

Towards Understanding

A Dementia Strategy for Nova Scotia

June 2015

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I hope the strategy looks at caring for those with dementia, and their families, from a practical viewpoint.

I hope the strategy remembers the ones who get left behind. I hope the strategy can pull together the resources needed to help.

Until you have navigated a man with dementia to the ladies washroom because you're not sure which one you should go to, I don't think you can truly appreciate just how important it is to get this strategy right.

Excerpt from Teresa Workman's "My Hope for the Strategy"
a written submission provided to Nova Scotia's Dementia project

Introduction

Today, more than 17,000 Nova Scotians are living with dementia. In the coming years, we expect that number to double as our population continues to age. While the numbers are significant, the impact on the individuals affected and their families can be devastating. Through conversations held around the province, those living with dementia, their families and caregivers shared their experiences, hopes and concerns when dealing with the disease. For some, the fear and isolation they felt was compounded by the stigma they faced in their neighbourhoods and communities. For others, the lack of knowledge about available services and support made an already difficult journey even more so. Nova Scotia's Dementia Strategy is designed to help change that.

“ There are so many different faces of dementia. The diagnosis affects everyone in that person's life. A bombshell dropped into living. ”

The plan to develop a strategy was announced in January of 2014. Like other jurisdictions, Nova Scotia recognized the importance of developing a strategy to improve the quality of life for people living with dementia, their families and caregivers. Along with the social costs of dementia, the financial costs are also significant. It is estimated that from 2008-2038, Nova Scotia will spend over \$24.5 billion in direct health costs, unpaid caregivers costs and indirect costs¹.

Nova Scotia's demographics also point to increased cases of dementia. Nova Scotia has one of the highest proportions of people aged 65 and over in the country, many of whom are living to an advanced age with multiple chronic health conditions. And, we know that with aging there is

¹ Rising Tide: The Impact of Dementia in Nova Scotia: 2008 to 2038. Risk Analytica, October 2009, page 8.

a higher risk of social vulnerability and frailty, both of which can increase the risk for the development of dementia².

Age isn't always a factor. While some believe that dementia is a normal part of aging, it is not. While most people who develop dementia are older, about 1 in every 1,000 under the age of 65 develop what is known as early onset dementia.

Given the demographic and funding challenges faced by Nova Scotia (and others around the globe) greater understanding of the disease is leading to a shift in thinking. Prevention is becoming a priority and care is being coordinated around an individual's needs that will help to maintain independence for as long as possible.

2 M. Andrew, A. Mitnitski, S. Kirkand, K. Rockwood, The Impact of Social Vulnerability on the Survival of the Fittest Older Adults, Age and Ageing, 2012: 41: 161-165, Oxford University Press

Developing the Strategy

To develop the strategy, an advisory committee was established to provide advice and recommendations to the Minister of Health and Wellness. The committee was co-chaired by the Alzheimer Society of Nova Scotia (ASNS) and the Department of Health and Wellness (DHW). Those on the committee brought a number of important perspectives to the table, including those living with dementia, those caring for them, health care providers and community support agencies.

To ensure an even broader range of voices and views were heard, public consultations were held across the province, coupled with online surveys and outreach to support groups. More than 700 people participated including people living with dementia, their families/caregivers and health care providers. Subsequent analysis of the input identified a number of common themes and issues of importance, including:

- Access to reliable information
- Increasing public awareness and understanding
- Early diagnosis
- Coordination of care and collaboration among health care providers
- Importance of relationships between health care providers and clients/families/caregivers
- The significance of primary health care
- The unique concerns of rural areas
- Stigma and fear of dementia

Diverse and underrepresented populations were also consulted. We talked with members of the Acadian, African Nova Scotian, Lesbian, Bisexual, Gay, Transgender and Intersex (LGBTI), Mi'kmaq and Immigrant communities. More outreach is needed to ensure diverse viewpoints and unique needs are addressed, however there are themes emerging for these distinct populations, including:

- The importance of culturally specific approaches to care and need for information sharing
- The significance and high expectations around the roles of caregivers

Gathering Insight and Input



Several local experts were consulted on a regular basis to ensure our objectives were clear, realistic and achievable. They offered invaluable advice and assistance on overall policy coherence, clinical care within the Nova Scotia system and on the needs of families and caregivers. Our appreciation goes to:

