

Dementia Care Action Plan

Public Engagement Feedback Summary



Department of Health and Community Services
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Glossary

Activities of Daily Living: basic self-care tasks that include routine activities people need to do every day including eating, bathing, dressing, toileting, transferring and continence care.

Advance Care Planning: is the process of dialogue, knowledge sharing and informed decision-making that must occur at any time when future or potential life-threatening illness, treatment options, and care interventions are being considered or revisited. It provides direction for when a person cannot make his or her own health care decisions and is ideally completed in advance of anticipated deterioration or an acute illness, including surgery.

Alzheimer Society: national not-for-profit organization working to improve the quality of life for Canadians affected by Alzheimer's disease and other dementias and advance the search for the cause and cure.

Capacity: the ability of an adult to understand information relevant to a decision where that decision concerns his or her health care, physical, emotional, psychological, financial, legal, residential or social needs and to appreciate the reasonable foreseeable consequences of a decision or the lack of a decision.

Care partner: person who provides concrete and emotional support, not as part of a job, but because they are related to the person by family, marriage, and/or friendship.

Care plan: a written plan that outlines a person's goals, objectives and the supports and services required to address their needs and achieve desired personal outcomes.

Clinical assessment: a dynamic and ongoing collaborative process that actively involves the client/resident and others to secure information to identify the client's/resident's values, goals, functional and cognitive capacity, strengths, abilities, preferences, resources, supports and needs.

First available bed option: requirement of a client to accept admission to a long term care home that is not their first choice to facilitate timely transfer from acute care.

HealthLine 811: a free, confidential, 24 hour telephone line, staffed by experienced registered nurses who can offer health advice, information and connect callers to resources and local services.

Home First: a health care management philosophy, aimed at facilitating a quick response to the provision of community-based services such as: home support, rehabilitation, nursing, counselling, and provision of medical supplies to clients with complex care needs to support them to remain at home and avoid emergency department visits, hospitalization and premature long term care placement.

Home Support: the provision of personal and behavioural supports, household management and respite at the minimum level to maintain individual independence. Home support services are intended to supplement, not replace, service provided by the individual family and/or support network. Services are non-professional in nature and are delivered by an approved home support agency or by a home support worker hired by the individual or family.

Individualized care plan: a written plan prepared by regional health authority in collaboration with a client/resident and the client/resident's substitute decision maker and family that outlines the client/resident's goals and objectives of care and the supports and services required by a client/resident to address his or her needs.

Long-Term Care Home: residential option that provides care to seniors and adults with complex care needs requiring daily access to nursing care.

Personal Care Home: licensed, privately owned businesses that provide care and accommodations to seniors and older adults requiring assistance with personal care and the activities of daily living.

Placement: refers to admission of a client in a home.

Resident: person accepted for placement and residing in a long term care home, a protective community residence or a personal care home.

Respite care: short stay residential option for clients requiring care and assistance that provides support and relief for families and caregivers who are caring for a client at home.

Purpose of the document

In Newfoundland and Labrador, there are approximately 9,600 people living with dementia according to the Alzheimer Society of Newfoundland and Labrador. This number is projected to increase to over 14,000 by 2035 as our population ages. The province must respond to the needs of people living with dementia, their families and care partners, now and into the future.

In The Way Forward, the Government of Newfoundland and Labrador made a commitment to implement a Dementia Care Action Plan. To ensure that this action plan is reflective of the diverse needs of the people living with dementia, their care partners, and the health care system, the Provincial Government launched a comprehensive public engagement consultation process.

Thank you to everyone who took the time to participate in this important conversation. This was a deeply personal issue for many participants and the conversations were difficult for some. Those attending in-person sessions were highly engaged, and written submissions were thoughtful and rich in detail. Participants acknowledged that there is some excellent work being carried out by individuals, community groups, and health care providers, and they identified many opportunities for further improvement. Through this process, government obtained the feedback necessary to help inform development of the plan.

This document summarizes some of the key themes heard in the consultations. All the ideas, comments, and opinions will be considered by government in the development of the Dementia Care Action Plan.

