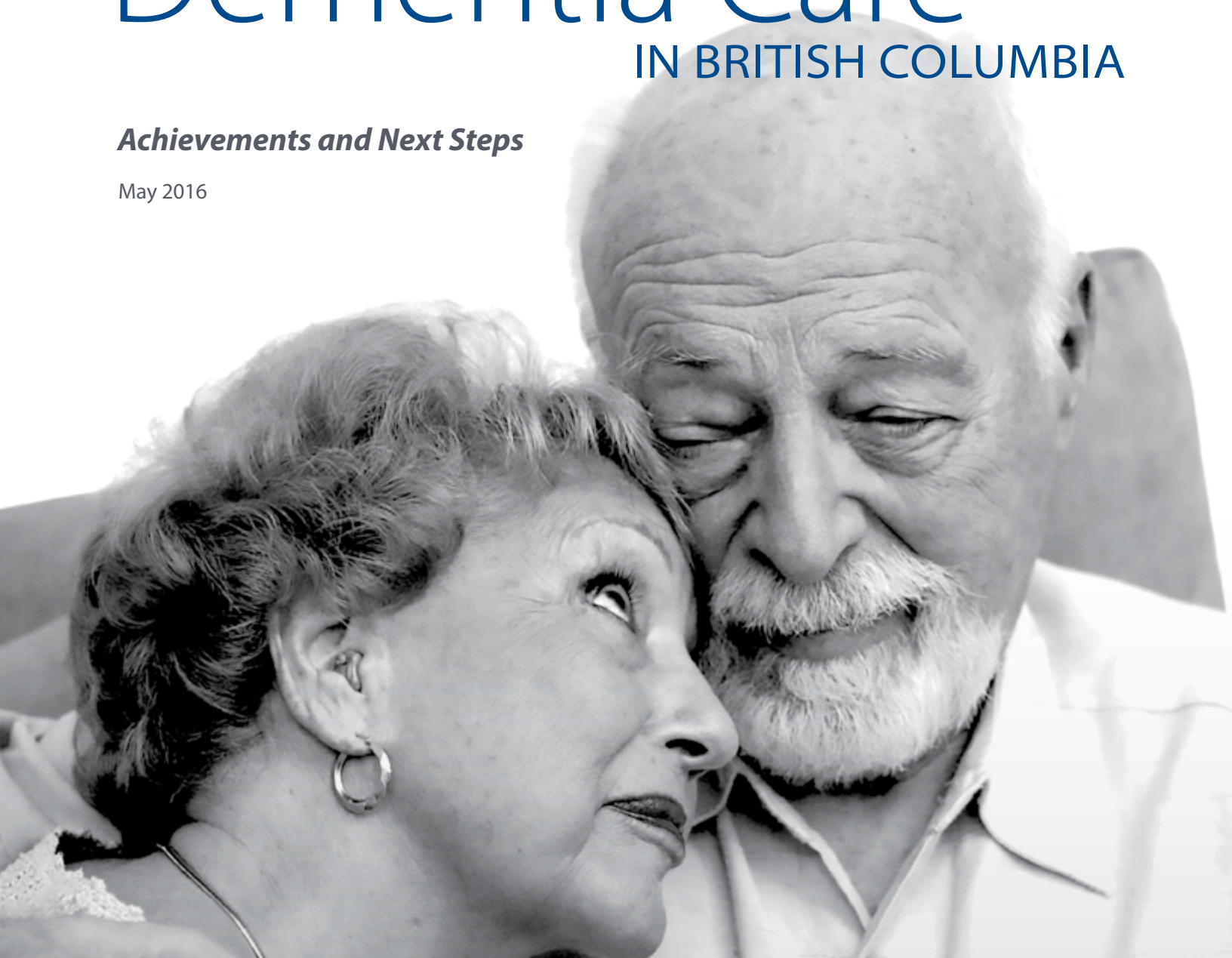


PROVINCIAL GUIDE TO
Dementia Care
IN BRITISH COLUMBIA

Achievements and Next Steps

May 2016



Ministry of
Health





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Executive Summary

Although many seniors will remain healthy and active throughout their lives, the likelihood that a person will require health services (and the amount of those services), increases dramatically as we age – especially for those over age 85. Seniors may require health supports to manage increasing frailty or chronic disease, including dementia, which can profoundly impact their ability to maintain independence and remain at home.