Dr. Paul Brown, Professor Emeritus, School of Public Administration, Dalhousie University

Dr. Janice Keefe, Professor and Director, Nova Scotia Centre on Aging, Lena Isabel Jodrey Chair in Gerontology, Mount Saint Vincent University

Dr. Kenneth Rockwood, Geriatrician, Professor of Geriatric Medicine and Neurology, Kathryn Allen Weldon Professor of Alzheimer Research, Dalhousie University

As well, in the fall of 2014, some of the best minds from around the globe were brought together to discuss what's needed for a successful strategy. This '**Best Brains**' session was moderated by **Dr. Gail Tomblin Murphy** of Dalhousie University's School of Nursing. Panel members offered feedback on the development of the framework for action, strategic goals, priority actions and included:

Dr. June Andrews, Professor and Director of Dementia Services, University of Stirling, Scotland

Dr. Howard Bergman, Chair of the Department of Family Medicine, Professor of Family Medicine and Oncology, McGill University, Quebec

Dr. Duncan Robertson, Senior Medical Director of the Strategic Clinical Network: Seniors Health, Alberta Health Services, Alberta

Dr. Samir Sinha, Director of Geriatrics, Mount Sinai Hospital, Ontario

Dr. Isabelle Vedel, Assistant Professor, Department of Family Medicine and Division of Geriatrics, McGill University, Quebec

Additionally, over 60 people participated in six working groups, providing input into the Advisory Committee regarding the strengths, capacity and gaps in the system. Each group focused on a separate theme, drawn from a review of the literature and the results of the department's online survey. They included:

- Public awareness
- Supports for families and caregivers
- Early diagnosis and management of care
- Coordination of care
- Education for health care professionals
- Research

Based on these identified themes, each working group developed draft recommendations. Building on this rich and comprehensive base of information and input, a framework for action was developed. Its overall objective was to create positive change for people living with dementia as well as their families and caregivers.

The conversations held around the province were as revealing as they were real. We have included some of the comments heard during the consultation process throughout the document, as well as some insights and information received prior to the consultation process. We are grateful for their candour and willingness to contribute to a more informed and enlightened journey for those living with dementia today, and those who will face similar challenges tomorrow.

“ When the behaviour became odd the family didn't know what was happening. They thought it was depression. When it was diagnosed, there was no receptivity to that diagnosis, which had huge implications to accessing help. ”

