

DEMENTIA-FRIENDLY NORTH SHORE

Action Plan



Funded by Union of BC Municipalities



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DEMENTIA-FRIENDLY NORTH SHORE

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1. Introduction	3
What is dementia?	3
Why is it important to become more dementia friendly?	3
What is a dementia-friendly community?.....	4
2. Action Plan Development Process	6
Community engagement process	6
3. Essential Partnerships	9
4. Next Steps: Putting Ideas into Action	11
A. Community Education & Advocacy.....	11
B. Training	11
C. Inclusive and Supportive Programs	12
D. Built Environment	12
E. Caregivers	13
5. Resources	15
Alzheimer Society of B.C.....	15
Municipal resources	15



1. Introduction

North Shore municipalities—the District of West Vancouver, District of North Vancouver and the City of North Vancouver—are working together to support people living with dementia and other cognitive impairments in remaining engaged, connected and active for as long as possible.

Building on global and regional dementia-friendly initiatives, municipal staff, community members and service providers helped shape this framework for how North Shore municipalities could facilitate and provide more dementia-friendly policies, resources, programs and services.

Recommendations include:

- Providing education to reduce stigma and increase understanding about dementia;
- Strengthening training to include communication, resources support strategies related to dementia;
- Increasing inclusivity of social and recreational programming for people living with dementia and their caregivers; and
- Expanding dementia-friendly improvements to the built environment to support connections and participation.

WHAT IS DEMENTIA?

Dementia is an overall term for a set of symptoms that are caused by disorders affecting the brain—it is not a normal part of aging. There are many types of dementia, including Alzheimer’s disease, vascular dementia, Lewy body dementia, and frontotemporal dementia. Dementia is not just about losing your memory—it can affect thinking, communicating and doing everyday activities.

WHY IS IT IMPORTANT TO BECOME MORE DEMENTIA-FRIENDLY?

An estimated 70,000 people in B.C. are living with some form of dementia, and this number is expected to double by 2031.

People are living longer than ever before, and those with dementia may live well in their community for a long time. However, changes to memory, behaviour and functional

abilities can profoundly affect the lives of people living with the disease and their relationships with others. A diagnosis can result in withdrawal from familiar people and places due to social and physical barriers that impact ordinary activities. This compounds the negative impact dementia can have on mental, emotional and physical health.

WHAT IS A DEMENTIA-FRIENDLY COMMUNITY?

Dementia-friendly communities value people living with dementia. Initiatives also help support caregivers, who risk isolation and poor health due to their role and responsibilities.

Dementia-friendly initiatives originated in countries with aging populations and a related increase in people living with dementia. Initiatives started in Japan before expanding to Australia, the United Kingdom and other parts of Europe, and Canada and the U.S. Dementia-friendly features benefit people of all ages and abilities by increasing understanding and supporting social and physical participation.

The Alzheimer Society of B.C. provides tools, information and education to communities that are working to become more inclusive, respectful and understanding of all persons living with dementia. Their vision is to create communities that are welcoming, inclusive and accessible to people living with dementia and their caregivers.



Dementia-friendly communities

- Build communities that value, include and respect people living with dementia;
- Support people living with dementia to have the highest quality of life possible through reducing stigma;
- Support people living with dementia to live safely and comfortably;
- Support a sense of belonging and independence;
- Reduce barriers that prevent full engagement with community;
- Build understanding and knowledge about dementia and how to communicate effectively;
- Improve general health and well-being for people living with dementia.^{2,3}

² www.alzheimer.ca/en/bc/About-dementia/Dementia-friendly%20communities/What%20is%20a%20dementia-friendly%20community

³ The Alzheimer Society of B.C. (2016). Dementia-friendly Communities Local Government Toolkit.

2. ACTION PLAN DEVELOPMENT PROCESS

The Dementia-friendly North Shore Action Plan evolved from the North Shore Seniors' Health Expo and Dementia-friendly Survey conducted in 2016. Survey responses indicated that stigma and service gaps related to dementia could be addressed more effectively. A tri-municipal working group was successful in their application for Union of BC Municipalities funding to follow-through on results.

The working group planned and facilitated activities to develop the action plan, with a focus on strengthening municipal capacity, programs and resources for people living with dementia and their caregivers. Members included staff from the three municipalities, Vancouver Coastal Health, Alzheimer Society of B.C., a resident and advocate living with dementia, and a gerontologist. A steering committee provided guidance; members included staff from a range of municipal departments as well as service organizations and businesses.

Resources included material from the Alzheimer Society of B.C. and Dementia-friendly community action plans developed in New Westminister (2016) and Burnaby (2017), as well as international reports.

