Developing Ontario's Dementia Strategy:

A Discussion Paper

September 2016

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Message from the Minister of Health and Long-Term Care

Ontario is committed to putting patients at the centre of our health care system. One of the ways our government is working to put patients first is by ensuring they have access to the right information and the high quality supports they need to live well.

Developing Ontario's Dementia Strategy: A Discussion Paper is a critical step in our government's work to develop a comprehensive strategy to address the needs of Ontarians with dementia and their care partners. We are committed to ensuring that the right supports are in place to help them on their journey, while also making sure they are treated with the dignity and respect they deserve.

I would like to thank Minister Indira Naidoo-Harris, who, through her previous role as my Parliamentary Assistant, spearheaded the work that resulted in this discussion paper. Through this discussion paper, we hope to create a conversation that will help inform the next steps in the development of our strategy to ensure the needs of patients, their families and their care partners are met. Together, with the help of all of our partners, we can develop a strategy that puts people and patients first.

Dr. Eric Hoskins
Minister
Health and Long-Term Care

Message from the Associate Minister of Education (Early Years and Child Care)

It was my honour to be part of the team of people dedicated to the development of a comprehensive strategy for dementia in Ontario. It has been a humbling and informative experience that will help to shape a strategy that will support Ontarians with dementia, their families and care partners.

There are approximately 228,000 people in Ontario currently living with dementia and we know that number will grow as our population ages. This knowledge was a constant source of inspiration, as well as the memory of my father-in-law, Tommy, who passed away after his battle with Alzheimer's just a few years ago.

The core vision for developing the dementia strategy is to make sure that all Ontarians with dementia, along with their families and care partners, are treated with respect, have the tools to make informed choices about their care, and are living well.

I want to thank everyone who has participated in the development of the strategy thus far. Thank you to the dementia patients and care partners who shared their very personal and important stories. It was crucial to receive guidance and insight from people with lived experience at every step of the process. Thank you to everyone on our expert panels. Your knowledge has been invaluable. Thank you, Premier Kathleen Wynne and Minister Eric Hoskins, for their leadership, dedication and foresight to develop a strong dementia strategy for Ontario.

Indira Naidoo-Harris

Indira Naidoo-Harris
Associate Minister
Education (Early Years and Child Care)

"Dementia has many faces — not just the stigmatized older person sitting in a wheelchair. We are young with children still at home, middle-aged people who had to retire from work earlier than planned. We are individuals with many different hopes and dreams. Help us to live well with dementia. Support us through a well-educated population, seamless medical model, and dementia-friendly communities."

Mary Beth Wighton, Board Member
Ontario Dementia Advisory Group

Introduction

Dementia is not a part of normal aging. It is a group of conditions that affect the brain and cause problems with memory, thinking, speaking or performing familiar tasks. A person with dementia may also experience changes in mood or behaviour that seem out of character. These problems gradually worsen over time and interfere with a person's ability to carry out daily activities and to live independently.[1,2]

While living with dementia can be challenging, it is important to remember that dementia does not change who a person is. Many people with dementia are capable of pursuing their interests, making decisions about their health, maintaining relationships and aging well.[3] Given the right opportunities and supports, Ontarians with dementia can continue to make positive contributions to their communities by sharing their lifetime of knowledge and experiences.

Care partners, including family members and friends, also play an important role in the lives of people with dementia. Even though being a care partner is demanding, many people find caring for a loved one or friend to be a meaningful experience. Ensuring care partners are supported in their caregiving responsibilities is critical for their well-being.

It is with this in mind that Ontario is committed to developing a comprehensive, forward looking dementia strategy to ensure that people with dementia and care partners:

- Are treated with respect;
- Have access to information that allows them to make the best possible choices regarding their health and well-being; and
- Are living well with dementia, helped by appropriate services and supports where and when they need them.

The purpose of this discussion paper is for the Ministry of Health and Long-Term Care to learn more about best practices in your communities, how to improve service delivery, and where investments are needed to better support people living with dementia and their care partners in living well. This includes ensuring that the services and supports available meet their needs, are equitable and are sustainable.