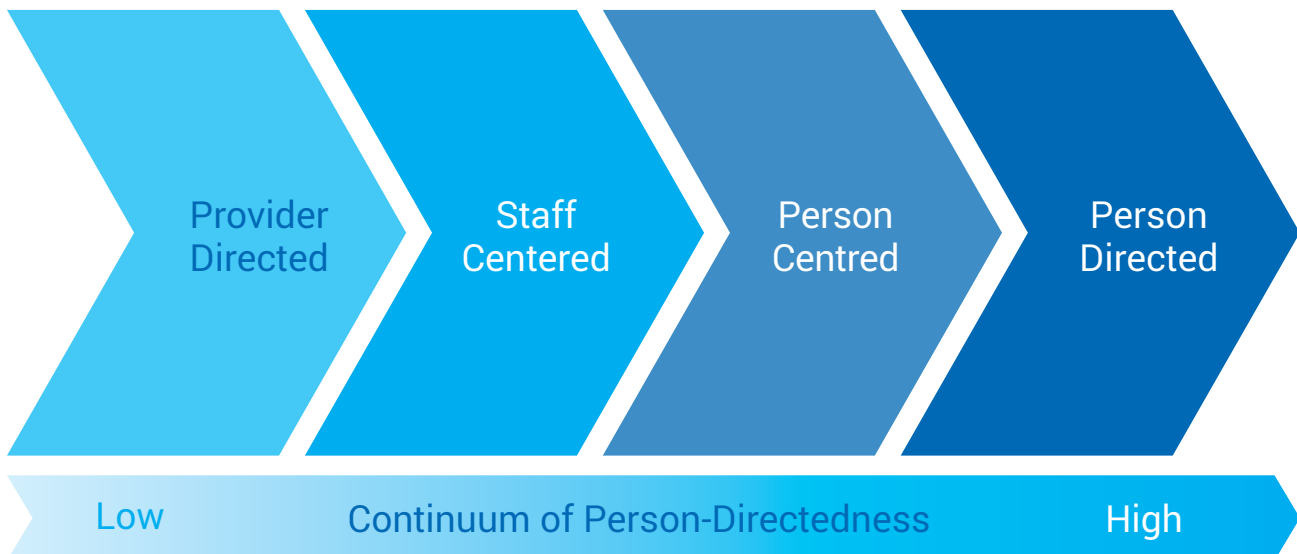
A Person Centred Approach

Experiencing dementia is a personal journey which differs for each individual and their family/caregiver. It is critical that health care providers and the health system generally takes into account this personal journey when interacting with individuals, their families and caregivers.

“ The current climate is not conducive to seeking help from the medical system, there’s no support, no knowledge and a lot of stigma. ”

A person centred approach needs to be part of the culture of care provided. Nova Scotia’s health system is working towards being more person centred or person directed which requires ongoing attention and commitment. In order to move to a more person centred approach, barriers to change must be identified and the corresponding policy, process and practice changes must follow.

Continuum of Person Directed Culture³



³ Adapted from M. Crotty, *Genesis HealthCare Corp.*, based on the model by S. Misorski and J. Rader, distributed at the Pioneer Institutes, 2005.

The dementia experience will differ for each individual and their family/ caregiver. Given the chronic and progressive nature of the disease, those living with it will have diverse and changing needs. For families and caregivers, it can also mean the experience of active grieving and the need for post end of life support. In order to be effective, the health system must take into account the personal nature of the dementia journey when interacting with individuals, their families and caregivers.

Responding to the needs of an older population requires a fundamental shift towards care that is coordinated around the full range of an individual's needs. Priority must also be placed on prevention and supports that help to maintain independence. Achieving this will mean the right mix of services at the right time and place. Effective dementia care supports this transformation of care for older adults.

The needs of caregivers must also be considered as an integral part of the dementia journey. According to the Canadian Institute for Health Information (CIHI), caregivers of people living with dementia provide 75 per cent more care than other caregivers and experience nearly 20 per cent higher levels of stress⁴. As the disease progresses, the demands on caregivers tends to increase. Evidence has shown that if caregiver needs are addressed, and their own health improved, long term care placement for the individual with dementia may be significantly delayed⁵.

Communities, and indeed society generally play an important role in supporting individuals with dementia and their families/caregivers. There must be a strong link between the health system and the community to provide the needed supports at multiple levels. Creating responsive communities means considering the supports that can be provided through age friendly communities and linking the excellent resources available through volunteers, faith based and service organizations.

4 *Caring for Seniors with Alzheimer Disease and Other Forms of Dementia*, Analysis in Brief, Canadian Institute for Health Information (CIHI), August 2010.

5 M. Mittleman et.al. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease, *Neurology* 2006; 67; 1592-1599.

A Framework for Action



The Dementia Strategy focuses on three areas to create positive change for those living with dementia. They are:

- Ensuring access to timely, accurate diagnosis and appropriate care and support for people living with dementia, their families and caregivers
- Enhancing health system capacity to provide coordinated dementia care and support that is person centred and culturally specific
- Increasing awareness and understanding through evidence informed information and education

Reality, Response, Results



For each area of focus, today's reality is identified, a response is provided and anticipated results are outlined. In so doing, the intention is to identify what must be addressed and why, and the change we hope to see as a result.

Reality

Many Nova Scotians do not have access to a timely, accurate dementia diagnosis, and appropriate ongoing care and support.

Despite the high numbers of individuals with dementia, the number of those who actually obtain a diagnosis and therefore receive appropriate treatment, is relatively low. Unfortunately, many don't understand the value of a diagnosis, and think "if I have the disease, there's nothing to be done anyway." Layer that with the stigma often associated with dementia, it's not surprising that many choose not to seek out information or try and hide their symptoms. A lack of information and understanding about dementia contributes to the isolation for those living with the disease. Even among health care providers, levels of understanding varies greatly, which can lead to an ineffective or delayed response for care and support.

It's critically important that awareness around the types of dementia and corresponding symptoms are understood by both those providing and receiving care. Additionally, it is important to help people understand that healthy living—and particularly physical exercise—may reduce the risk of developing dementia. A timely diagnosis is important, and there are a number of supports and services available.