In 2012, the Ministry of Health released *The Provincial Dementia Action Plan for British Columbia*¹ to demonstrate government’s continued support for people with dementia (major neurocognitive disorder²) and their families. The plan committed to specific priorities designed to improve the health and quality of care for people with dementia – from prevention through to end of life. The 2012 action plan priorities included:

- ▶ **PRIORITY 1:** *Support Prevention and Early Intervention*
- ▶ **PRIORITY 2:** *Ensure Quality Person-Centred Dementia Care*
- ▶ **PRIORITY 3:** *Strengthen System Capacity and Accountability*

Built around a system-wide approach, the plan aimed to increase individual, family, community and health service capacity to provide early, safe and appropriate person-centred care. It supported people living with dementia in British Columbia to remain within their communities to the greatest extent possible – reducing or delaying transition to residential care – and recognized the important role of family caregivers. The plan also supported

increased awareness of brain health strategies and provided early access to support and information to manage the physical, behavioural and psychological symptoms of dementia.

Notable achievements arising from the 2012 action plan include the following:³

- ▶ Updated HealthLink BC, SeniorsBC, and Home and Community Care websites and print resources with information on brain health, planning for healthy aging and living with dementia.
- ▶ Expansion of the Alzheimer Society of B.C.’s First Link® dementia support program which connects people with dementia and their care partners to support services, education and information at any stage of the journey.
- ▶ Health-care professionals are being provided with dementia care training through the P.I.E.C.E.S.TM Canada (**P**hysical, **I**ntellectual, **E**motional health, **C**apabilities, **E**nvironment, **S**ocial self) program, which provides a systematic framework for assessment and care planning using a person-centred approach.⁴
- ▶ The 48/6 Model of Care for hospitalized seniors, in use in hospitals and all acute inpatient care settings, focuses on screening and assessment in six key care areas and the development of a personalized care plan within 48 hours.

1 www.health.gov.bc.ca/library/publications/year/2012/dementia-action-plan.pdf

2 Dementia is not itself a disease but is caused by a variety of diseases including Alzheimer’s disease. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) now uses the term “major neurocognitive disorder” instead of “dementia.” As well, the DSM-5 recognizes a less severe type of cognitive impairment, “mild neurocognitive disorder.”

3 See details in Appendix A.

4 www.piecescanada.com

- ▶ A funding partnership between the Michael Smith Foundation for Health Research, Brain Canada, the Pacific Alzheimer Research Foundation, and Genome BC supports a new British Columbia Alzheimer's Research Award and the Djavad Mowafaghian Centre for Brain Health.

Since release of the action plan, the Ministry of Health launched its current strategic plan, *Setting Priorities for the B.C. Health System* (2014).⁵ This plan identifies the need for continued improvements to dementia care. This includes support and training for formal and informal caregivers, and a more adequate service framework for the different stages of dementia (linked to the expansion of home and residential care options). The accompanying policy paper, *Primary and Community Care in BC: A Strategic Policy Framework*,⁶ identifies practical recommendations, including the need to integrate dementia care planning into all activities that support seniors care. This *Provincial Guide to Dementia Care in British Columbia* (guide), sets the direction for planning dementia care services and supports in the province.

To meet current and future population and patient health care needs, the guide provides a comprehensive approach to the dementia journey – from diagnosis to end of life. The aim is to reduce the risk of dementia, and to improve the lives of people living with dementia, their families and caregivers. The priorities and deliverables outlined in this guide are based on: consultation with interest groups, including people living with dementia and caregivers; best practices from research literature; analysis of population health and resource use data; and strategic guidance from *Setting Priorities for the B.C. Health System*.