The Consultation Process

Between October 23, 2019, and January 13, 2020, consultations were held to inform development of a Dementia Care Action Plan for the Province. In total 482 people participated through various ways:

- Public consultations in four locations across the province (Corner Brook; Happy-Valley-Goose Bay, St. John's and Gander);
- A questionnaire for the general public on engageNL;
- A questionnaire for primary care providers (physicians and nurse practitioners);
- Interviews with family members of people living with dementia;
- Contributions by phone/email/letters; and,
- Focus groups with regional health authority staff; staff of the Office of the Senior's Advocate; and physicians specializing in gerontology and geriatric psychiatry.

Summary of participation	Number of people participating
In-person public consultations	109
RHA focus groups	196
Focus group for physicians	14
Focus group for Office of the Seniors' Advocate Staff	3
Family caregiver interviews	7
EngageNL public questionnaire	134
EngageNL physician questionnaire	5
e-mail submissions	14
Total	482

Summary of Feedback

People want actions developed in consultation with individuals living with dementia, their care partners, and their care providers. The actions must be culturally appropriate, and customized for the area where they are delivered. Participants felt actions should be informed by best practices for care and service delivery in other jurisdictions, and reflective of the diversity of those living with dementia and their care partners.

The consultation focused on three areas: A) awareness and education, B) services and supports for people living with dementia and their care partners, and C) workforce development. For each area, participants were asked to identify gaps, make suggestions, and to respond to proposed actions. While all feedback to address gaps will be considered, this document reflects the most common themes in the consultation process.

A. Awareness and Education

Participants felt there is a gap in understanding of the risk factors of dementia and when to seek a diagnosis or help. We heard there is a need for a better understanding of the fact that dementia affects more than a person's memory. We also heard that people do not understand that there is more than one type of dementia, and that the Alzheimer Society provides services to people with all types of dementia.

People experience stigma with dementia. This stigma means families experience difficulties discussing dementia with others. Some participants expressed the desire for dementia friendly communities and more acceptance of people living with dementia.

In addition to information on the diagnosis, participants expressed the need for more information about advance health care planning, and accessing services and supports.

A. Awareness and Education

Proposed Action 1: Increase the capacity of the HealthLine to provide information about dementia.

The response to this action was mixed. Some participants described the HealthLine as a service they use when deciding whether or not to go to the emergency department. There was a concern that it could promote inappropriate use of emergency departments. Some participants stated that there is no need for an additional source of information as most people use the internet to look for information.

However, others expressed that it would be helpful to have a 24 hour line to call if they needed information. Some participants suggested this service may be helpful for people concerned about their own memory who wanted to talk to a health care provider anonymously.

Participants felt public awareness on use of the HealthLine would be required for this to be successful. People also felt the HealthLine would need to provide information about how to access services and that staff should be knowledgeable about dementia.

Quote: "The option of 811 is good for 'right now' solutions when the family is unsure"

A. Awareness and Education

Proposed Action 2: Development of standardized information package ‘toolkit’ for clients upon diagnosis.

A toolkit would provide information to patients upon diagnosis and include general information about dementia, health care planning, and support and services available. Participants suggested this could be helpful to receive upon diagnosis. They advised that the information should be tailored to include local supports and services, and kept current. Participants expressed that information in the toolkit needs to be customized for the person and their type of dementia. People felt this should include information about services and how to access them, as well as information on financial planning. Participants felt the information should be available online and in paper format, and there should be a separate toolkit for families and health professionals.

Some participants expressed concern that this might be a duplication of material already available through the Alzheimer Society. Others felt that the amount of information available is overwhelming, and expressed that there needs to be a centralized online portal with a patient navigator to ensure people get the information they need.

A. Awareness and Education

Proposed Action 3: Partner with the Federal Government on the development and delivery of public awareness campaigns.

Some participants felt that partnering with the Federal Government is an opportunity to access resources to support public awareness campaigns. However, some felt money for public awareness campaigns could be better used to provide services and supports to people living with dementia.

There was a need identified for dementia friendly communities. Participants expressed a need for social events that could support residents with dementia, and a need for more understanding from businesses and service providers, including shorter wait times and more patience and understanding for people with dementia.

B. Supports and Services for People Living with Dementia and their Care Partners

Timely diagnosis delivered appropriately

People noted challenges with receiving a timely diagnosis. Some people expressed that their loved ones had advanced dementia and were living on a protective care unit in long-term care, but they still did not have an official diagnosis of dementia.

Participants felt they needed support with future planning and caring for the person with dementia. However, we heard that the assessment process takes time and leaves little time for physicians to provide support after delivering a diagnosis of dementia.