Without timely and accurate information and diagnosis, it's difficult to plan for the future. People may not identify their wishes regarding care, particularly as it relates to end of life care. And, they may not be attending to financial or legal matters. People are often unaware of the progressive nature of dementia, and may not realize that their needs

will change over time. When linked to the appropriate supports and services, meeting these changing needs over time can be much easier. In conversations around the province, Nova Scotians identified primary care providers as one of the main links to accurate information about available services and supports. Therefore, it's important that these providers have the necessary tools and resources to provide to those seeking help. Health care and support systems must be able to respond to diverse needs effectively, in a culturally specific manner, organizing care around dementia with the goal to improve health and the quality of life.

“ Family doctors need more information and resources and need to know where to direct people. When you get a diagnosis, there should be someone that you can see asap to provide information, resources and support. ”

Response

- Build a best practice toolkit for primary health care providers that targets dementia diagnosis, treatment, long term management and care planning. This should include education modules for those using the kit through accessible and appropriate vehicles (such as the web)
- Enhance the First Link Program (offered through the Alzheimer Society) to help primary health care clinicians connect those newly diagnosed to the information, services and support that may need now, and through their journey with dementia
- Continue work on the Electronic Medical Record (EMR) to facilitate easy access and sharing of medical records for a range of health providers
- Develop an ongoing assessment approach focused on the unique needs of families and caregivers. Begin by assessing effectiveness of existing tools, enhance where necessary or develop new assessment tools when required

- Enhance existing programs and services for people living with dementia, such as 811, by including dementia protocols, providing more training and information to 811 nurses and developing a stronger link with the Alzheimers Society
- Change program eligibility around the Supportive Care Program⁶ to include those with dementia under 65, and revise the Caregiver Benefit⁷ program to include the caregivers of those with dementia
- Increase access to home and facility based respite care
- Review programs and services offered in both the Departments of Health and Wellness and Community Services(including adult day programs) to improve accessibility and coordination for those living with dementia
- Work with the provincial palliative care strategy team to enhance end of life care for people living with dementia, their families and caregivers

Results

We will expect to see increased rates of diagnosis and better care through a more responsive primary health care system. The early detection of dementia can mean the world of difference to those living with it. Early diagnosis opens the door to treatment, education, counselling and other services that can delay decline, prevent crisis, ease the burden on caregivers and possibly delay transition into long term care.

It's critically important that awareness around the types of dementia and corresponding symptoms are understood by both those providing and receiving care.

⁶ The Supportive Care Program provides \$500 monthly for home support services (like personal care, respite, meal, household chores) for those with cognitive impairments. Up to \$495 annually may be available for snow removal services.

⁷ The Caregiver Benefit is intended for caregivers of low income adults with a high level of disability or impairment, as determined by a Home Care assessment. If the caregiver and the recipient both qualify, the caregiver receives \$400 monthly.

Additionally, helping people to understand that healthy living may reduce the risk of developing dementia, that a timely diagnosis is important and that there are a number of the supports and services available is vital.

“ Make it easy to find services, get hours of support that work for the family/person and less fighting for the services that should be accessible and coordinated. Consider the challenges of those living in rural areas.”

Reality

There is currently a lack of effective coordination of ongoing dementia care and support across the health system that is person centred and relationship focused.

Navigating the health system is difficult. When services and supports are not coordinated, it's even more confusing. The lack of coordination across the health system and settings can create barriers for those trying to access appropriate care and service. As a result, planning can be piecemeal, and when care needs change, transitions can be ineffective.

We know that not all primary health care providers are linked to care provided by geriatricians, psychiatrists or physicians with specific skills in the care of the elderly. This lack of coordination diminishes the impact of available resources. One of the biggest concerns voiced throughout the consultations was the lack of recognition of caregivers as partners when planning care. Considering the critical role caregivers provide, it is imperative they understand, and can contribute to, a care plan moving forward. On a broader scale, caregivers and individuals living with dementia can and should play a larger role in the development of policies and programs delivered across all health settings. As well, there is an ongoing need to develop programs and services that are culturally specific and appropriately responsive to diverse populations.

In order to do so, members from these communities should be involved in developing these care programs and services to ensure cultural competence.

