Dementia Care Action Plan

2023-2026

Newfoundland & Labrador

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Introduction

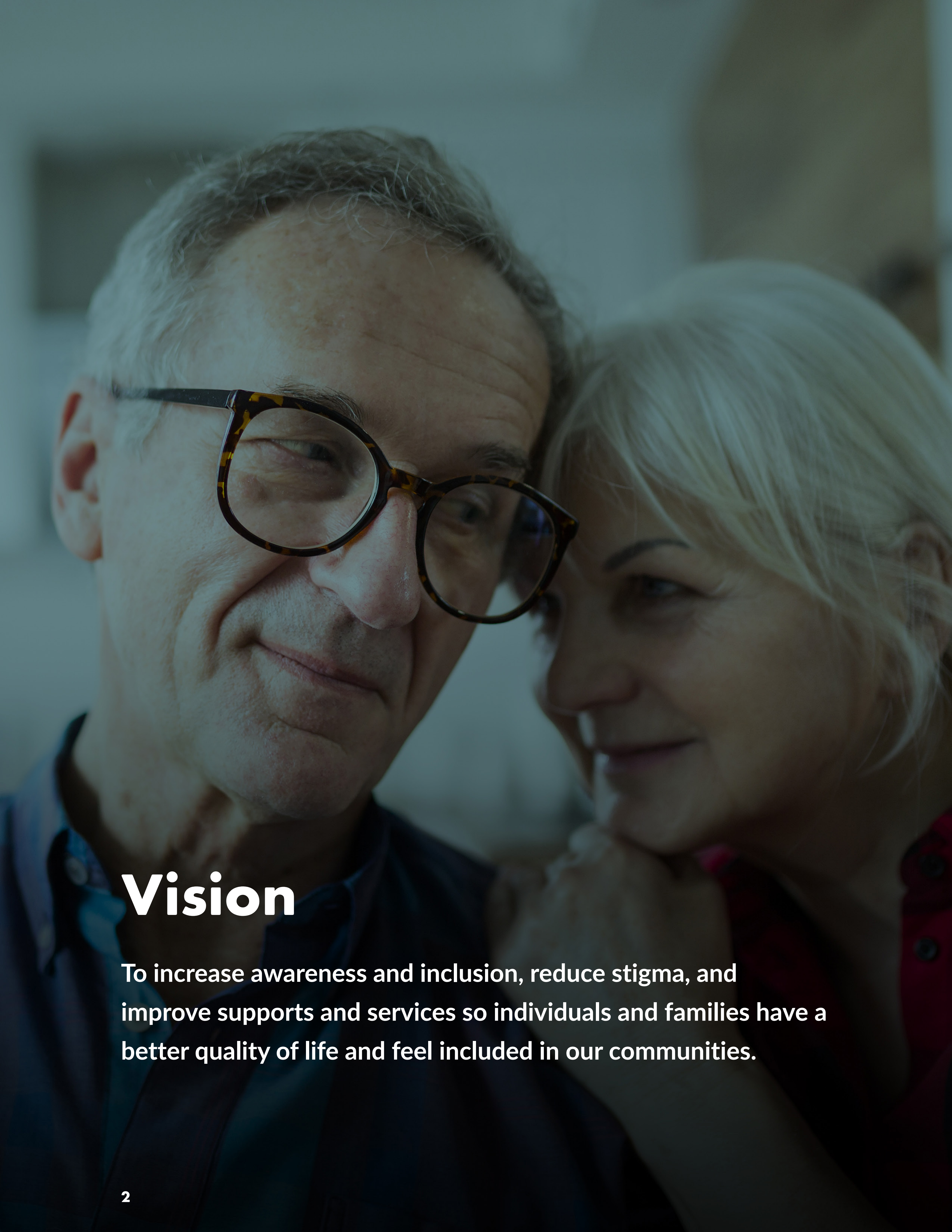
Dementia is a disorder of the brain resulting in a progressive loss of cognitive abilities affecting memory, language, orientation, judgment, problem-solving skills, and behaviour. Dementia is a complex chronic disease that also affects a person's physical functioning, eventually leading to a loss of independence. The dementia journey differs for each individual, their care partners, and families. As the disease progresses, individuals require significant assistance and support.