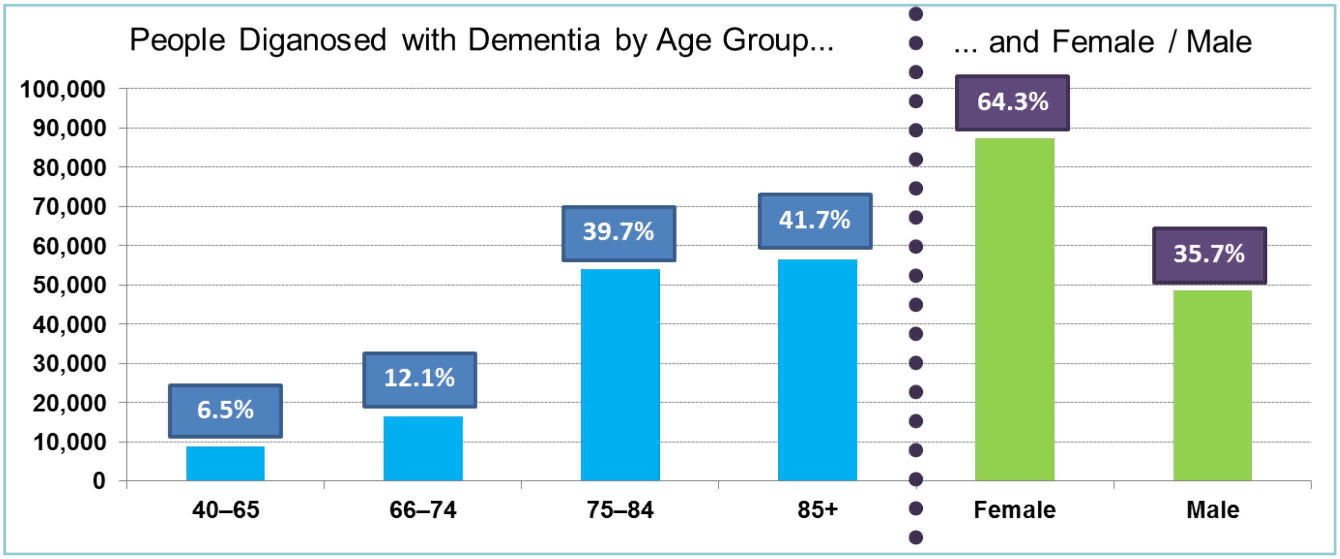
We invite you to contribute your thoughts on how to better support Ontarians with dementia and their care partners. Your feedback is important and will help inform the development of Ontario’s dementia strategy. To find out about opportunities to share your views, please visit ontario.ca/dementia or send your comments to dementiastrategy@ontario.ca.

Prevelance

Alzheimer’s disease and vascular dementia are the most common forms of dementia, but there are many other types, including Lewy body dementia, frontotemporal dementia and Parkinson’s disease with dementia.[4]

It is estimated that close to 228,000 Ontarians are currently living with dementia. As Ontario’s population ages, it is expected that these numbers will rise to 255,000 people in 2020 and over 430,000 people by 2038.[5] While dementia is most common among people over the age of 65, almost seven per cent of dementia diagnoses in Ontario are made in people between 40 and 65 years old. Additionally, about 64 per cent of people diagnosed with dementia are women.[6]

Percentage of Ontarians Diagnosed with Dementia, by Age Group and Sex[7]



Impact

The health and social consequences of dementia can have a substantial impact on families, friends, care partners and people living with dementia, as well as the health care system. With the right care and supports, it is possible for people with dementia and their care partners to be healthy and live well, while ensuring the sustainability of Ontario's health care system.

People living with dementia may face various challenges that can affect their well-being and ability to manage changes resulting from dementia. For example, dementia is a leading cause of dependency and disability among seniors and most people with dementia have two or more chronic health conditions.[8,9] People may also experience stigma. This can make it difficult for a person with dementia to ask for help at home, in the workplace and from health care providers. Stigma may also cause others to treat a person with dementia differently and delay a person in planning for their future care needs.[10,11]

Caregiving responsibilities can also have a significant impact on the physical and mental health of family and friends.[12] Care partners of people living with dementia often report high levels of stress, loss of sleep, depression and feeling worried or frustrated.[13,14,15,16] These effects are even more pronounced for those who live with a person with dementia.[17,18] While caregiving can be a positive experience in terms of strengthening the relationship with a person with dementia, caregiving demands may also lead to challenges at work and losing opportunities to spend time with friends, exercise and participate in social or volunteer activities.[19,20] As dementia progresses, the demands on care partners also increase. In Ontario, care partners of seniors with dementia provide up to 75 per cent more hours of care than care partners of seniors without dementia.[21,22,23]

It is estimated that from 2008-2038, dementia will cost Ontario close to $325 billion.[24] This includes health care as well as other costs, including lost wages or out-of-pocket expenses experienced by people with dementia and their care partners. When compared to individuals without dementia, people living with dementia visit a doctor more frequently, have a higher number of prescriptions, and are twice as likely to visit an emergency department or be hospitalized for preventable issues. People with dementia are also more likely to remain in hospital longer than necessary while waiting for appropriate housing or rehabilitation services.[25,26,27,28,29]

Context for Action

In February 2015, the Ministry of Health and Long-Term Care released *Patients First: Action Plan for Health Care*. This plan places the person directly at its centre and provides a framework for improving the health care experiences and the health outcomes of all Ontarians. An important part of this plan is improving access to dementia supports.[30]

Many initiatives are currently underway to strengthen person-centred health care and support people with dementia in living independently. For example, *Patients First: A Roadmap to Strengthen Home and Community Care* outlines steps being taken to improve how care is delivered in Ontario's home and community care sector. This includes ensuring greater consistency in care, a better understanding of the services available, and providing more supports for care partners. In addition, the ministry has proposed changes to expand the mandate of Local Health Integration Networks (LHINs) so they are accountable for the planning and performance of primary care and the delivery of home and community care services. These proposed changes aim to create a health system that works efficiently to support patients, including people living with dementia and their care partners, to better access the services they need.[31]

The ministry also recognizes the importance of ensuring that Ontario's health system has the capacity to meet the current and future needs of people living with dementia and their care partners. In collaboration with Cancer Care Ontario, the Ontario Brain Institute, and the Institute for Clinical Evaluative Sciences, work is underway to develop a dementia capacity planning model that will enable planners and policy makers to consider multiple options for the delivery of health care, including innovative models of care, in meeting the needs of people with dementia.