Quote: “We were years trying to get a diagnosis – repeated assessments yielded little understanding.”

Medical management

We heard that people with dementia have complex care needs, and often have other chronic conditions as well as dementia. Some participants expressed that physicians need more training

in dementia and care of the older adult. It was raised that the current fee structure does not allow sufficient time to provide comprehensive primary care.

There was also concern expressed about access to medications covered under the Newfoundland and Labrador Prescription Drug Program. Some participants expressed that best practices in dementia care need to be considered when deciding what medications should be covered under the plan.

Support for care partners

Some care partners felt there are gaps in the Community Support Program, noting that if you do not need or accept home care there are no other services offered or available. Some families feel too much is expected of them with respect to caring for their loved one with dementia, especially if the family member is female.

Some care partners indicated that participation in support groups is a positive experience. It was suggested that families of newly diagnosed individuals could be partnered with a mentor, another care partner who has experience with supporting a person with dementia. Some care partners also expressed the need for increased access to meaningful activities for people with dementia. There was positive feedback about the Alzheimer Society Café of Memories where care providers and people with dementia both attend.

Quote: “The mental and physical health of family caregivers must receive greater attention.”

Access to recreational opportunities

Participants felt access to meaningful recreational activities was important and that in general this is lacking across all settings. In community there are limited activities available suitable for many people with dementia, which contributes to social isolation. Concerns were raised regarding lack of equitable access to recreational activities for residents with dementia in long term care who require higher levels of supervision and support. Suggestions for recreational therapy included animal therapy and inter-generational programming.

Home care services

Some participants credited their home support worker(s) with their loved one being able to remain at home. While it was acknowledged that many home support workers are helpful and compassionate, some participants expressed that the Home Support Program could be improved if home support workers were trained and confident in working with people with dementia, and if workers were given adequate information about the client they would be supporting. Some participants also suggested having home care agencies become accredited would improve the service.

Concerns were raised about timely access to support, largely owing to challenges in finding home support workers particularly in more rural communities. It was also raised that some health care providers are requesting formal capacity assessments, which may delay service delivery. Some participants felt that assessments for home care do not adequately capture the needs of a person with dementia.

Quote: “Patients want to go home, supports should be reflective of patient’s desires.”

Access to residential care

Participants expressed concern that people with dementia are waiting too long in acute care for access to long term care home. They also expressed there is confusion about the types of care

available and the importance of ensuring appropriate level of service is matched to resident need. It was recommended that standard definitions of care options are established, used consistently provincially and shared with families.

There was support for the home first philosophy, but also concern the philosophy is not being implemented as expected. There is a perception that the resources are not there to support it. There is a belief that some people are entering long term care prematurely; and that others are returning home when a residential option would be more appropriate. There is also a perception that you have to apply for long term care to get access to resources to support someone at home.

Participants expressed concern about the impact of first available bed policies in separating people living with dementia from their families and friends, and causing people to go through multiple moves. There was a suggestion that it should first appropriate bed. There was a suggestion to develop residential options for people who have memory and issues, but do not require access to 24-hour nursing care. These were referred to as “step down,” units by some participants.

Personal Care Homes

There was concern that personal care homes cannot support people who demonstrate common behaviours associated with moderate to advancing dementia. Some expressed a need for residential settings that could support these behaviours in the community. Lack of personal care homes in some areas was identified as a problem.

Long Term Care Homes

There was a lot of feedback provided related to long-term care. Participants appreciated the complexity of working in long-term care and expressed that there are many excellent and caring staff identifying innovative ways to support residents.

Concerns about long-term care were also identified including the need for more staff, especially frontline care staff. Some participants advocated for legislation for minimum staffing levels. There was also a need expressed for greater allied health (social workers, occupational therapists, physiotherapists, recreation workers), and increased presence of management on units. There were concerns expressed about staff members being present on the units but not using their time to attend to the needs of the residents. There was concern raised about lack of attention to the emotional needs and quality of life of residents. Some felt staff burnout and decreased sensitivity is impairing empathy and understanding towards residents. There was a need expressed for recognition that staff providing this care experience workplace stress, and suggestions there should be greater support for health care staff.

There were opportunities identified to increase family involvement in the care planning. Some families raised the concern that they are not involved in care planning and not given access to the care plan.