The Priorities:

PRIORITY 1: *Increase public awareness and early recognition of cognitive changes.*

GOAL: *Increase healthy behaviours by promoting brain health and improve access to early diagnosis, intervention and community support programs.*

PRIORITY 2: *Support people with dementia to live safely at home for as long as possible, including caregiver support.*

GOAL: *Improve supports that allow people with dementia to remain at home and better support transition to residential care when needed.*

PRIORITY 3: *Improve quality of dementia care in residential care, including palliative and end-of-life care.*

GOAL: *Strengthen standards for dementia care in residential care to provide quality care for individuals who cannot live at home.*

PRIORITY 4: *Increase system supports and adoption of best practices in dementia care.*

GOAL: *Improve health-care professional and caregiver knowledge and ability to deliver safe, well-informed dementia care using best practices.*

One of the Ministry of Health's priorities is to better meet the needs of older adults with moderate to complex chronic conditions. This guide calls for services that allow people with dementia to live safely at home for as long as possible, with smooth transition to residential care when needed. This includes the ability to receive palliative and end-of-life care in their home. Responsive service delivery

5 www.health.gov.bc.ca/library/publications/year/2014/Setting-priorities-BC-Health-Feb14.pdf

6 www.health.gov.bc.ca/library/publications/year/2015/primary-and-community-care-policy-paper.pdf

and flexible care models are needed to support people with dementia to be cared for at home rather than in emergency departments and acute care in-patient beds.

As frailty is compounded by an increased prevalence of dementia and other forms of cognitive decline, this guide will support health authorities to meet the needs of frail seniors and people with complex chronic conditions.

The guide contains concrete actions for the ministry, health authority staff, and communities to include in their planning processes. Some actions will be led by the ministry (e.g., working with educational institutions to increase dementia care competency

among future health-care professionals) and others by health authorities (e.g., incorporating dementia friendly design into residential care homes). Health authorities will be responsible for work plans with actions that have targets and measures aligned to the ministry policy papers (e.g., primary and community care policy paper⁷). The list of deliverables and implementation leads are provided in Appendix B. A framework identifying provincial measures and reporting requirements is being developed.

When implemented, the actions will help those affected – people with dementia, their families and caregivers – to live with continued meaning, enjoyment and quality of life.



7 www.health.gov.bc.ca/library/publications/year/2015/primary-and-community-care-policy-paper.pdf

Introduction

Dementia (major neurocognitive disorder⁸) is a broad term applied to a group of signs and symptoms seen in a variety of diseases affecting the brain. Dementia is not itself a disease but is caused by diseases such as Alzheimer’s disease. Impairment of higher brain functions such as memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgement and executive function (a mental process that helps us plan, organize, remember instructions and focus our attention) are all possible outcomes of dementia.⁹ Changes in behaviour and mood are also common.

Dementia impacts roughly 62,000 British Columbians and is expected to rise to 87,000 by 2024.¹⁰ This increase marks dementia as one of the biggest health challenges for B.C., elsewhere in Canada and around the world.

TABLE 1: PREVALENCE OF DEMENTIA IN B.C. BY AGE GROUP, 2014/15

Age Group (years)	40–64	65–84	85+	Total
Dementia Prevalence by Age Group	4,740	27,835	29,142	61,717
Dementia Prevalence Rate by Age Group	0.3%	3.9%	23.3%	2.4%
Distribution of Dementia Prevalence by Age Group	8%	45%	47%	100%

The rising number of people with dementia correlates to British Columbia’s aging population. Although dementia is not a normal part of aging, the risk of developing dementia increases with age. In 2014/15, 47% of those with dementia were aged 85+, followed by 45% aged 65 to 84, and 8% had early onset under the age of 65 (See Table 1)

Nearly a third of British Columbia’s population is over the age of 50.¹¹ By 2022, one in five British Columbians will be over 65 years old.¹² The impact of dementia will grow as the proportion of seniors in British Columbia’s population increases over the next ten to fifteen years.¹³

The majority of care and support for people with dementia is provided by caregivers such as family members, friends and/or neighbours. In 2011, caregivers in Canada provided over 400 million unpaid hours looking after someone with dementia.¹⁴ This support allows those living with dementia to remain safe at home for as long as possible. However, the demand placed on caregivers can affect their physical, emotional and financial well-being. It is critical that caregivers are supported to continue in their caring roles.