The ministry will work to ensure that common strategic goals related to dementia care will be met across these initiatives and policies, including standards and models of care, throughout the development of Ontario's dementia strategy and beyond. The ministry will also work towards developing an evaluation framework to measure the success of the strategy and its implementation.

Work to Date

The ministry has been working across government, as well as with health care stakeholders, social service providers, researchers, care partners and people living with dementia, to identify and better understand service gaps, challenges and opportunities to support Ontarians in living well with dementia. Some of this work includes:

- Forming a Dementia Strategy Advisory Group to provide advice on the development of a dementia strategy;
- Consulting with working groups, established to examine brain health, research and innovation, service delivery and the experiences of people living with various stages of dementia and their care partners;
- Hosting roundtable discussions in eight communities across the province to hear about local gaps in service, best practices and personal challenges.

The release of this discussion paper marks the next phase of Ontario's dementia strategy development. The ministry is now seeking further input from people across the province, including people living with dementia, their care partners, family members, friends, health care professionals, and other individuals who work with people with dementia. To find out more about opportunities to share your views, please visit ontario.ca/dementia.

Creating Supportive and Inclusive Communities for People Living with Dementia and their Care Partners

As we move forward in developing the dementia strategy, we must all work together to develop effective approaches to empower people living with dementia and their care partners to live meaningfully, to live well and to participate in their communities. This includes recognizing the diversity of experiences of people living with dementia and those of their care partners.

For example:

- There are many different types of dementia.
- Ontario's population is diverse – Indigenous peoples, Francophone populations, ethno-cultural groups and LGBTQ2S communities all face different challenges and have different needs for culturally-appropriate care.
- The availability of support services, including transportation, health care services or housing options, may differ across the province.
- A person's financial situation and the extent of their social networks may also influence their ability to live well.

Developing Ontario’s Dementia Strategy

Based on research and our work to date, we have identified six key themes that will guide the development of Ontario’s dementia strategy:

- Supports for people living with dementia;
- Accessing dementia services;
- Coordinated care;
- Supports for care partners;
- Well trained dementia workforce; and
- Awareness, stigma and brain health.

The following sections explore each of these themes and ask questions. Your answers to these questions and thoughts about these themes will help inform the development of Ontario’s dementia strategy.

> "Upon receiving a diagnosis of dementia, you may have the feeling that the stuffing has been knocked out of you. A support group will help put that stuffing back in place by helping you realize that you are not alone. Such a group will help you to regain your confidence and carry on with your life. After all, with the exception of the diagnosis, you are the same person today, with the same likes and needs, as you were yesterday."
>
> **Bill Heibein, Board Member**
> **Ontario Dementia Advisory Group**

1. Supports for People Living with Dementia

Being diagnosed with dementia can be a shock. However, receiving an accurate diagnosis as soon as possible is important to enable a person to properly plan and live well with dementia.[32,33,34] For example, delays in diagnosing dementia can mean missing out on treatments that slow changes in memory and thinking or delaying the use of services designed to help a person live independently for as long as possible.[35,36]

These delays can happen for a variety of reasons. Some people may not visit their family doctor or family health team because they do not recognize the symptoms of dementia.[37,38,39] Others may avoid a diagnosis because they fear being isolated from friends, having to move into a long-term care home or losing their driver's licence.[40,41,42] Screening for dementia and making a diagnosis can also be challenging for family doctors and nurse practitioners. Some may not recognize the symptoms of dementia or may lack the time to make a diagnosis. Others may be unfamiliar with screening tools, may be uncertain about accurately diagnosing different types of dementia or may have limited access to specialist resources.[43,44,45,46,47,48]

As a person with dementia grows older and their needs become more complex, a variety of services are needed that respond to the unique physical, psychological and social needs of a person with dementia.[49,50,51] Across Ontario, many successful initiatives have emerged that aim to support people living with dementia. For example, primary care-based memory Clinics,[52,53] Regional Geriatric Programs,[54,55] Specialized Geriatric Services,[56,57] and Behavioural Supports Ontario[58,59] have helped to break down barriers and foster partnerships to help people live well with dementia.

It is also important to ensure that supports are available that empower people with dementia to continue to enjoy meaningful and active lives. This includes providing assistance and offering programming that enable a person to live at home and participate in their community for as long as possible.[60,61,62] For example, adult day programs enhance the well-being of people with dementia by offering opportunities to participate in meaningful social and recreational activities. More specifically, these programs help reduce boredom, support mental health and provide emotional support for people with dementia. Adult day program staff are also important members of the care team and can be helpful in identifying new care needs or adverse effects of medications.[63,64,65,66,67,68]

What We Heard

- A variety of services are needed to support a person with dementia in living well.
    - These may include medical services, home care services, social opportunities such as those offered through adult day programs, a range of supportive housing options, including retirement homes and long-term care homes, legal services, palliative care and transportation services.
    - People living with dementia have wisdom and knowledge to share with others. Peer support groups are one way that information can be shared among people with dementia.
    - There are opportunities to provide care that better meets the needs of people with dementia and their care partners, including in the home and community, in long-term care or retirement homes, in hospitals and in hospice settings.