COMMUNITY ENGAGEMENT

Engagement activities included focus groups, the Dementia-friendly Forum and the North Shore Seniors' Health Expo. Participants included municipal staff, community members and service providers. They identified five key priorities:

- Increase community education about dementia, resources and services.
- Strengthen training for staff and caregivers.
- Provide inclusive and supportive community programs and services.
- Improve built environment safety, accessibility and way finding (particularly to reduce risks related to wandering behaviour).
- Address caregiver needs.

Focus Groups

More than 80 people from across the North Shore participated in a total of seven focus groups between May and October. Participants shared common experiences and identified gaps in services and resources.

1. Municipal staff
(four focus groups organized by department):
 - Library, Parks, Recreation and Policy Planning
 - Fire, Police, North Shore Rescue and Bylaw Enforcement
 - Planning, Taxation and Licensing
 - Built Environment (Planning, Transportation, Engineering, Design). This session included a walking interview led by an advocate who is living with dementia.
2. Not-for-profit service providers and for-profit service provider staff (two focus groups)
3. Community members living with dementia and their caregivers (one focus group). Participants shared experiences from diagnosis to reaching end of life.

Dementia-friendly Forum

Over 40 people participated in a five-hour forum on September 8. Though the agenda was designed to focus on community members in the morning and service providers in the afternoon, most participants wanted to remain for the full forum, which allowed for rich, integrated discussion and shared learning. Facilitation by the BC Healthy Communities Society provided collaboration opportunities.

North Shore Seniors' Health Expo

The final engagement event drew 800 seniors and community members to learn from speakers and exhibitors, and researchers focusing on seniors' cognitive, physical, social and financial well-being. Over 175 people attended a presentation on dementia by Dr. Heather Palmer, and nearly 20 took time to speak with the Dementia-friendly North Shore coordinator about their experiences with dementia.



FOCUS GROUPS

Engagement Activity Themes

- **Emotional engagement:** Participants shared the emotional response to dementia and the complex visible and invisible needs of people in all stages of the disease. They also shared the challenge of being proactive in situations that could change moment-to-moment; embracing a “new normal” takes energy and it sometimes felt easier to withdraw.
- **Balance:** Participants described the challenge of balancing work responsibilities and time pressures when serving someone with high needs due to cognitive changes that impacted memory, communication or behaviour.
- **Helplessness and loss:** Participants shared a sense of helplessness when they were unable to provide appropriate assistance, and the sense of loss when regulars in programs could no longer participate.



3. ESSENTIAL PARTNERSHIPS

Partnerships across a wide range of organizations and individuals are essential for Dementia-friendly initiatives and actions to be effective.

Health Authority

Health professionals fill critical roles for people living with dementia. They can often provide expertise and resources to municipal and community representatives.

The Alzheimer Society of B.C.

Working in communities throughout the province, the Society supports, educates and advocates for people living with dementia, as well as enabling research into the disease. Specifically in this partnership, they share their expertise in a sustainable way through printed and web resources, as well as in-person training programs. As part of a national federation, the Society is a leading authority on the disease in Canada.

Caregivers

Caregivers are essential to the link a person living with dementia has with their community. However, care can be very intensive, particularly at later stages of the disease. Caregivers are often older adults caring for other older adults; their own health and personal needs can be compromised, resulting in sudden, unanticipated events with few back-up options.

Home Support: Private and Public

Professional home care businesses provide critical services to individuals, either through health authority referral or directly to consumers. They offer a unique perspective on how people living with dementia are managing; regular contact can help them observe changes in cognition or behaviour that others might miss. People also sometimes share concerns with professionals that they are reluctant to share with family or friends, which can open the door to interventions, sooner rather than later.

Emergency Responders

Call-outs for falls or wandering go first to emergency responders; identifying patterns or changes early can allow care providers to assess and revise care plans to help avoid critical events or acute illness. As with other project participants, emergency responders shared the emotional impact of responding to calls that involve dementia and wandering.

Additional stakeholders

Staff at recreation centres and other community agencies that offer recreation and social programs can be the first to notice changes in their clients.

Housing providers—including independent living residences, supportive housing, residential care and dementia-care facilities—can be involved in planning, as they are in a position to observe changes in residents' capacity or well-being, and can reach out to offer help if they know how to do so appropriately.

With information and training, transit drivers, pharmacists, grocery and pharmacy cashiers, and even coffee-shop staff can reach out to offer help when a customer or someone they work with is showing signs of cognitive loss. They could also provide “eyes-on-the-street,” for people who are wandering, or share information about resources.



Wouldn't it be great to have relaxed lanes in grocery stores? People who need more time to count out payment or manage their purchases can do so without fear of being stigmatized or under pressure.



4. Next Steps: Putting ideas into action

The Dementia-friendly North Shore Action Plan provides actions that municipalities can approach individually or by working together, based on priorities, policies and programs. Actions are based on working group and steering committee expertise, literature review of best practices, and community engagement activities.