According to the Alzheimer Society of Newfoundland and Labrador, in 2021 there were over 10,000 people living with dementia in the province. According to the Canadian Institute for Health Information, in Canada, the prevalence of dementia in persons less than 65 years of age is approximately three per cent. While not a normal part of aging, the risk of developing dementia increases with age. The number of people with dementia in Newfoundland and Labrador is anticipated to increase to over 14,000 by 2035, as the population continues to age. As the need for supportive services is anticipated to increase, a continued focus on opportunities to support individuals to live well in their homes and communities is critical to providing better outcomes for individuals and to support sustainability of the health care system.

The Government of Newfoundland and Labrador recognizes that dementia is a complex condition and meeting the diverse and changing needs of people living with dementia and their families will require an evidence-based, individualized and coordinated approach to service delivery that recognizes the rights of people living with dementia and the importance of enjoyment of life.

This three-year plan outlines actions to improve the lives of individuals and families living with dementia. Implementation of actions in the plan will increase awareness of dementia and create safe and accepting communities where individuals living with dementia are active and engaged. The plan also focuses on improving diagnosis, coordination of care, and enhancing supports and services for individuals and families living with dementia.

The plan is consistent with the Department of Health and Community Services' strategic plan to improve population health, increase quality care and access, and enhance health innovation. This plan is also closely aligned with Health Accord NL.



Vision

To increase awareness and inclusion, reduce stigma, and improve supports and services so individuals and families have a better quality of life and feel included in our communities.

Background

Many organizations and countries are implementing actions to address the needs of people living with dementia and their families. In 2019, the Federal Government released **A Dementia Strategy for Canada: Together We Aspire** (canada.ca/national dementia strategy). The objectives of the strategy are to prevent dementia; advance therapies and find a cure; and improve the quality of life for people living with dementia and their caregivers. Provinces and territories collaborated with the Federal Government to inform development of the strategy and are actively engaged in supporting its implementation.

Individuals living with dementia face significant challenges in upholding their human rights. A diagnosis of dementia may result in the assumption of incompetence and with that, a loss of independence and decision making rights. In recognition, the World Health Organization and the United Nations have highlighted the importance of a human rights based approach when addressing dementia. To increase awareness about upholding and respecting the human rights of individuals with dementia, the Alzheimer Society of Canada developed the Canadian Charter of Rights for Persons with Dementia. This document empowers individuals living with dementia to ensure their rights are protected and respected.

The actions outlined in this plan are consistent with recommendations from the World Health Organization, the United Nations and the Canadian Charter of Rights for Persons with Dementia. As actions are implemented, it will be necessary to challenge assumptions and perceptions, and strengthen approaches to service delivery to ensure the rights, dignity, and choices of people living with dementia are valued and respected.

To ensure this action plan is reflective of the diverse needs of people living with dementia, their care partners, families and the health care system, the Provincial Government launched a comprehensive public engagement consultation process. Multiple opportunities were available to participate, including in-person public consultations, focus groups for physicians and regional health authority staff, and questionnaires available through the engageNL website. In addition, the Department of Health and Community Services consulted with staff of the Office of the Seniors Advocate, and conducted interviews with family caregivers. In total, feedback was received from over 480 individuals. Actions have also been informed through consultation with the Alzheimer Society of Newfoundland and Labrador and regional health authorities during implementation of other related initiatives. The plan identifies actions based on best practices in dementia care that reflect a person-centred and strengths-based approach, and is aligned with other provincial government priorities and the national dementia strategy.

The plan will explore opportunities to leverage and build on existing strategies and action plans, including Health Accord NL, **Chronic Disease Action Plan, Healthy People, Healthy Families, Healthy Communities: A Primary Health Care Framework for Newfoundland and Labrador, Towards Recovery: The Mental Health and Addictions Action Plan for Newfoundland and Labrador, the Provincial Advisory Council on Aging and Seniors Activity Plan**, and the **Provincial Advisory Council on Persons with Disabilities Activity Plan**. The development of the Dementia Care Action Plan is linked to the **Department of Health and Community Services' Strategic Plan** (2020-2023).