- Services should reflect the unique needs and choices of people with dementia, should work towards supporting their strengths and capabilities and should be consistent across the province.
    - Engaging people with dementia in decision-making is important to ensure that their wishes are respected as symptoms get worse. This includes having discussions about end-of-life care and power of attorney as early as possible.

- People who develop dementia at an earlier age may face additional challenges, such as loss of income, and loss of supplementary health benefits or pensions if they leave the workforce earlier than planned.

- Primary care providers may lack the necessary knowledge, time or supports to make accurate dementia diagnoses and to work with individuals in managing their care.
    - There are opportunities to assist these individuals by examining how family doctors, specialists, nurses, social workers, personal support workers and therapists work together to provide excellent care and to link people with dementia to the services they need.

What We Heard

- Dementia can cause people to behave in ways that they did not previously. Enhanced supports for those experiencing responsive behaviours at home, in hospitals and in long-term care homes are needed.

- Encouraging greater collaboration between researchers and service providers may be beneficial for developing high quality treatment and intervention options.

Issues to Consider

Making Ontario an exceptional place to live with dementia means supporting a person from diagnosis to end-of-life. There are opportunities to deliver higher quality dementia care services in Ontario. For example, we also heard that:

- Ontario’s health system should explore ways to expand specialized services, such as primary care-based memory clinics, to assist in diagnosis and to match people with dementia to the right health and community services.
- Improving the availability of transportation services across Ontario may help those with dementia maintain independence and develop stronger connections to their community.
- The expansion of services that assist people with dementia who are experiencing responsive behaviours at home, in hospitals and in long-term care homes should be examined.

What Do You Think?

- What supports or services do you think are essential to enable a person living with dementia to remain at home and be active in their community for as long as possible?
- What are some characteristics of high quality programs that help people with dementia and their care partners to live well?
- How can health care providers, home care providers, retirement homes and long-term care homes help to empower people with dementia to live well?
- What types of supports would help manage responsive behaviours at home, in hospitals, in retirement homes or in long-term care homes?
- What can we do to help health care professionals in diagnosing dementia?

"A dementia diagnosis does not come with a manual and a GPS, so people with dementia and their care partners need assistance to learn about services that are dementia friendly. The First Link program, offered by Alzheimer Societies in Ontario, can assist in navigating the system more efficiently to meet the clients' needs. Connecting persons with dementia to the right services, while providing counselling and support, is a priority in order to allow them to continue to live independently for as long as possible."

Lorraine LeBlanc, Executive Director
Alzheimer Society of Sudbury-Manitoulin, North Bay and Districts

2. Accessing Dementia Services

While a variety of supports are available to Ontarians with dementia, accessing these services can be challenging.[69,70,71,72] A person may be unsure about where to go when a problem develops or when their needs begin to change. Long wait times to see a health professional or language barriers can also lead to delays in getting treatment or other help. Services such as adult day programs may be too costly for some or may not be available or accessible in all communities.[73,74,75,76]

Asking for help from support services can also be difficult and it may not be sought until a crisis is faced.[77] The search for help can be even more difficult when a person with dementia lives alone or does not have a care partner to support them as their needs change.

In Ontario, organizations such as the Alzheimer Society offer a variety of services and supports at the time of diagnosis and beyond. For example, the Alzheimer Society of Ontario's First Link program has been successful in reducing some of these barriers by linking individuals with available supports as early as possible following diagnosis.[78,79]

Communities and the people who live and work in them also play a vital role in helping care partners and people with dementia to live well. Keeping people with dementia in mind while designing transportation, housing, health, social and other services can go a long way in supporting individuals to live meaningfully and independently.[80,81,82]

What We Heard

- People living with dementia and their care partners may have difficulty finding out what services are available and how to access them.
- Being able to access health care and community services that fit one's goals and existing needs may reduce crisis situations that lead to unnecessary emergency department visits or moving from home earlier than desired.
- To live well, people with dementia and their care partners should have the opportunity to choose from a variety of services that are flexible and tailored to their unique needs.
- People with dementia are important members of society and capable of meaningfully contributing to the communities they live in. Empowering people with dementia to maintain their hobbies, interests and skills is important to strengthening their health and well-being.
- Ontario has strong technology development and dementia research communities.
    - Involving people with dementia and their care partners in these efforts is important for improving or developing new and equitable dementia care services.
- Improving administrative data quality for dementia care services has the potential to assist researchers and health system leaders in planning for the future dementia population needs.

Issues to Consider

Empowering people with dementia and their care partners to live well means ensuring they have access to the right information and services at the right time. There are several ways that Ontario might be able to encourage better access to these services and supports. For example, we also heard that:

- A single resource that provides up-to-date and credible information may reduce barriers in accessing information about dementia, dementia research and available services.
- Guidance for health system administrators on what services should be available to people with dementia and their care partners is necessary to ensure that these services are consistent and of high quality throughout the province.
- Wait list systems for dementia care services and long-term care homes should be examined to help people with dementia live at home for as long as possible, without unnecessary hospital visits.

What Do You Think?

- How would you like to access information about dementia and the services available in your community?
- How can we better support people with dementia and their care partners in accessing services that would best meet their needs?
- What best practices or initiatives have been successful in improving access to care for people with dementia and their care partners?
- What barriers currently limit access to palliative care services for people with dementia?

