge of dementia and its risk factors; and undertake research to assess effectiveness to enable the use of this knowledge to support expansion of the project's reach.

Budget 2019 provides \$50 million over five years, starting in 2019–20, to support the implementation of the national dementia strategy and to work with key stakeholders to:

- increase awareness about dementia through targeted campaigns and activities that focus on prevention, reducing risk and stigma;
- develop treatment guidelines and best practices for early diagnosis; and
- improve our understanding of the prevalence and effects of dementia on our communities.



THROUGH THIS STRATEGY, WE ASPIRE TO A CANADA WHERE:



There is a complete understanding by researchers and those living in Canada of the risk and protective factors linked to dementia.

A strong evidence base on prevention interventions exists and is available so that all people living in Canada are aware of actions they can take to prevent dementia.

All people living in Canada have access to built and social environments that support their ability to pursue healthy living in ways that may reduce their risk of developing dementia.



Dementia research priorities are established in a broad inclusive manner and annual investment in dementia research in Canada exceeds one percent of dementia care costs.

Research design always includes efforts that ensure findings can be understood, adopted and quickly put into practice so that new dementia therapies are more readily available.

People living with dementia and caregivers are active participants and partners in research to develop new therapies and find a cure.



Dementia stigma no longer exists in Canada.

A compassionate timely diagnosis is available to all people living in Canada and provides the person diagnosed with dementia with all available resources and supports.

Integrated, person-centered quality care based on best practices is available across all care settings and people living with dementia feel welcomed and well-cared for.

Care providers and caregivers have access to the resources, training and supports needed to provide quality care.

All caregivers have access to the resources and supports required to protect their own well-being.

Further information on dementia, including a full version of this strategy, is available here:
www.canada.ca/en/public-health/services/diseases/dementia.html





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