See Resource section for additional ideas.

A. COMMUNITY EDUCATION & ADVOCACY

Reducing stigma and isolation was identified as a key priority to keep people living with dementia involved in the community. This can be achieved by increasing access to resources and services that support wellbeing and health.

ACTIONS

- Develop community education campaigns to increase understanding of dementia, resources and services.
- Identify and nurture municipal and community champions through focus groups, surveys, forums, training and other tri-municipal activities.

Recommended content

- Explanation of dementia (types, symptoms, contributing factors, how to seek diagnosis).
- What to do or say when you see changes in behaviour that may indicate cognitive loss.
- How to maintain connections through effective communication (“Connect, don’t correct.”)
- List of service providers and resources (health, community and business).
- Promote dementia-friendly programs and places (library, parks, recreation and culture, as well as tax deferral and other financial programs).
- Provide information about planning tools, such as Power of Attorney and Representation Agreements.
- Promote volunteer opportunities, training and resources.
- Explain changes in municipal planning and design that may impact people living with dementia.
- Explain benefits for people of all ages and abilities.

Other ideas and considerations

- Use a variety of print and social media tools, including bookmarks, posters and directories.
- Develop a one-call system or information hub, with dedicated mental health lines.
- Provide inter-generational education through school districts and recreation centres.
- Support service provider capacity to meet community needs.

B. TRAINING

Increasing understanding of dementia can increase support networks and reduce stress for staff, community members living with dementia and caregivers. It can also increase efficient and effective use of resources and magnify reach.

ACTIONS

- Train municipal staff about dementia and how to support community members living with dementia.
- Identify, train and support municipal and community champions.

Recommended content

- Dementia-Friends Training and Train the Trainer by Alzheimer Society of B.C.
- Effective communications, including a “Question List” of what to ask first.
- How to respond to confusion or agitation respectfully, appropriately and effectively.
- How to support safe participation in activities when the disease progresses.
- How to manage risk of wandering, and policy if wandering occurs.
- How to escalate response in an emergency.



- When and how to refer people or escalate support to emergency response services. Police consider a person living with dementia who goes missing an emergency that requires immediate assistance. Dialing 911 and MedicAlert® Safely Home is imperative, in addition to non-emergency police lines and TransLink.
- Policy and procedures when serving/working with people living with dementia. For example, how do you assess the level of support needed? What do you do when caregivers aren't able to support participation—or when there isn't a caregiver?

Other ideas and considerations

- Conduct the Alzheimer Society of B.C. Dementia Friends and the Train the Trainer program developed in the City of Vancouver.
- Consider privacy issues and policies about when and how staff should contact family about concerns or share them with others. It is also important to have training about when it is appropriate to “flag” someone of concern, either by family/caregiver, staff or police.
- Provide clear direction about responsibilities when a community member's needs or expectations may go beyond a role or capacity.

C. INCLUSIVE AND SUPPORTIVE PROGRAMS

Expanding inclusivity to address the needs of people living with dementia and their caregivers can help continued participation and engagement in community activities and relationships.

ACTIONS

- Provide support or adaptations so people living with dementia can continue with familiar activities.
- Waive fees for caregivers or others who provide support.
- Offer and/or designate dementia-friendly recreational and cultural activities and events.

- Support affordable meal programs to encourage engagement and connection.
- Provide space or other support for adult day programs.
- Building in a social aspect to recreation programs, such as sharing refreshments.
- Provide quiet spaces and support at large events or festivals for rest and orientation.

Other ideas and considerations

- Challenges to providing inclusive and supportive programs can include:
 - Variability across municipal programs, structures and processes;
 - Difficulty supporting social, recreational participation when health conditions become more complex;
 - Balancing municipal and health authority roles/responsibilities (i.e. who should fund and manage day or respite programs?).

D. BUILT ENVIRONMENT AND COMMUNITY SERVICE

Age-friendly and dementia-friendly environments support people of all ages and abilities by improving safety and way finding in the community.

ACTIONS

- Connect decision-makers with other communities doing similar and successful work on age and dementia-friendly built environments.
- When creating municipal standards and plans for the built environment, use different perspectives/lenses to ensure that the needs of people with different abilities and disabilities (e.g. age, dementia, mobility, auditory or visual impairment, etc.) are considered.