"Providing excellent care for people with dementia and their care partners requires better coordination, relationships and connections. By coordinating people, ideas and resources, we can surface our collective wisdom to achieve the changes we need for today and tomorrow."

Dr. J. Kenneth Le Clair, Geriatric Physician
Providence Health Care

3. Coordinated Care

Coordinated care happens when a person with dementia, care partners, health care providers and community service providers work together to make a plan to ensure that people living with dementia and their care partners get the care they need. This is especially important for a person with dementia as their care needs become more complex over time.[83]

Coordinated care is vital to improving the experience of people with dementia and their care partners. It ensures smooth navigation and connections between health care and other service providers as their needs change. For example, when all health care providers responsible for a person's care are aware that they recently left a hospital, providers can follow up more quickly and reduce the chances of the person needing to visit the hospital again. [84, 85] It can also be frustrating when a person is unsure of what to do after visiting their doctor or when communication breakdowns happen between health care providers.[86] This can result in an inefficient use of time for the person with dementia, their care partners and health care providers.

Across Ontario, health system partners continue to strive to better coordinate and integrate primary care, home and community care, public health and the hospital care sector, among others.[87,88] As we look to improve service delivery, we are examining lessons learned from initiatives such as Health Links[89,90] and exploring new ways to provide better coordinated care for people with dementia and their care partners. For example, the Champlain Local Health Integration Network has introduced care coordinator coaches to assist people with dementia and their care partners in navigating the care system and to help coordinate access to the right services.[91,92]

What We Heard

- Changes, such as receiving a dementia diagnosis, loss of mobility or an illness, can result in the need for a new type of care, including receiving services at home, going to a hospital or moving into a retirement or long-term care home.
    - It is important that, during those changes, people with dementia and their care partners are able to quickly and seamlessly access information and services needed.

- Health care providers face challenges in connecting people with dementia and their care partners to community programs aimed at enhancing quality of life. For example:
    - Adult day programs may have limited capacity to accept new participants, eligibility criteria may not allow those with higher care needs to attend, or programs may not be affordable.

- When a person with dementia moves across the health system, there can be a loss of information and duplication of efforts. Barriers preventing the effective exchange of information may include:
    - Variations in information contained within health records.
    - Documentation formats that are difficult to comprehend quickly.
    - A lack of knowledge of what information can or cannot be shared between providers.

- Examining opportunities for sharing research and best practices between care providers and organizations is important for improving service delivery.

Issues to Consider

People with dementia and their care partners may need to access a variety of services and interact with many service providers as their needs change. Living well with dementia means experiencing seamless transitions during these interactions. Coordinated care is vital to improving this experience. For example, we also heard that:

- Providing a single point of contact to help coordinate care may help to reduce confusion, avoid duplication of efforts and improve access to the right mix of services.
- Exploring ways to share and scale best practices and other innovations across the health system may help improve services for people with dementia and their care partners.
- Examining documentation processes within health care settings is important to ensure they are enabling high quality, person centred care.

What Do You Think?

- What would make it easier for people with dementia, their care partners and care providers to navigate available services and supports?
    - Why would this be helpful and what challenges would be faced in introducing this solution?

- Have you experienced or observed seamless, well-coordinated dementia care?
    - What made it successful and was there any room for improvement?

- What can be done to improve communication between health care providers?
    - What challenges exist that prevent health care providers and health care organizations from sharing information or best practices?

“Care partners are doing their best to manage day-to-day challenges, but because timelines as to the progression of dementia are tough to predict, planning for the future—especially considering the situation may have care partners living in denial, anger or depression—is incredibly difficult.

A centralized source of information about available services, the progression of dementia, how to make a home environment more useable, and how to know if one qualifies for government assistance for care services would be extremely valuable. We have amazing people creating informative content and providing useful services, but I see tremendous duplication of efforts by not having a steward to manage the process of informing people about their options for help.”

Mike Auty, Care Partner

4. Supports for Care Partners

Care partners or caregivers include family members or friends who work in partnership with a person living with dementia to provide care and support. For the purposes of this document, the term care partner is used to refer to these individuals.

The term “care partner” recognizes that people with dementia should have the opportunity to participate in decision making about the health and social services they need, while acknowledging family and friends as playing an important role in helping a person with dementia to live well. This includes providing emotional and social support, helping to access services and providing assistance with activities such as bathing, eating, shopping, going to appointments and managing money.

While being a care partner can be a rewarding experience, responsibilities can also take an enormous physical, emotional and financial toll. For example, care partners of people with dementia have an increased risk of developing their own health problems and often experience high levels of stress and social isolation.[93,94,95,96,97] The level of stress also increases if they are caring for someone who experiences responsive behaviours.[98,99,100,101,102,103] Care partners may also have other responsibilities that are difficult to balance, such as a job or young families at home.[104]

Care partners also need to be supported when caring for a person with dementia. This includes having access to respite care services, such as adult day programs or overnight care for people with dementia, and being able to gain practical skills for caregiving.[105] For example, Baycrest Health Sciences’ day programs for people with frontotemporal dementia have been helpful in reducing care partner stress.[106] Beyond respite care, adult day programs offer other valuable resources and supports for care partners of people with dementia, such as education and support groups. Collectively, these types of programs can reduce stress, provide emotional support, improve health, reduce social isolation and enhance care partners’ capacity to appropriately respond to responsive behaviours.[107,108,109,110,111] Similarly, training programs such as the Reitman Centre CARERS (Coaching, Advocacy, Respite, Education, Relationship and Simulation) program are also helpful in offering knowledge, skills and emotional support to care partners of people with dementia.[112]

