

Towards Understanding

Informing Nova Scotia's Dementia Strategy

September 2014

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*I'm dancing with Alzheimer's.
We are partners on the dance floor of life.
My heart plays the music and I'm in the lead.
I am not thrilled with my dance card,
but we're having fun; making the best of it.
Tomorrow is a new dance."*

Faye Forbes

Member, Nova Scotia Dementia Strategy Advisory Committee



Introduction



Every day, more Nova Scotians are facing the same circumstances. Alzheimer's disease and related dementias affect about 1.6 per cent of our population. It's estimated that more than 17,000 Nova Scotians are currently living with some form of the disease. As our population ages, we expect to have double the number of seniors living with dementia by the year 2038. The impact is staggering. For the individuals and families living with dementia, it can be devastating. Knowing when, how, and where to access services can help. It's one of the reasons government is developing a dementia strategy for Nova Scotia to be released Spring 2015.

The more we learn about this disease, the better equipped we are to deal with it. It affects each person and each family differently. There is no cure. It's a progressive illness, often spanning 10–12 years. As a result, the care and support needed for those living with the disease changes over time.

The Department of Health and Wellness and the Alzheimer Society of Nova Scotia are co-leading an Advisory Committee to guide and help develop a dementia strategy for the province. At the heart of the strategy is the desire to put people living with dementia, and their families and care partners, first. Care partners includes family members, significant others, or friends who work in partnership with the person living with dementia and provide unpaid support and care.

The strategy is being developed to provide a more coordinated, inclusive, and culturally competent health-care response to those living with dementia. The objective is to help people living with dementia—and their families or care partners—enjoy a better quality of life.

Background



First, what is dementia? Contrary to what many believe, it is not a normal part of aging. It is a term used to describe a group of diseases that affect the brain and cause a progressive decline in the ability to think, speak, remember, and carry out normal, daily activities. The most common form of dementia is Alzheimer's disease, making up more than 64 per cent of all cases. Dementia affects mainly seniors, although about 1 person in every 1000 under the age of 65 develops dementia¹. Other types of dementia include vascular dementia (20 per cent), vascular dementia due to stroke, dementia of the Lewy body type, Parkinson's disease, Pick's disease, and Huntington's disease.

The cause appears to be a complex interaction of genetics, lifestyle, and environment. Age is the biggest risk factor. Twice as many women will develop Alzheimer's disease, many believe due to declining estrogen levels. Physical activity, healthy food choices, avoidance of brain injury, and treatment of depression can also help to reduce the risk of developing dementia.

Nova Scotia isn't alone in dealing with this disease. Dementia is one of the biggest global public-health challenges facing our generation. Other jurisdictions have developed strategies and recommended approaches to help individuals and families live well with dementia. We can learn from their experience. We do know that estimates of dementia cases vary significantly, for a number of reasons. The disease is difficult to diagnose, especially in the early stages. Memory problems, misunderstandings, and inappropriate behavior often evident in the early stages of dementia are often attributed to aging or to the personality of the individual—or they are ignored. As a result, the disease can

¹ Alzheimer Society of Canada.
www.alzheimer.ca/en/about-dementia/early-onset-dementia

go undiagnosed even as it progresses to the more serious stages. Earlier diagnosis provides the opportunity to access treatment and supports, and to plan for the future.

Like other jurisdictions, we share common issues and challenges relating to dementia. We are also unique in many ways. Nova Scotia has the highest proportion of people aged 65 and over (17.7 % in 2013) and one of the fastest aging populations. Naturally, demographics differ across the province. The oldest population (over 65) resides in Guysborough, Queens, and Annapolis counties. The youngest population, (18–64) live in Halifax, Hants, and Antigonish counties. The majority of those with dementia are 65 and over. Those living in rural areas may not have the same access to services and supports as those in urban locations, placing additional challenges on individuals living with dementia and their family and care partners.

More women than men will be affected by dementia, and they are more likely to live alone as they age.

Care partners (especially spouses) play a critical role in supporting people living with dementia. According to a recent report of the Canadian Institute for Health Information, seniors with dementia who were newly admitted to residential care were twice as likely to be unmarried (widowed, separated, divorced, or never married).