Response

- Review and revise policies, procedures and practices in both the Department of Health and Wellness and the Nova Scotia Health Authority to ensure they are responsive to the changing needs of those living with dementia, offering seamless transitions between different types of care
- Conduct an inventory of existing Nova Scotia Health Authority healthservices and supports that can benefit those living with dementia, cross checking for accessibility and coordination
- Build a dementia care pathway across the system that incorporates equitable, culturally competent care and resources, developed through a collaborative planning and accountable approach
- Improve communication and coordination among health care providers
- Establish and evaluate demonstration sites (one urban and one rural) focused on coordination of dementia care across collaborative primary health care teams,community based seniors clinics, continuing care, geriatric specialty services, and seniors mental health services
- Examine community-based roles to support people living with dementia, their families and caregivers to identify gaps, highlight promising practices and identify required educational and functional supports for possible expansion
- Enhance dementia care by identifying core competencies for relevant health care providers. DHW will then work with training organizations to ensure core competencies are adapted into the curricula and professional development opportunities

- Recognize and respect the diversity of Nova Scotia's underrepresented populations. Engage them to identify their needs regarding dementia information, care and support
- Use existing tools (such as Nova Scotia's Health Equity Protocol) to help identify priority actions to further develop equitable and culturally specific programs and supports

Results

People living with dementia, their families and caregivers will be engaged in their own care and are recognized as partners. Programs and policies will be accessible, equitable, person centred and culturally specific. Health care providers will have the training, understanding and awareness that will allow them to deliver culturally competent care. Care across settings will be better coordinated. Primary health care providers will be supported by--and linked to--specialized services such as geriatric medicine, psychiatry, memory clinics and mental health providers. As needs change, the transition to different types of care will be seamless. There will be more effective community based dementia care, helping individuals to avoid hospital when appropriate and further functional decline where possible.

“ Caregiving has kept me connected in a close way with my husband, who has Alzheimer’s disease. My patience has grown as his limitations have increased. His appreciation for the smallest of things I do for him, always seems to strengthen our love for each other.”

Reality

There is a lack of awareness and understanding about dementia in the public and varying levels of knowledge among health care providers.

Even though we live in an information age, it's not always easy to discern what information on dementia is reliable or relevant. Many of us are not aware and informed about dementia, unless we are personally touched by it. As a result, more of us are unaware that a healthy lifestyle can lower the risk of developing the disease. We need to help Nova Scotians understand that what's good for the heart is also good for the head. And, ongoing physical activity can continue to have benefits, enhancing the quality of life after a diagnosis.

The stigma still associated with the disease can stand as a barrier to supports and services. For caregivers, having reliable information about how to support the person with dementia is of paramount importance—yet accessing that information can be difficult. Health providers may not always have the needed skills to recognize the specific and unique needs of individuals and their caregivers and they may not be connected to credible information that can offer appropriate care and support.

Response

- Develop an education campaign which will focus on: risk factors; benefits of a healthy lifestyle; physical activity; sources of information and support; the importance of a timely diagnosis and the ability to live well with dementia
- Leverage the partnership between DHW and the Health Care Innovations Working Group to influence content and promote participation in a series of Pan-Canadian webinars and a National Dementia Symposium
- Inventory and evaluate existing education/information resources for caregivers to ensure components related to relationship loss; active grieving; activities of daily living; management of responsive behaviours are included

- Provide appropriate education and training to families and caregivers through organizations like the Alzheimer's Society, who can further build capacity by engaging and working with community partners
- Explore the feasibility and possible methods to provide practical skills training (in areas like personal care, transfers and lifts) for caregivers
- Ensure accessible and appropriate education is available for: primary health care providers, acute and tertiary care staff (beginning with emergency department staff) and continuing care staff working in long term and home care settings
- Facilitate information sharing through online collaborative spaces, repositories and newsletters among organizations like the Nova Scotia Health Authority, the Alzheimer Society of Nova Scotia, the Nova Scotia Health Research Foundation and academic and community partners
- Facilitate access to timely and relevant information for health care providers and the public, using sources like the Canadian Consortium on Neurodegeneration in Aging, brainXchange, and the Canadian Longitudinal study on aging (among others)

Results

Access to valid, reliable and understandable information will be widely available. Those facing a diagnosis will know where to turn for helpful information and support. Awareness regarding dementia among the broader community will increase, and therefore the stigma that adds to the sense of fear and isolation will decrease.