What We Heard

- Care partners are an important part of the care team for people with dementia.
- Accessible and flexible dementia services are needed to meet the needs of both care partners and people living with dementia. These services may include:
    - **Home care services** that help people with dementia in activities such as taking a bath or cooking a meal and that offer respite for care partners.
    - **Respite care services**, such as adult day programs or overnight care, that allow family members to take breaks from their caregiving responsibilities, while ensuring that the person they are caring for has their needs met.
    - **Health care services** offered to people with dementia in their home. These may include visits from nurses, doctors and other health care professionals.
    - **Education and training** that helps care partners develop knowledge and skills to support themselves and a person with dementia in living well.
    - **Social support services** that help maintain the well-being of care partners, including support groups, counselling services, workplace supports and recreational opportunities where both a person with dementia and their care partner can participate in activities together.
- Emerging consumer technologies may be helpful for some care partners in terms of managing care responsibilities and creating supportive environments that foster the ability to live well with dementia.
- It will be important to leverage existing research programs, initiatives and networks across Canada in order to develop innovative solutions that support the independence, health and quality of life of care partners and people with dementia.

Issues to Consider

Enabling care partners to live well means ensuring that they are supported in their caregiving responsibilities, while being able to maintain their own health, independence and well-being. While some services and supports are currently available to help care partners cope with caregiving responsibilities, there are opportunities to provide better care for family members and friends who assist a person with dementia. For example, we also heard that:

- Respite care services should reflect the complex health and social needs of people with dementia and care partners.
- Many excellent education and training programs are available for care partners of people with dementia. Expanding the availability of these programs throughout the province may be one way to help care partners learn about what to expect and to be better supported in their caregiving responsibilities.
- There may be opportunities to better support care partners and people with dementia by allowing them to decide what services they need or want and to determine how money is spent on these services.

What Do You Think?

- What services or supports (for example, home care or adult day programs) are effective in assisting care partners of people with dementia?
    - Why are these effective?

- Are there any services that are currently not available that should be?
    - How would these services assist care partners in managing their caregiving responsibilities?

- Are there any services or supports currently offered that care partners feel are not very effective?
    - What advice would you give to improve them?

5. Well Trained Dementia Workforce

There are many professionals who can help people with dementia and their care partners to live well. People who work outside health care also have a role in ensuring people with dementia and their care partners live active, meaningful lives. They include people working in:

- Public services, including transportation, housing, police services, fire services, community centres and recreation.
- Private businesses, including grocery stores, banks, restaurants and private transportation.
- Non-profit organizations, including clubs and recreation organizations, religious organizations and charitable organizations, such as United Way-funded agencies.

All of these people are part of the dementia care workforce. Dementia-specific education and training can help them to provide excellent services to people with dementia and their care partners and to support the strengths of people with dementia. This might include training in identifying or diagnosing dementia, understanding responsive behaviours, communicating with people with dementia or working in interdisciplinary teams.[113,114,115,116]

Educators and professional organizations across Ontario continue to work towards identifying best practices in dementia care, developing knowledge and skills among new graduates and existing health care providers, and encouraging health care providers to lead change within their organizations. For example, Ontario Centres for Learning, Research and Innovation in Long-Term Care aim to enhance the quality of care in long-term care homes through education, research and evidence-based service delivery.[117] Organizations such as the Registered Nurses' Association of Ontario also offer evidence-based best practice guidelines on dementia to assist nurses and other health care professionals working with people with dementia and their care partners.[118]

Outside of health care settings, family, friends and other community members are instrumental in creating supportive community

The following list of health service providers play key roles in delivering high quality care:

- Dieticians
- Doctors
- Emergency medical service staff
- Nurses
- Occupational Therapists
- Personal Support Workers
- Pharmacists
- Physiotherapists
- Social Workers

environments for people with dementia.[119] For example, in some regions, resources and toolkits are available to assist individuals in making communities, public spaces, businesses and workplaces more dementia-friendly.[120,121]

What We Heard

- Education and training are only part of the answer to providing excellent care. Other elements needed to help change the culture of dementia care include:
    - **Supports** to enable those working with a person with dementia to put what they have learned into practice.
    - **Clear Processes** that make it easier to implement new and innovative technologies or ways of delivering care.
    - **Strong leadership** within organizations to support more dementia-friendly services.
    - **Policies and practices** that promote person-centered care.

- Interdisciplinary teams play an important role in providing high quality care and in supporting people with dementia and their care partners to live well.
    - Understanding how individuals within these teams can better work together, including ensuring optimal staffing levels, skills and mix of team members, is necessary to help build capacity within the health care system.

- There are opportunities to develop research capacity throughout the dementia care system and to build on existing dementia care knowledge and research evidence.

Issues to Consider

Promoting excellence and enabling people to live well with dementia means ensuring that Ontario has an adequately staffed and well trained dementia care workforce in the public and private sectors. There are opportunities to support health care and other service providers in their understanding of dementia and to build on existing skills they use to provide high quality care services. For example, we also heard that:

- Examining ways to provide accessible education to personal support workers and other professionals who work directly with people with dementia is important for delivering high quality dementia care services.
- There is a need for an enhanced dementia curriculum for practicing health care providers and managers as well as for those preparing to enter into practice.