- Consider changes to standards that guide the design of the built environment to accommodate typical needs of people with dementia, including:
 - Adjust pedestrian crossing times for people who move more slowly or have difficulty with perception or balance.
 - Increase availability and safety of public washrooms. (Connecting and coordination with businesses or identifying dementia-friendly locations could help address this issue.)
 - Increase benches, lighting, drinking fountains and bike parking. (Loss of pay phones impacts people who may not be able to afford or manage a cell phone.)
 - Ensure signs are clear, consistent and easily understood.
 - Provide designated routes for pedestrians, bikes, cars, buses, and deliveries in mixed-use areas.
 - Provide drop-off and pick-up parking spots, with adequate distance from the curb for people to get in and out of the car safely, without having to walk too far to their destination.
- When designing programs and services for the community, consider the particular needs of people with dementia, for example:
 - Provide support for making tax payments, and support for managing garbage and recycling services to reduce anxiety issues.
 - Work with agencies on alternatives to community mailbox delivery, which can be difficult to use.
 - Develop protocols for emergency response during an earthquake or other unanticipated event.

Other ideas and considerations

Challenges to providing Dementia-friendly built environments can include:

- Balancing form and function for engaging environments that are also safe;
- Meeting the varied needs of people with different abilities/disabilities

E. CAREGIVERS

Respite and support groups for caregivers were identified as a key priorities to maintain the social, physical and emotional well-being of caregivers.

ACTIONS

- Consider different needs of people in early vs. later stages of dementia.
- Reduce financial barriers to participation in activities and programs, particularly when care needs increase.
- Provide peer-to-peer programs that may be based on relationships to the person living with dementia (child, spouse, sibling) as well as gender.
- Promote relevant health, transportation, housing and financial programs.
- Advocate for caregiver needs and appropriate respite care and day programs.

Other ideas and considerations

Challenges to providing respite can include:

- Feelings of guilt;
- Cost to participate in programs.



The Alzheimer Society of B.C. has some great info on emergency preparedness:

<http://alzbc.org/emergency-prepare>



5. Resources

ALZHEIMER SOCIETY OF B.C.

Families across British Columbia are affected by Alzheimer's disease or other dementias. The Alzheimer Society of B.C.'s ultimate vision is a world without dementia; that vision begins with a world where people living with dementia are welcomed, acknowledged and included.

The Society's First Link® dementia support connects people living with dementia and their care partners to support services, education and information at any stage of the disease. People who are concerned about dementia or who have questions about the disease can call the First Link® Dementia Helpline at 1-800-936-6033 from anywhere in the province.

The Society has 15 Resource Centres across the province that offer support, education and programs. These include:

- Support groups for people experiencing the early symptoms of dementia, and for families and caregivers.
- Education sessions and series for those living with dementia and for caregivers, to learn more about dementia, explore strategies to cope with changes and maximize the quality of life at different points of the disease.
- Minds in Motion®, a fitness and social program for people diagnosed in the early stages of dementia and a care partner.

To learn more about programs and services offered by the Society, people can visit www.alzheimerbc.org, call the First Link® Dementia Helpline or connect with their local Alzheimer Resource Centre.

ALZHEIMER SOCIETY OF B.C. CONTACT

First Link® Dementia Helpline

Province-wide: 1-800-936-6033

Lower Mainland: 604-681-8651

Hours: Monday to Friday, 9 a.m. to 4 p.m.

Alzheimer Resource Centre— North Shore and Sunshine Coast

Phone: 604-984-8348 or 604-984-8347

Toll-free: 1-866-984-8348 or 1-855-984-8347

Email: info.northshore@alzheimerbc.org

212 - 1200 Lynn Valley Road

North Vancouver, B.C. V7J 2A2

The Alzheimer Society of B.C.'s Dementia-Friendly Communities initiative exists to support municipalities, the professional sector, community groups and the general public to become dementia-friendly through planning, tools, education and partnership.

The Society has developed a Dementia-Friendly City Train the Trainer program that instructs frontline municipal staff on how to deliver the Alzheimer Society of B.C.'s standardized Dementia-Friendly City education to staff and volunteers in their workplace.

This program aims to educate city staff about dementia, reduce stigma, raise awareness and provide practical suggestions about supporting people living with dementia in the community.

Municipal resources

- Dementia-friendly Communities Local Government Toolkit (Alzheimer Society of B.C.)
- Burnaby Dementia-friendly Community Action Plan (2017)
- New Westminster Dementia-friendly Community Action Plan (2016)
- Vancouver Train the Trainer Program (2016)

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- Amica Mature Lifestyles
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- BC Healthy Communities
- Chambers of Commerce
- City of North Vancouver Staff
- District of North Vancouver Staff
- District of West Vancouver Staff
- Hollyburn Family Services
- Lionsview Seniors Planning Society
- Silver Harbour Centre
- North Shore Neighbourhood House

- North Shore Search & Rescue
- North Vancouver City Library
- North Vancouver District Public Library
- North Vancouver Fire Department
- North Vancouver Recreation Commission
- Nurse Next Door
- RCMP
- Squamish Nation
- Tsleil-Waututh Nation
- Union of B.C. Municipalities
- Vancouver Coastal Health
- West Vancouver Fire & Rescue Services
- West Vancouver Memorial Library
- West Vancouver Police Department

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