Nova Scotians will understand that regular physical activity and good cardiovascular health provides benefits not only for the heart, but the head as well. Prevention and protective factors are well understood and Nova Scotians are aware of the impact that diet and exercise can, and will have, on their quality of life.

Health care providers will be supported in delivering care that is evidence-based and connected across sectors and settings. The importance of education for providers will be recognized and enabled as part of a system that is accessible, welcoming and responsive.

Caregivers will know where to turn for information, for respite and for practical advice on new challenges that can arise each day. The wealth of information from provincial, national and local sources are better connected, easier to access and navigate.

Implementing the Strategy



Woven throughout the many conversations held around the province is the need to coordinate and collaborate. That's especially true for the many strategies and programs currently underway across government. The Dementia Strategy will achieve optimal success when linked with the Palliative Care Strategy, the refreshed Continuing Care Strategy and the Mental Health and Addictions strategy, to name a few. Similarly, the strategy must align with work underway in primary health care, including the demonstration projects around different models of care to improve overall system dementia diagnosis and management.

It's also important to leverage existing programs in new ways. Active Living programs encourage physical activity, and these can be used to promote risk reduction and management of the progression of dementia. As well, the ongoing work of the Department of Community Services in transforming the Disability Support Program will help with the assessment of residential community capacity to support people with dementia.

The intent of the strategy is to provide the foundation that will lead to improved care and supports. A three year plan is proposed, recognizing the complexity around implementation and the fact that change does take time. The timeframe also allows the strategy to be informed and guided by ongoing health system planning through DHW and the Nova Scotia Health Authority.

Conclusion



We do understand how important it is to get this strategy right. That's why we have consulted broadly, and ensured the voices of those living with the disease helped to illuminate the path forward. We also know that in order to be successful, there must be a renewed focus on research and evaluation. It is challenging to set priorities and plan for dementia related care when there is limited knowledge about how effectively programs and services are meeting the needs of Nova Scotians with dementia. The lack of data impacts program planning, monitoring and evaluation. And, the useful dementia related research that does exist isn't being applied to care practices. That has to change.

Nova Scotia's Dementia Strategy must be evaluated. A variety of activities and actions will need to be monitored or formally evaluated. There is also a need to determine the appropriate data to collect across the health system to support individual care, system planning, evaluation and research. Lastly, dementia related research priorities must be established and aligned with the implementation of the strategy. In this way, we can better guide the investment of scarce resources and create a system that is both responsive and innovative for all Nova Scotians.

“Dad is happy tonight, and in the end, that's all I want for him. If I can't take this disease away, I hope I can make him feel safe, comfortable and loved. Alzheimer's is not going to win tonight.”

Appendix A

Vision & Guiding Principles

In advance of the consultations, a discussion paper was released to help spark the dialogue, it is available here novascotia.ca/dhw/dementia.

The paper outlined the vision and guiding principles that are intended to underline and be embedded in the actions that will be taken as part of Nova Scotia's Dementia Strategy.

Vision

People living with dementia, their families and caregivers, have a better quality of life through an accessible, welcoming and inclusive system that is responsive, innovative, and culturally specific.

Guiding Principles

To ensure the strategy is grounded in a common set of values and philosophy, guiding principles were established as a foundation, and are meant to be reflected as priority actions are acted upon. They include:

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

Enhancing Capacity: Informed and knowledgeable individuals, families, caregivers and health providers have the skills and abilities that are essential to effectively understanding and supporting the needs of people living with dementia, including their families and caregivers.

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

Appendix B

Dementia Strategy Advisory Committee

Timeframe: 6 Advisory meetings were held between April 2014 and April 2015.