What Do You Think?

- What skills, abilities, standards and best practice guidelines do health care professionals need in order to provide excellent dementia care?
- What opportunities should be available to help health care professionals acquire this knowledge or these skills?
    - If you work with people with dementia or their care partners, what supports could your organization or LHIN offer to help you provide high-quality services? What barriers exist that may prevent you from attending to the needs of a person with dementia?
    - What supports are needed to put knowledge and skills learned through training opportunities into practice?

6. Awareness, Stigma and Brain Health

Combating stigma associated with dementia is important for living well. For example, a lack of awareness and understanding, including not knowing the possible signs and symptoms of dementia, contributes to the stigma experienced by people living with dementia. Rather than focusing on abilities and promoting the physical and mental health of people living with dementia, stigma often reduces people to a series of labels or behaviours. These can lead to false assumptions or negative stereotypes, such as a person not being capable of making care decisions or meaningful contributions to their community. Stigma may also affect employment, result in social isolation or exclusion and may discourage people from seeking a diagnosis.[122,123,124]

In Ontario, some initiatives that aim to raise awareness about dementia have been successfully developed and implemented. For example, the ReThink Dementia program in the Champlain LHIN is designed to increase awareness about brain health and to provide concise, easy to find information about dementia.[125,126,127] Similarly, the Alzheimer Society of Ontario's Finding Your Way program aims to raise public awareness of the risks of going missing among people with dementia and provides information on how to respond to missing person events.[128]

Many factors contribute to a person's risk of developing dementia. Some cannot be changed, including age and genetics. However, it may be possible to reduce this risk by making healthy lifestyle choices as early as possible in life. In general, the things that keep the heart healthy also keep the brain healthy. Maintaining a healthy diet, exercising regularly and participating in social activities have been shown to improve brain health and may prevent or delay the onset of dementia.[129,130,131,132,133,134]

It is also important to promote health and wellness once someone is diagnosed with mild cognitive impairment or dementia. This means ensuring that opportunities are available for these individuals and their care partners to live a healthy lifestyle and to participate in daily activities that are meaningful and contribute to a good quality of life.

What We Heard

- All Ontarians need accessible and credible information to assist them in:
    - Understanding dementia, including its signs, symptoms and treatments.
    - Reducing their risk of developing dementia.
    - Supporting people with dementia in living well.
    - Reducing stigma faced by people with dementia and their care partners.

- Health care professionals, non-profit organizations, educators and researchers play important roles in promoting brain health, reducing aging and dementia-related stigma, and supporting the development of dementia-friendly services and communities.

Issues to Consider

There may be opportunities to better support Ontarians in maintaining a healthy brain, in developing a better understanding of dementia and in promoting health among those living with dementia. For example, we also heard that:

- Public education campaigns and health promotion programs that provide information on dementia may be useful to reduce dementia-related stigma and to increase awareness about dementia risk factors.
- Programs that encourage children, youth and people living with dementia to work and learn together offer rich opportunities for interaction, raise awareness and reduce stigma related to dementia. These programs can empower people living with dementia to continue making meaningful contributions to their communities.

What Do You Think?

- What kinds of public awareness and health promotion programs could help reduce stigma or improve Ontarians' understanding of brain health and dementia?

- What would communities that are inclusive of people with dementia and their care partners look like?
    - What resources and services are necessary to help support this vision?

- Ontario has a strong dementia research community, with researchers investigating causes, prevention, detection, treatment approaches and strategies for maintaining quality of life, among other research.
    - Looking ahead, what research areas should be given priority?

Conclusion

The Ministry of Health and Long-Term Care is committed to listening to Ontarians living with dementia, families, care partners, health care providers and others who provide support to people living with dementia.

The ministry welcomes and values your feedback. Your responses will provide insight to help inform the development of a comprehensive and effective dementia strategy for Ontario.

To find out more about opportunities to share your views, please visit ontario.ca/dementia or send your comments to dementiastrategy@ontario.ca.

Thank you for your participation in this important work. Together we will develop a dementia strategy for Ontario.

Words to Know

Adult Day Programs:	Supervised programming for seniors, including people with dementia, in a group setting. Services may include art, music, exercise and other activities, meals, and assistance with personal care (e.g., eating).
Alzheimer's Disease:	A type of dementia that causes problems with memory, thinking, behaviour, mood and emotions, physical abilities and the ability to perform familiar activities. Alzheimer's disease is the most common type of dementia, accounting for approximately 65 per cent of cases. While most people who develop Alzheimer's Disease are over the age of 65, some people in their 40s or 50s also develop it.
Care Partner:	Family members or friends who work in partnership with a person who has dementia to provide care and support.
Care Provider:	Paid individuals who provide and manage care for people with dementia and their care partners. These individuals may also assist in other support roles including teaching, research and managing health programs. Health care providers may include personal support workers, social workers, nurses, doctors and managers.
Health Links:	An integrated model of care where a team of health care providers, including primary care, specialists, hospitals, long-term care and home care, provide coordinated care to Ontario's complex patient population.
Hospices:	Home-like settings that provide palliative care services to individuals and families, and offer an alternative to dying at home or in a hospital.