The plan also aligns with other initiatives to improve supports for individuals living with dementia, including the Home First Initiative and the Provincial Home Dementia Care Program, which provides access to medical care for people living with moderate to advanced dementia at home. In partnership with the Alzheimer Society of Newfoundland and Labrador, the Department of Health and Community Services supported home and personal support workers to complete the Dementia Passport ™, an online dementia training platform.

Governance

Improving dementia care through implementation of the Dementia Care Action Plan, will require collaboration from a number of stakeholders including provincial government departments, health professionals, researchers, communities, and individuals and families living with dementia. To support development and implementation of the plan, a Dementia Action Council was established. The Dementia Action Council is comprised of representatives from government departments, regional health authorities, the Alzheimer Society of Newfoundland and Labrador, and individuals with lived experience.

The Department of Health and Community Services and the Dementia Action Council will oversee implementation of the Dementia Care Action Plan. Small operational teams may be formed to support implementation of specific initiatives and will report to the Council. The Council will also provide advice to the Minister of Health and Community Services on matters related to dementia.

Implementation

The Dementia Care Action Plan was developed to create change in perceptions about dementia, increase understanding and acceptance, and improve supports and services to enhance the quality of life for people living with dementia. Implementation will require a coordinated effort from government departments, regional health authorities, private service providers, community groups, communities and families to advance the actions outlined in this plan.

The Dementia Care Action Plan will be implemented over a three-year timeframe with short, medium and long-term actions. The timeframe for actions was determined based on the complexity of the action, whether work was already underway, and readiness for change. Actions will be completed as follows:

- Short-term: 10 actions to be substantially completed in year one (March 2024)
- Medium-term: 13 actions to be substantially completed in year two (March 2025)
- Long-term: 13 actions to be substantially completed in year three (March 2026)

Annex A includes a list of the short, medium and long-term actions and identifies the responsible body for leading implementation.

Four Focus Areas

Focus Area 1: Increase Awareness, Reduce Risk of Dementia, and Address Stigma

Emerging research evidence suggests activities to support a healthy lifestyle, such as eating well, physical activity and preventing head injuries, may reduce the risk of developing dementia. Significant work is ongoing in the province to increase healthy behaviours and improve health outcomes; opportunity exists within this work to incorporate information on dementia risk reduction.

Individuals may delay a diagnosis due to a lack of knowledge of symptoms of dementia, fear, or embarrassment. In addition, individuals living with dementia and their families can often feel very isolated due to the stigma associated with a dementia diagnosis. Increasing understanding and acceptance will help foster social inclusion, and enable people living with dementia to remain active participants in their communities and improve their quality of life.

Raising awareness of dementia will support risk reduction, promote social inclusion, reduce stigma, increase awareness of the rights of individuals with dementia, increase knowledge of signs and symptoms, support early diagnosis, and improve access to care, treatment and supports.

Actions:

1.1 Work with the regional health authorities and regional wellness coalitions to ensure health promotion initiatives include a focus on brain health and dementia risk reduction. (S)

1.2 Provide public education on signs and symptoms of dementia, including the different types of dementia, young onset dementia, the benefits of early diagnosis, and the various types of supports and services available. (S)

1.3 Work with stakeholders including the Department of Children Seniors and Social Development, the Alzheimer Society of Newfoundland and Labrador, municipalities and community groups to implement actions to increase dementia inclusive communities and ensure dementia is incorporated into existing or planned age-friendly community initiatives. (M)

1.4 Work with the Alzheimer Society of Newfoundland and Labrador to support business owners to make their services more dementia friendly. (M)
1.5 Work with the Alzheimer Society of Newfoundland and Labrador to support delivery of training and resources to ensure first responders have an understanding of dementia and are better prepared to provide support to people living with dementia and their families. (M)
1.6 Work with the Department of Education to increase age appropriate awareness of dementia, social inclusion and stigma reduction in K-12 school curriculum. (M)

Focus Area 2: Diagnosis and Coordination of Care

A timely and accurate diagnosis is essential to access appropriate treatment, care and support, and to provide time for individuals to plan for their future in a manner that maximizes independence in decision making.