The 2012 dementia action plan recognized the important and unique needs of caregivers while working to improve care for people living with dementia. This guide carries forward that recognition and approach by promoting a person-centred philosophy of care. In dementia care, a person-centred philosophy of care means the person with

8 The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) now uses the term “major neurocognitive disorder” instead of “dementia.” As well, the DSM-5 recognizes a less severe type of cognitive impairment, “mild neurocognitive disorder.”
 9 Adapted from the Dementia Service Framework, Ministry of Health (2007)
 10 Population Health Surveillance and Epidemiology, Ministry of Health, Dementia (age 40+ years), data extracted December 2015
 11 Ministry of Health (February 2014). Setting Priorities for the B.C. Health System. p 21.
 12 Ibid.
 13 Ministry of Health (November 2012). The Provincial Dementia Action Plan for British Columbia. p 5.
 14 Alzheimer Society of Canada (September 2012). A new way of looking at the impact of dementia in Canada. www.alzheimer.ca/en

dementia is valued and treated as an individual with unique qualities, strengths and abilities. Health care is delivered in a culturally appropriate way that respects the individual's cultural, linguistic and spiritual needs. Person-centred care also respects the importance and value of family and friends. This approach creates a positive environment in which the person living with dementia can experience relative well-being.

Our goal is to better meet the needs of older adults with moderate to complex chronic conditions. The guide calls for services that allow people with dementia to live safely at home for as long as possible,

with smooth transition to residential care when needed. This includes the ability to receive palliative and end-of-life care in their home environment.

Responsive service delivery and flexible care models are needed to allow this vulnerable population to be cared for at home rather than in emergency departments and acute care in-patient beds. The guide supports health authorities in achieving meaningful outcomes for people with dementia and their caregivers that are effective and sustainable.



Dementia Care, Achievements and Next Steps

The Provincial Dementia Action Plan for British Columbia (2012) and related provincial strategies have set us on the right course for improving the lives of people with dementia.

Since the release of the 2012 dementia action plan, the Ministry of Health launched its current strategic plan, *Setting Priorities for the B.C. Health System (2014)*.¹⁵ This plan identifies the need to improve dementia care. This includes support and training for formal and informal caregivers, and developing a more adequate service framework for the different stages of dementia linked to the expansion of home and residential care options. The accompanying policy paper, *Primary and Community Care in BC: A Strategic Policy Framework*,¹⁶ identifies practical recommendations, including the need to update actions from the 2012 dementia action plan.

Over the last three years, we have seen more evidence-based information and resources made publicly available, as well as improved training of health-care professionals. This *Provincial Guide to Dementia Care in British Columbia* (guide), integrates dementia planning into all activities that support care for people with dementia.

To meet population and patient health needs moving forward, the guide provides a comprehensive approach to the dementia journey – from diagnosis to end of life. It places the needs of people with dementia, their families and caregivers first.

Method and Structure of the Guide to Dementia Care

Development of the guide was informed by a review of dementia plans from around the world. The review identified key elements for moving forward:

- ▶ The importance of including the person with dementia in decision making;
- ▶ The valuable role families and communities play in supporting people to live well with dementia;
- ▶ The need to strengthen and enable the health-care system to deliver person-centred dementia care through education and research; and,
- ▶ Inclusion of targets and measures to track progress.

These elements are fundamental to best practice approaches in care and education methods. B.C.'s guide combines these elements with the work being done in communities, with provincial expertise, and with the voices of people who live the experience of dementia.

During the development of this guide, we heard from:

- ▶ People living with dementia, their families and caregivers;
- ▶ Alzheimer Society of B.C.;
- ▶ Health-care professionals, including geriatricians and geriatric psychiatrists;
- ▶ Primary care providers, including family doctors and nurse practitioners; and,
- ▶ Health authority representatives.

15 www.health.gov.bc.ca/library/publications/year/2014/Setting-priorities-BC-Health-Feb14.pdf

16 www.health.gov.bc.ca/library/publications/year/2015/primary-and-community-care-policy-paper.pdf



We also received advice from an advisory committee.¹⁷

The guide is structured around the dementia journey travelled by people with dementia, their families and caregivers. This includes changes in the living environment (e.g., need for family and/or caregiver support to allow individuals to remain at home), and decisions about care such as a move to residential care or receiving palliative and end-of-life care. These transitions often call for additional health care and other support services. The functional decline caused by the disease can also prompt significant life and care-planning decisions, and decrease quality of life for people with dementia, their families and caregivers.