Frontotemporal Dementia:	A type of dementia that affects parts of the brain that involve personality, behaviour and language. Changes associated with frontotemporal dementia may include becoming more withdrawn, inappropriate social behaviour and speaking less or difficulty finding the right words. Frontotemporal dementia is a rarer type of dementia and tends to occur between the ages of 40 and 75.
Home and Community Care:	Services that support people who require care in their home or in the community. If you qualify, the Ontario government pays for some of these services. Private companies also provide these services for a fee. Home care services may include health care services (e.g., nursing care, occupational therapy), personal care services (e.g., eating, dressing, bathing), homemaking services (e.g., shopping, house cleaning), and end-of-life care (e.g., pain management, medical supplies). Community care services may include adult day programs, transportation services, and palliative care services in hospices.
Lewy Body Dementia:	A type of dementia that affects parts of the brain that involve thinking, memory and movement. Changes associated with lewy body dementia may include visual hallucinations, changes in sleep patterns, memory loss, stiffness of muscles, shaking, and slow movement. Lewy body dementia is a rarer type of dementia and tends to occur in people over the age of 60.
LGBTQ2S:	LGBTQ2S (lesbian, gay, bisexual, trans or transgender, queer, and two spirit) is intended to include diverse sexual orientations, gender identities and gender expressions.
Local Health Integration Network:	Regional health authorities responsible for planning, integrating and funding health care services in Ontario. There are 14 Local Health Integration Networks funded by the Ministry of Health and Long-Term Care.

Long-Term Care Home:	A residence designed for people who require the availability of 24-hour nursing care and other supports. Long-term care homes receive government funding, with residents paying a co-payment for accommodations. These homes are sometimes referred to as nursing homes.
Mild Cognitive Impairment:	A person with mild cognitive impairment may experience problems with memory, language, thinking or judgment that are greater than those experienced in normal aging. In general, these changes are usually not serious enough to interfere with a person's ability to carry out daily activities or to live independently. A person with mild cognitive impairment is at increased risk of developing dementia.
Nurse Practitioner:	A Registered Nurse with advanced university education who can provide a full range of health care services to individuals and families. These services may include diagnosing and treating injuries or illnesses, ordering and interpreting diagnostic tests, and prescribing medications. Nurse Practitioners work in a variety of settings, including in hospitals and community-based clinics.
Palliative Care:	A type of health care for individuals and families who are living with an incurable illness that is usually at the advanced stage. Palliative care services help individuals live their remaining time in comfort and dignity. Care is focused on relief of pain and other symptoms, as well as on the psychological, social, cultural, spiritual and emotional needs of each person and their family. Palliative care may be provided at home, in hospitals, in long-term care homes or in hospices.
Parkinson's Disease with Dementia:	Parkinson's disease affects parts of the brain that involve movement, resulting in stiffness of muscles, shaking and slow movement. As this disease progresses, some people may also develop dementia. This may result in changes such as visual hallucinations, memory loss and difficulty concentrating or thinking.

Personal Support Worker:	A care provider who provides assistance for individuals, including those with dementia. For example, this may include assisting with activities such as dressing, bathing, eating and exercising, as well as providing emotional support and companionship. Personal support workers provide care at home, in retirement homes, in hospitals and in long-term care homes.
Primary Care:	The first point of contact with the health system. Primary care providers, such as family doctors and nurse practitioners, support people throughout their lifetime by providing comprehensive care that promotes their health and well-being. This includes assessing, diagnosing and managing illnesses, promoting healthy behaviours and helping to coordinate health needs when a referral to other health care providers is required.
Responsive Behaviours:	A term used to describe how a person's actions, words or gestures may be a response to circumstances within their personal (e.g., an infection), physical (e.g., noise, lighting) or social (e.g., boredom) environment that may be important, frustrating or confusing to a person. Examples of responsive behaviours include actions interpreted as agitation, aggression and wandering, among others. Placing negative labels on a person living with dementia (e.g., challenging, aggressive) can strongly influence how a person with dementia is perceived or treated. The term responsive behaviours is intended to assist care partners and care providers in providing high quality care by using language that encourages these individuals to understand the actions of a person with dementia and respond in appropriate, compassionate ways.
Respite Care Services:	A term used to describe care that allows care partners and family members to take a temporary break from their caregiving responsibilities at home. Respite care services may include providing a person with dementia and care partners with access to adult day programs, overnight care or staying at a long-term care home for a short time, and home care services.

Retirement Home:	A privately-owned residence that provides rental accommodation with care and services, primarily for people who are 65 years or older who can live independently with some support. One of the services offered may be a dementia care program. Residents pay for accommodation and services provided within the retirement home.
Social Worker:	A care provider that helps individuals and families develop knowledge and skills needed to enhance their well-being as well as offering counselling, advocacy and assistance in accessing supportive health and social services. Social workers may work in the community, in hospitals and in long-term care homes.
Vascular Dementia:	A type of dementia caused by restricted blood flow to the brain, such as from a stroke. Changes associated with vascular dementia may include confusion, memory problems and difficulty concentrating or organizing thoughts. It is a common form of dementia, accounting for approximately 20% of all cases.

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