People living with dementia and their families interact with many parts of the health care system, including family doctors, hospitals, home support services, residential care, and palliative and end-of-life care. The health care system is complex and can be challenging to navigate. Individuals require accurate information about the resources, programs and services available to enhance quality of care for people living with dementia, and need help to access them at different stages of the dementia journey. This journey is different for everyone and requires an individualized approach as the disease progresses and a person's needs change. A coordinated, integrated and person-centred approach is required to support appropriate referral pathways and seamless transitions.

Actions:

2.1 Identify and implement opportunities to support an interdisciplinary approach to diagnosis and increase the capacity of providers to improve diagnosis of dementia across the care continuum. (L)
2.2 Ensure care providers have access to evidence-based diagnostic tools and current information on community based resources, to promote timely and appropriate referrals to supports and services. (M)
2.3 Increase access to geriatric specialists for individuals living with dementia with complex needs. (M)

2.4 Develop a best practice toolkit for supporting individuals living with dementia and their families. (L)
2.5 Develop dementia care pathways for use by clinicians supporting individuals through the dementia journey. (L)
2.6 Expand use of the HealthLine to provide support to individuals living with dementia and referral to other health services. (L)
2.7 Implement client navigators to support individuals and their families to access support and services throughout the dementia journey. (S)
2.8 Ensure individuals living with dementia have access to an interdisciplinary team with a dedicated case manager to support care coordination and transitions. (M)
2.9 Implement an awareness campaign on advance care planning including development of updated written material. (S)

Focus Area 3: Supports and Services for Individuals Living With Dementia, their Care Partners and Families

Individuals living with dementia and their families need timely access to the supports and services that will improve quality of care and enhance quality of life. Many individuals living with dementia want to remain in their home communities. Supporting the medical, behavioural and social needs of individuals, particularly people living in rural and remote communities, will be important in achieving this goal. Increasing access to innovative technologies and virtual care will help support individuals living with dementia and their families.

While there are a number of quality programs and services available to support individuals with dementia, it is recognized a new approach to service delivery is needed. Individuals need services that respect and embrace their individual preferences, incorporate past experiences, promote independence, and quality of life.

Accessing and navigating the acute care system can be extremely challenging for individuals living with dementia and their families. In the 2018 report, Dementia in Canada, the Canadian Institute for Health Information noted that individuals living with dementia experience longer wait times in emergency departments, and have longer lengths of stay in acute care than people without a diagnosis of dementia. Improving access to community-based care will help reduce unnecessary acute care visits and support individuals in more appropriate environments. Opportunities also exist to improve the experience of individuals living with dementia who require acute care services.

Care partners and families provide significant support to individuals living with dementia. Supporting a family member or friend living with dementia can be challenging and demanding, particularly as the disease progresses and dependence increases. In addition, many individuals with dementia exhibit responsive behaviours and personality changes, which can be difficult for families to cope with. Care partners need improved access to resources and services to help them in their care partner role.

Actions:

3.1 Ensure individuals living with dementia who are accessing health and community services have individualized support plans based on the person's needs and individual preferences. (S)

3.2 Expand the Provincial Home Dementia Care Program to support increased numbers of individuals living with dementia to remain at home. (S)

3.3 Increase access to behaviour management specialists to provide support with behavioural and psychological symptoms of dementia in community, personal care homes, and long-term care homes. (S)

3.4 Increase community-based residential supportive care options for people living with dementia who do not need daily access to nursing care. (M)

3.5 Improve supports for care partners. (L)

3.6 Identify and implement opportunities in acute care to improve quality of care of individuals living with dementia. (L)

3.7 Ensure the unique needs of individuals with dementia and their families are considered in palliative and end-of-life care. (S)

3.8 Enhance use of technology, including virtual care, to support people with dementia and their care partners. (L)

3.9 Improve integration and increase capacity of primary care providers and community health teams in providing dementia care. (L)

3.10 Identify and implement opportunities to improve quality of care and quality of life, including enhanced social and recreational programming, across all care settings. M)

3.11 Identify and implement opportunities to improve quality of care and quality of life for individuals living with dementia in residential care homes, including opportunities to make long-term care homes more familiar and less institutional, with an increased focus on person-centred care, and flexible delivery of programs and services. (M)