People expressed that long-term care facilities are institutional and unfamiliar; and that the care often revolves around facility needs instead of resident needs. We also heard that infection control standards present barriers to providing residents a home-like environment.

Quote: “Caring for dementia patients is more than a job. It is providing 24 hour care for people in their home, even when their home is a LTC facility”- family submission

We heard suggestions for improving the long-term care experience for people living with dementia. Many of these suggestions focused on staff including providing more training and support for staff in the management of behavioural symptoms of dementia. We heard that there should be an emphasis on the “soft” skills when selecting employees such as emotional intelligence and empathy. Participants suggested providing mentoring for staff and more recognition of people who provide good care to residents with dementia. Participants also suggested that volunteers could play a role in supporting residents with dementia in long term care.

Quote: “Management oversight and strong leadership create conditions for staff success.”
Public session

B. Supports and Services for People Living with Dementia and their Care Partners
Proposed Action 1: Increased Access to Adult Day Programs to Provide Meaningful Activities for People Living with Dementia and Respite for Care Partners.

There was strong support for increased access to adult day programs. Participants indicated that adult day programs could support people to live at home longer. However, there were mixed opinions about where this service should be offered. Some felt it was important to have it as part of a long term care home to help with a potential future transition to living in long term care home. Others felt their loved one would not attend if it was in a long term care home and some felt programs should be in the community and more normalized.

Participants advised that adult day programs need staff who are knowledgeable about supporting people with dementia and activities that reflect the need and interests of participants.

Transportation and fees were identified as potential barriers to participation in adult day programs. Participants also expressed that not all people with dementia will be interested in participating in adult day programs.

B. Supports and Services for People Living with Dementia and their Care Partners
Proposed Action 2: Improved Care Co-ordination Across Healthcare Settings Through All Stages of the Disease.

Feedback suggested that there is a need for improved communications across health care settings, programs were described as operating in silos and this is a source of frustration for clients, care partners and health care providers.

Suggested actions to improve care coordination included a shared documentation system to allow access to a complete health record across health care settings and education for health care workers about what information they should be sharing about a client/patient/resident. Some participants suggested a staff position should be created to support people with dementia and their care partners from time of diagnosis through end of life. This person would help people with dementia and their care partners navigate the health system and provide emotional support for individuals with dementia and their care partners.

C. Workforce Development

Many participants felt dementia is a speciality area and that all health care providers need training in dementia, particularly to support people who display behavioural symptoms of dementia. There was support for standardized training such as Gentle Persuasive Approach. However, there was concern that people are not using best practice concepts and there is a need for re-training. It was also raised that additional education is required regarding competency assessments. Opinions differed with respect to modes of training. Some participants felt in-person sessions were crucial to fully engage staff. Others felt that a variety of tools like webinars and online training should be offered. Some participants advised that emotional intelligence and compassion are equally important as medical care when providing support to people with dementia and should be incorporated into training and educational programs.

The majority of participants indicated that personal/home support workers need specific training on responding to the behavioural symptoms people with dementia can sometimes experience. Without this training, participants advised that workers can actually contribute to the care stress instead of relieving it.

A need for training in the appropriate use of medications to manage behaviour (particularly antipsychotics) was identified. Some participants felt these medications are requested too often and in situations where they are not indicated. Others expressed concern that people who need these medications may not be getting access to them.

C. Workforce Development

Proposed Action 1: Partner with the Alzheimer Society of Newfoundland and Labrador in development of Dementia Passport™.

There was support for providing education and resources. There was some concern expressed about the title “Dementia Passport,” that it might not communicate to the user that it is an educational program.

C. Workforce Development

Proposed Action 2: Implement Dementia Education Requirements for Home Support Workers and Workers in Personal Care Homes Who are Working with People Living with Dementia.

There was overwhelming support for this action. This was a recurrent theme that care workers need additional training in dementia care to support people to age in place.

C. Workforce Development

Proposed Action 3: Partner with the Federal Government and other Jurisdictions on the Development and Implementation of Clinical Practice Guidelines and Standards of Care.

Participants felt Newfoundland and Labrador should look for every opportunity to partner with other jurisdictions to avoid duplication and ensure consistency in standards of care provincially and nationally.

Next Steps in the Development of the Dementia Care Action Plan

All input from in-person engagement sessions, online questionnaires and other submissions will be carefully considered as the department works toward the development and implementation of a Dementia Care Action Plan.