Six Strategic Directions



The Nova Scotia Dementia Strategy Project Team and Advisory Committee have reviewed the strategies of Australia, France, Germany, Scotland, UK, US, and several Canadian provinces. Not surprisingly, many of the strategies have common themes. Common themes include prevention; early diagnosis and quality treatment; providing coordinated care across the span of the disease; and the need to support the care partner. In order to build on the knowledge that has been gathered and reviewed—and to ensure our dementia strategy is tailored to Nova Scotians—we need to hear from Nova Scotians.

Along with reviewing the strategies of other jurisdictions, current programs available within Nova Scotia were also examined. Those directly delivering the programs were asked to identify current services, any gaps in those services, and suggestions to help inform Nova Scotia's dementia strategy. Through this work six areas of focus have emerged as the foundation on which Nova Scotia's strategy will be built. They are fundamental to support care and treatment and to achieve better outcomes. They are all equally important and all connected. They include

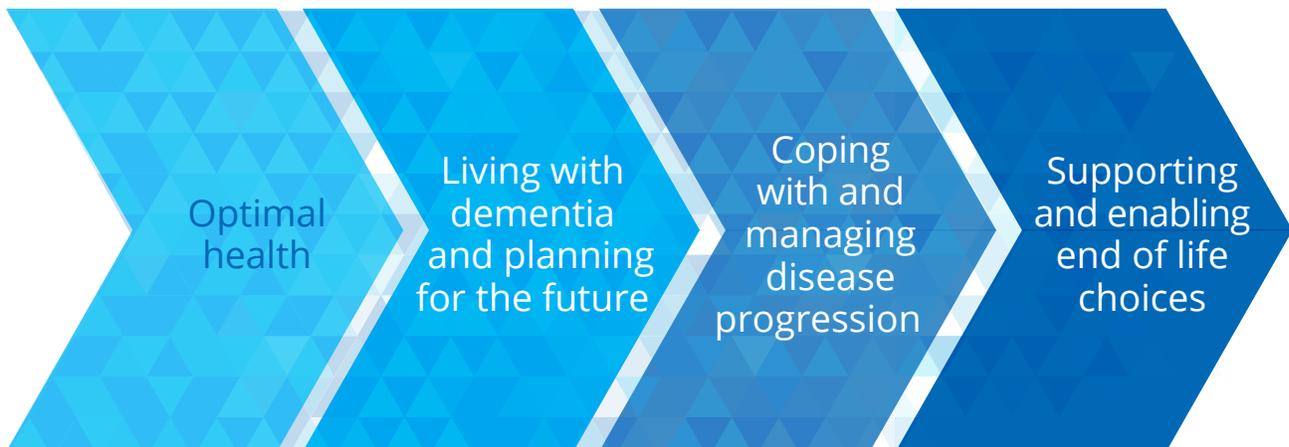
- public awareness
- early diagnosis and treatment
- support for families and care partners
- informed health-care providers
- coordinated care
- research

Now it's time to add your voice. For each strategic direction, we will be asking for your advice based on a series of questions. Your answers will help to further inform and shape Nova Scotia's dementia strategy—and ultimately help those living with dementia to live well.

The Personal Journey



Dementia affects each person in a different way. If the consideration of the disease is from the perspective of the individual, a way to depict the experience can be as follows:



Public Awareness



A lack of reliable information and understanding about dementia can contribute to the stigma that surrounds those living with the disease. In order to improve the health and quality of life for those living with dementia, it must be treated like any other chronic health condition. It must be managed appropriately across the health-care system—beginning with prevention, to early detection and diagnosis, to disease management.

The promotion of healthier lifestyles can help to reduce the risk of developing dementia. Making healthy food choices, being physically active, reducing stress, and protecting the brain from injury can all make a difference. The steps needed to reduce the risk of developing dementia are similar to reducing the risk of heart disease. We can help people to understand that what's good for the heart is also good for the head.

In reducing stigma, we increase acceptance. And we reduce the social isolation that individuals and families feel when living with dementia. We can help Nova Scotians understand that it is possible to live well with dementia, and help them to do so.

Please tell us

How easy has it been to access information about

- Reducing the risk of developing dementia
- Dementia
- Where or how to get help

What advice would you give to

- Improve access to reliable information
- Make it easier to get help
- Increase understanding in the community

Early Diagnosis and Treatment



Like any illness, the earlier the diagnosis, the earlier treatment can begin. Supports can then be provided to help those living with dementia. Improved awareness means that individuals and families will have a better idea of what to expect and can begin to plan for the future. Symptoms can then be more effectively managed. The health-care experience of those living with dementia is a complex and dynamic process—which can be improved for many, beginning with early detection.