3.12 Identify and implement opportunities to better support individuals diagnosed with young onset dementia and their families, recognizing the unique challenges experienced. (M)
3.13 Expand dementia support groups for individuals living with dementia and their care partners. (L)
3.14 Identify and implement opportunities for intergenerational programming where children, youth and younger adults interact with individuals living with dementia through formal, informal or volunteer-based programming. (L)

Focus Area 4: Professional Learning and Development

A knowledgeable and skilled workforce is essential in providing competent and compassionate dementia care. Primary care providers are often the first clinician a person living with dementia encounters; ensuring these providers have dementia training can lead to earlier diagnosis, better management of dementia, and connection to important supports and services. It is also important that all frontline staff have some level of dementia training to have a better understanding of dementia, to become more aware of the rights of people with dementia, and to ensure respectful interactions with people living with dementia. Providers supporting individuals living with dementia need access to the most current and evidence-based information to inform their practice.

Actions:

4.1 Identify core competencies particular to dementia care for relevant care providers and ensure competencies are embedded across the health care system. (S)
4.2 Implement minimum educational requirements for home and personal support workers, including dementia specific training for staff working directly with individuals living with dementia. (L)
4.3 Ensure health care providers who regularly support individuals with dementia complete advanced dementia care education including a focus on person-centred care and empathy training. (S)
4.4 Increase educational opportunities for primary care providers and community health teams to support early detection and improved management of dementia. (M)

4.5 Ensure all regional health authority staff have access to training and resources to ensure staff have an understanding of dementia and are better prepared to provide support to people living with dementia and their families. (L)
4.6 Advocate for inclusion of dementia training in all undergraduate and postgraduate health professional training programs. (L)
4.7 Support creation of a provincial network of clinicians to share information on evidence based resources and best practices in dementia care. (M)

Accountability and Performance Monitoring

Performance monitoring is important to ensure actions are effectively implemented within the timelines identified. An evaluation plan will be developed with input from stakeholders to measure the impact of initiatives on the lives of individuals and families living with dementia. This will require an analysis of data gaps and development of a plan to collect appropriate data to inform the evaluation and improve performance management. Annual progress reports on the implementation of the Dementia Care Action Plan will be prepared and available publicly.

Actions may be refined in light of new and emerging evidence on best practices in dementia care. Any changes to the plan will be made following a review of research, evaluation of actions and in consultation with the Dementia Action Council.

Glossary

HCS - Health and Community Services

RHAs - Regional Health Authorities

CSSD - Children Seniors and Social Development

AS - Alzheimer Society of Newfoundland and Labrador

EDU - Education

NLCHI - Newfoundland and Labrador Centre for Health Information

Actions, Timelines and Responsibilities

Short-Term Actions (by March 2024)

#	Actions	Responsibility
1.1	Work with the regional health authorities and regional wellness coalitions to ensure health promotion initiatives include a focus on brain health and dementia risk reduction.	**HCS, RHAs, CSSD**
1.2	Provide public education on signs and symptoms of dementia, including the different types of dementia, young onset dementia, the benefits of early diagnosis, and the various types of supports and services available.	**AS, RHAs**
2.7	Implement client navigators to support individuals and their families to access support and services throughout the dementia journey.	**RHAs**
2.9	Implement an awareness campaign on advance care planning including development of updated written material.	**HCS, CSSD, RHAs**
3.1	Ensure individuals living with dementia who are accessing health and community services have individualized support plans based on the person's needs and individual preferences.	**RHAs**
3.2	Expand the Provincial Home Dementia Care Program to support increased numbers of individuals living with dementia to remain at home.	**HCS, RHAs**
3.3	Increase access to behaviour management specialists to provide support with behavioural and psychological symptoms of dementia in community, personal care homes and long term care homes.	**RHAs**
3.7	Ensure the unique needs of individuals living with dementia and are considered in palliative and end of life care.	**HCS, RHAs**
4.1	Identify core competencies particular to dementia care for relevant care providers and ensure competencies are embedded across the health care system.	**HCS, RHAs, AS**
4.3	Ensure health care providers who regularly support individuals with dementia complete advanced dementia care education including a focus on person-centred care and empathy training.	**RHAs**