The guide's first three priorities touch on transitions along the journey. The fourth priority is focused on improving system supports in terms of a skilled, informed, collaborative and respectful health-care workforce.¹⁸

There are a total of fifteen deliverables whose achievement will require the collaboration of many stakeholders. The ministry will be accountable for leading some deliverables, health authorities others, and some deliverables will be jointly led by health authorities and the ministry. Deliverables and accountabilities are summarized in Appendix B.

17 Refer to Appendix C for complete list of Guide to Dementia Care Advisory Committee members.

18 Workforce refers to all people (e.g., volunteers, housekeeping, health-care professionals, etc.) involved in the provision of assistance, care, information or support services to people with dementia, their caregivers or families at home and in all health-care settings.

PRIORITY 1: Increase public awareness and early recognition of cognitive changes.

GOAL: Increase healthy behaviours by promoting brain health and improve access to early diagnosis, intervention and community support programs.

In national and international dementia plans reviewed, raising public and health-care professionals' awareness of dementia and reducing stigma came out as top priorities. People's lack of understanding about dementia can lead to the misconception that behavioural and psychological symptoms of dementia are a normal part of aging. People may not know that risk factors such as smoking, type 2 diabetes and hypertension (particularly in midlife) may increase the risk of developing dementia. In addition, because of the stigma attached to dementia, people may avoid their doctors if they fear diagnosis or they may delay accessing support in their communities.

Early diagnosis and intervention can improve the quality of life for individuals with dementia and their families and have been shown to be cost-effective for the health-care system.^{19,20} Yet, dementia remains underdiagnosed. Many health-care professionals lack the confidence and skills required to provide an accurate diagnosis.^{21,22,23} Professionals may also be unaware of the resources available following diagnosis.²⁴ Information on the medical support and treatment available, along with earlier connection to appropriate resources, helps allow for a better quality of life for those diagnosed and their caregivers.

Community supports and awareness also positively affect quality of life. If people with cognitive changes or a diagnosis of dementia feel accepted in their communities, they are better able to continue the activities that give their life meaning. A diagnosis of dementia does not mean enjoyment and value in life are over. With early detection, connection to community supports and overall community awareness, people diagnosed with dementia can live fulfilling lives and be active members of the community.

Finally, quality of life can be enhanced by advance care planning. By planning early and continuously throughout the dementia journey, people with cognitive changes and their families can communicate wishes for their finances, health care and end-of-life care before the decision-making ability is lost. Planning will help ease the stress and discomfort at end of life when wishes and beliefs that have guided an individual through their life are discussed and decisions are documented.

19 Report by the Comptroller and Auditor General. (July 2007). Improving services and support for people with dementia. National Audit Office: pp 7, 9.

20 United Kingdom Department of Health. (February 2009). Living well with dementia: a national dementia strategy. www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

21 Turner, S, Iliffe, S, Downs, M, et al. (July 2004). General practitioners' knowledge, confidence and attitudes in the diagnosis and management of dementia. *Age and Ageing* 33(5): pp 461-467.

22 Pimlott, NJ, Persaud, M, Drummond, N, Cohen, CA, et al. (May 2009). Family physicians and dementia in Canada: part 2. Understanding the challenges of dementia care. *Canadian Family Physician* 55 (5): pp 508-509.e1-7. www.cfp.ca/content/55/5/508.full.pdf

23 Alzheimer Society of Ontario. (June 2014). People, partners & possibilities: transforming dementia care in the community. Pre-symposium survey: synthesis of feedback. brainxchange.ca/Public/Files/Primary-Care/ASO_Symposium_Survey_Synthesis_June-2014.aspx

24 Ibid.

DELIVERABLES:

- 1.1** *Increase understanding of dementia and continue to expand community information and support programs (e.g., dementia-friendly communities) for people with dementia and their caregivers.*
- 1.2** *Increase awareness of healthy behaviours associated with risk reduction for certain types of dementia, and promote brain health for all ages while targeting midlife individuals.*
- 1.3** *Enhance the ability of health-care professionals to detect and diagnose cognitive changes, provide appropriate and culturally sensitive treatment, and link people with dementia and their families to information and community supports such as First Link®.*
- 1.4** *Support and promote early advance care planning for people with major cognitive changes and their caregivers.*



PRIORITY 2: Support people with dementia to live safely at home for as long as possible, including caregiver support.