Member	Organization
Dr. Melissa Andrew	Geriatrician, Nova Scotia Health Authority (NSHA), and Associate Professor of Geriatric Medicine Dalhousie University
Lloyd Brown (co-chair)	Executive Director Alzheimer Society of Nova Scotia
Angus Campbell	Executive Director Caregivers Nova Scotia
Dr. Keri-Leigh Cassidy	Clinical Academic Director Geriatric Psychiatry/ Seniors Mental Health Program, NSHA
Janice Chalmers	Staff Educator Northwood Homecare
Krista Connell	Chief Executive Officer Nova Scotia Health Research Foundation
Heather Fifield	Family caregiver
Reverend Faye Forbes	Person living with dementia
Patricia Harrington	District Manager, Seniors Health, NSHA
Ruby Knowles (co-chair)	Executive Director, Continuing Care Department of Health and Wellness
Lorna MacPherson	Director, Services for Persons with Disabilities Department of Community Services
Sharon Davis-Murdoch	Special Advisor to the Associate Deputy Minister on Diversity and Social Inclusion Department of Health and Wellness

Brenda Nicholson	Director of Resident Care Alderwood Nursing Home, Baddeck
Tony Prime	Coordinator, Adult Mental Health Department of Health and Wellness
Faizal Nanji	Director Corporate Strategy and Policy Department of Seniors
Dr. Merv Shaw	Group of IX Seniors' Advisory Council of Nova Scotia, Senior and Retired Doctors section of Doctors Nova Scotia
Dr. Celina White	Doctors Nova Scotia, family physician

Project Support	Organization
Susan Baikie	Department of Health and Wellness
Joanne Collins	Department of Health and Wellness

Appendix C

Dementia Strategy Working Groups

Improved Public Awareness

Chair: Linda Bird	Alzheimer Society of Nova Scotia
Work Lead: Kim Clarke	Continuing Care, Department of Health and Wellness (DHW)
Dr. Keri-Leigh Cassidy	Geriatric Psychiatry, Nova Scotia Health Authority (NSHA)
Patricia Harrington	Continuing Care, NSHA
Lynn Langille	Public Health, DHW
Phyllis Marsh-Jarvis	Health Association of African Canadians
Michele McKinnon	Strategic Project Executive, DHW
Gayle Ogilvie	Seniors' Community Health Team, NSHA
Joan Parks-Hubley	Alzheimer Society of Nova Scotia
Tony Prime	Mental Health & Addictions, DHW

Strengthening Support for Families/Caregivers

Chair: Dr. Janice Keefe	Mount Saint Vincent University, Centre on Aging
Work Lead: Susan Baikie	Continuing Care, DHW
Derrick Babin	Victorian Order of Nurses
Rajeane Boudreau	Association of Black Social Workers
Angus Campbell	Caregivers Nova Scotia
Janice Chalmers	Northwood Homecare Ltd.
Crissy Doucette	Continuing Care, NSHA
Heather Fifield	Family Caregiver

Dr. Wenda MacDonald	Alzheimer Society of Nova Scotia
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Pat Miller	Alzheimer Society of Nova Scotia
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Early Diagnosis and Management

Chair: Dr. Chris MacKnight	Geriatric Medicine, NSHA
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Work Lead: Sam Aiton	Continuing Care, DHW
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Dianne Ardern	Alzheimer Society of Nova Scotia
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Dr. Ajantha Jayabarathan	Family Physician
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Tom MacNeil	Senior LINCS Program, NSHA
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Carmen Celina Moncayo	Immigrant Services Association of Nova Scotia
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Mary Jo Monk	Primary Health Care, DHW
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Cheryl Smith	Primary Health Care Nurse Practitioner, NSHA
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Dr. Brian Steeves	Family Physician and Continuing Care Medical Director, NSHA
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Dr. Celina White	Doctors Nova Scotia, family physician
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Improved Education for Health Care Providers

Chair: Marlene MacLellan	Nova Scotia Community College, Health Studies
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Work Lead: Louise Boudreau	Department of Seniors
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Rhonda Atwell	African Diaspora Association of the Maritimes (ADAM)
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Trish Bilski	Veterans Services, QEII Health Sciences Centre
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Yvonne Briggs	Continuing Care, NSHA
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Dr. Jeannie Ferguson	Psychiatrist, NSHA
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Jody MacDonald	Alzheimer Disease and Other Dementia Care Course
Christie Nickerson-Rac	Collaborative Learning Centre, Maplestone (Shannex) in collaboration with Dalhousie University
Ruth Slack	Seniors' Clinic, NSHA
Dr. William Webster	Dalhousie University, Health Professions