Please tell us

Given your experience with a dementia diagnosis,

- How has the information you received helped you to plan for the future, manage the disease, and take steps to care for you and your family?
- What were the biggest challenges with getting a dementia diagnosis?
- What advice would you give to improve the experience?

Support for Families and Care Partners



We know that most seniors want to age at home and maintain their independence for as long as possible. To do so, services provided in the community must be considered with a dementia lens to better understand how to meet the needs of the individual and their care partners. Over half of individuals living with dementia identify a child or child-in-law as their primary care partner. The burden on adult children is growing as they provide support to seniors who are frailer. Given the significant role that families and care partners play in supporting people living with dementia, we need to understand what information, supports, and relief is needed to help them maintain and sustain their health and well-being. It's also critical that those living with dementia are aware of the services available that can help to keep people at home for as long as possible. Research tell us that families and care partners are not clear on what to expect regarding dementia, and are not sure where to access services.

Please tell us

How easy is it for families and care partners to access

- Information
- Support
- Relief

What advice would you give to improve supports for families or care partners?

Informed Health-Care Providers



Helping to educate and train staff dealing with the issues of dementia care can include everything from the early identification and effective management of dementia, delirium, and responsive behaviours. We know that health-care providers with the knowledge and skills to meet the needs of people living with dementia demonstrate an improved understanding of the disease and, therefore, also have an increased ability to meet health-care needs. In order to deliver quality care and treatment, a holistic, person-directed approach to care is needed. A holistic approach takes into account all aspects of people's lives and the factors that affect them.

Please tell us

What has been your experience with health-care providers in meeting the needs of

- People living with dementia
- Families or care partners

What advice would you give on how your health-care provider could help you more?

Coordinated Care



Care is coordinated when health-care providers across the system work together and share information so that Nova Scotians can access the best care at the right time and in the right place.

A person-directed approach to care is one that is easy for those living with dementia to navigate. It ensures that families and care partners are being heard and their needs are being considered.

Good communication across the system enables individuals to access services when and where they are needed.

Please tell us

Given your experience with receiving care and supports in different settings across the health system and in the community,

- In what ways were these supports and services accessible and coordinated
- What advice would you give to improve the access and coordination of care?

Dementia Research



Informed decision making helps us to achieve optimal health. Ongoing research is available regarding the prevention of dementia and how to live well with dementia. While there is information available, many Nova Scotians may not be able to understand the information, determine whether it's credible, and know whether it's relevant to their situation. Information from research that is easily understood, and of good quality, can help individuals to make good lifestyle choices and find ways to maximize their quality of life. It can also help individuals cope with the progression of the disease and enable end-of-life care decisions. End-of-life care decisions are ideally informed by the persons wishes and values regarding the type of care they want to receive when they can no longer make such decisions.

Please tell us

How can ongoing research results be made relevant and accessible to people living with dementia and their families and care partners?

Conclusion



We want to learn from those living with dementia as we develop a strategy for Nova Scotia. Our work will be rooted in the vision and guiding principles developed by the Advisory Committee, as we continue our process to help those living with dementia to live well.

Vision



People living with dementia and their families/care partners have access to a welcoming and inclusive system that is responsive, innovative, and culturally specific.

Guiding Principles



Person Directed and Relationship Focused: The person and their family/care partners are valued, empowered, and engaged to make decisions and choices enabled by respectful, trusting relationships.

Inclusive, Culturally Competent, Safe, and Equitable: The different needs of Nova Scotia's diverse populations are valued and integrated to support equitable access in a responsive and inclusive system.

Integrated and Coordinated: The existing system promotes collaboration and is enhanced to provide access to a range of relevant, flexible, and coordinated services and supports.

Enhanced Capacity: Informed and knowledgeable individuals, families/care partners, and health-care providers have the skills and abilities that are essential to effectively understand and support the needs of people living with dementia and their families/care partners.

Accountability and Quality Care: Continuous quality improvement and sustainability are achieved through leadership that enables evidence-based decision making, monitoring, evaluation, and leading practice.