Medium-Term Actions (by March 2025)

#	Actions	Responsibility
1.3	Work with stakeholders including the Department of Children Seniors and Social Development, the Alzheimer Society of Newfoundland and Labrador, municipalities and community groups to implement actions to increase dementia inclusive communities and ensure dementia is incorporated into existing or planned age-friendly community initiatives.	**HCS, CSSD, RHAs, AS, municipalities**
1.4	Work with the Alzheimer Society of Newfoundland and Labrador to support business owners to make their services more dementia friendly.	**AS**
1.5	Work with the Alzheimer Society of Newfoundland and Labrador to support delivery of training and resources to ensure first responders have an understanding of dementia and are better prepared to provide support to people living with dementia and their families.	**AS**
1.6	Work with the Department of Education to increase age appropriate awareness of dementia, social inclusion and stigma reduction in K-12 school curriculum.	**HCS, EDU**
2.2	Ensure care providers have access to evidence based diagnostic tools and current information on community based resources, to promote timely and appropriate referrals to supports and services.	**HCS, RHAs**
2.3	Increase access to geriatric specialists for individuals living with dementia with complex needs.	**RHAs**
2.8	Ensure individuals living with dementia have access to an interdisciplinary team with a dedicated single point of contact to support care coordination and transitions.	**RHAs**
3.4	Increase community based residential supportive care options for people living with dementia who do not need daily access to nursing care.	**HCS, RHAs**

#	Actions	Responsibility
3.10	Identify and implement opportunities to improve quality of care and quality of life including enhanced social and recreational programming, across all care settings.	**HCS, RHAs, AS**
3.11	Identify and implement opportunities to improve quality of care and quality of life for individuals living with dementia in residential care homes, including opportunities to make long term care homes more familiar and less institutional, with an increased focus on person centered care, and flexible delivery of programs and services.	**HCS, RHAs**
3.12	Identify and implement opportunities to better support individuals diagnosed with young onset dementia and their families, recognizing the unique challenges experienced.	**HCS, RHAs, AS**
4.4	Increase educational opportunities for primary care providers and community health teams to support early detection and improved management of dementia.	**HCS, RHAs**
4.7	Support creation of a provincial network of clinicians to share information on evidence based resources and best practices in dementia care.	**HCS, RHAs, AS**

Long-Term Actions (by March 2026)

#	Actions	Responsibility
2.1	Identify and implement opportunities to support an interdisciplinary approach to diagnosis and increase the capacity of providers to improve diagnosis of dementia across the care continuum.	**RHAs**
2.4	Develop a best practice toolkit for supporting individuals living with dementia and their families.	**HCS, RHAs, AS**
2.5	Develop dementia care pathways for use by clinicians supporting individuals through the dementia journey.	**HCS, RHA**
2.6	Expand use of the HealthLine to provide support to individuals with dementia and referrals to other health and services.	**HCS, RHAs**
3.5	Improve supports for care partners.	**HCS, RHAs**
3.6	Identify and implement opportunities in acute care to improve quality of care of individuals living with dementia.	**HCS, RHAs**
3.8	Enhance use of technology including virtual care, to support people with dementia and their families.	**HCS, RHAs, NLCHI**
3.9	Improve integration and increase capacity of primary care providers and community health teams in providing dementia care.	**HCS, RHAs**
3.13	Expand dementia support groups for individuals living with dementia and their care partners.	**AS**
3.14	Identify and implement opportunities for intergenerational programming where children, youth and younger adults interact with individuals living with dementia through formal, informal or volunteer based programming.	**CSSD, RHAs, HCS, AS**
4.2	Implement minimum educational requirements for home and personal support workers, including dementia specific training for staff working directly with individuals living with dementia.	**HCS**
4.5	Ensure all regional health authority staff have access to training and resources to ensure staff have an understanding of dementia and are better prepared to provide support to people living with dementia and their families.	**RHAs**
4.6	Advocate for inclusion of dementia training in all undergraduate and post graduate health professional training programs.	**HCS**

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