Better Coordination of Care

Chair: Dr. John Campbell	Mental Health and Addictions, NSHA
Work Lead: Sam Aiton	Continuing Care, DHW
Lewis Bedford	Acute and Tertiary Care, DHW
Darlene Boliver	Family Caregiver
Mary Anne Johnston	Mental Health and Addictions, NSHA
Beverley Madill	Union of Nova Scotia Indians
Shauna Maltby Doane	Mental Health and Addictions, NSHA
Marie McPhee	Long Term Care, NSHA
Wendy McVeigh	Access and Flow, NSHA
Mark Scales	Seniors' Clinic NSHA

Research

Co-Chair: **Dr. Melissa Andrew** Geriatric Medicine, NSHA

Co-Chair: **Krista Connell** Nova Scotia Health Research Foundation

Work Lead: **Susan Baikie** Continuing Care, DHW

Dr. Sultan Darvesh Geriatric Medicine, Dalhousie University

Dr. Mary Gorman Geriatric Assessment Unit, NSHA

Glen Hougan Nova Scotia College of Art and Design

Dr. Janice Keefe/
Pam Fancey Mount Saint Vincent University,
Nova Scotia Centre on Aging

Susan Stevens Continuing Care, DHW

Appendix D

Consolidated Summary of Consultations

Community Consultations (Sept.-Nov. 2014)

No.	Date	Group	Location	No. of attendees
1	Sept 26, 2014	Health Care Providers	Bridgewater	25
2	Sept 26, 2014	People with dementia & family/caregivers	Bridgewater	0/8/6 ¹
3	Oct 2, 2014	Health Care Providers	Sydney	25
4	Oct 2, 2014	People with dementia & family/caregivers	Sydney	1/6/4 ²
5	Oct 9, 2014	Health Care Providers	Truro	23
6	Oct 9, 2014	People with dementia & family/caregivers	Truro	2/16/5 ³
7	Oct 23, 2014	Health Care Providers	Cornwallis	26
8	Oct 23, 2014	People with dementia & family/caregivers	Cornwallis	0/6/3 ⁴
9	Oct 30, 2014	Health Care Providers	Dartmouth	64
10	Oct 30, 2014	People with dementia & family/caregivers	Dartmouth	2/22/11 ⁵
11	Nov 6, 2014	Health Care Providers – Geriatrics	Halifax	18
			Total	273

- 1 This group included 0 self-identified people living with dementia, 8 caregivers and 6 health care providers.
- 2 This group included 1 self-identified person living with dementia, 6 caregivers and 4 health care providers.
- 3 This group included 2 self-identified people living with dementia, 16 caregivers and 5 health care providers.
- 4 This group included 0 self-identified people living with dementia, 6 caregivers and 3 health care providers.
- 5 This group included 2 self-identified people living with dementia, 22 caregivers and 11 health care providers.

Nova Scotia Department of Health and Wellness Online Surveys (Oct.-Nov. 2014)

Date	Group	Responses
Oct 1 – Nov 14, 2014	Health Care Providers	17
Oct 1 – Nov 14, 2014	People with dementia & family/caregivers	36
Oct 1 – Nov 14, 2014	French-speaking	3
Total		56

Alzheimer Society of Nova Scotia Online Survey (October 1-November 21, 2014)

Group	No. of participants	
Health Care Providers ⁶	40	
People living with dementia & family/caregivers [*]	22	
Total		62⁷

* This group includes people living with dementia, family members, caregivers, neighbours, and friends.

⁶ Health care provider includes health care professionals and service providers working across all health care settings, non-profit organizations, and community service groups and organizations.

⁷ Some respondents only provided demographic information and did not answer the questions; they are not included in totals.

Consultation with underrepresented populations

No.	Date	Group	Location	No. of attendees
1	Oct 7, 2014	Acadian	Halifax & Telehealth (Pointe de l'Eglise, Tusket, Petit de Grat, Pomquet)	21
2	Dec 2, 2014	Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI)	Halifax	8
3	Dec 5, 2014	African Nova Scotian	East Preston	2
Total				31

Alzheimer Society of Nova Scotia Conference Participants

Group	No. of attendees
Health care providers	125
People living with dementia/caregivers	28
Service providers	11
Educators	2
Chief Executive Officers	1
Government workers	1
Lawyers	1
Students	1
Other	11
Total	
181	

Dementia Support Group Discussions

Group	No. of groups
Alzheimer Society of Nova Scotia	8
Caregivers Nova Scotia	9
Total	17

Appendix E

Dementia Strategy Model for Change