GOAL: Improve supports that allow people with dementia to remain at home and better support transition to residential care when needed.

Care at home²⁵ with appropriate supports can reduce or delay the need for unnecessary hospital and/or residential care admissions. People with dementia often stay longer in acute care (i.e., emergency departments and inpatient hospital care) and this can result in a decline in health.^{26,27} Thirty per cent of seniors admitted to acute care are discharged at a significantly reduced level of functional ability, and are unlikely to regain their previous level of independence.²⁸ In addition, an acute care stay may lead to premature admission to residential care.²⁹ Dementia-specific care guidelines and better management of existing conditions at the primary care level are needed to reduce the risks of unnecessary hospitalizations.³⁰ A focus on returning the person with dementia to live safely at home, with support if required, is essential.

Caregivers play a critical role in allowing people with dementia to remain safely at home. However, as the disease progresses and care needs increase, caregivers may feel overwhelmed. This is especially true if the person with dementia experiences behavioural and

psychological symptoms such as agitation, sleep disturbance, psychosis or wandering. Caregivers need access to a range of supports, including flexible respite programs. Living well with dementia applies not only to people with dementia but also to their caregivers.

While the majority of people with dementia continue to live at home (approximately 60 per cent), the other roughly 40 per cent live in residential care,³¹ with wandering a common trigger leading to this transition.³² Changes in the brain can lead to confusion and disorientation, which may result in people with dementia becoming lost and putting their safety at risk. Risk reduction through appropriate home care services, support, education and awareness can alleviate the stress and safety concerns that accompany wandering.

25 "At home" refers to living with cognitive changes or major neurocognitive disorder and relying on caregiver support to remain at home. While residential care is home for those who live there, "at home" as used in this document means that residential care admission is deferred.

26 Donnelly, M, McElhaney, J, Carr, M. (November 2011). Improving BC's care for persons with dementia in emergency departments and acute care hospitals.

27 Canadian Institute for Health Information (November 2012). Analysis in brief: health system performance. Seniors and alternate level of care: building on our knowledge.

28 Fraser Health. 2010. 48/6 model of care. <https://bcpsqc.ca/clinical-improvement/48-6/resources/>

29 Donnelly, M, McElhaney, J, Carr, M. (November 2011). Improving BC's care for persons with dementia in emergency departments and acute care hospitals.

30 Ibid.

31 BC Ministry of Health, Chronic Disease Information Registries, 2013/14, Alzheimer's Disease and Other Dementia Measures Report.

32 Canadian Institute for Health Information (August 2010). Analysis in brief: types of care. Caring for seniors with Alzheimer's disease and other forms of dementia.

DELIVERABLES:

- 2.1** *Review, modify and/or expand home care services, including flexible respite programs and supports for people with dementia and their caregivers.*
- 2.2** *Review and enhance workplace policies for people with dementia and caregivers.*
- 2.3** *Develop and implement a strategy to address wandering that spans from prevention through to the safe return of the individual.*
- 2.4** *Develop a care pathway for the identification, management and care of people with dementia, starting with diagnosis and including transitions in care.*



PRIORITY 3: *Improve quality of dementia care in residential care, including palliative and end-of-life care.*

GOAL: *Strengthen standards for dementia care in residential care to provide quality care for individuals who cannot live at home.*

When living safely in the community with home support is no longer an option, people with dementia may need residential care or other supportive care models. Roughly 40 per cent of people with dementia in British Columbia are living in residential care.³³ Residential care models need to incorporate standards of care specific to the needs of residents with dementia. The model needs to focus on respecting and responding to the needs of the person in care, their families and their caregivers.

Many people with dementia experience behavioural and psychological symptoms such as agitation or aggression. These symptoms may be a person's way of responding to their surroundings or communicating an unmet need. Assessment and care planning approaches should look to leading practices to manage these complex health needs and behaviour changes, while reducing inappropriate use of antipsychotic drugs as treatment.

Physical design in residential care requires attention as well. People with dementia are sensitive to their psychosocial environment. Appropriate levels of stimulation are needed to prevent individuals from becoming more confused or agitated.^{34, 35} Some research suggests that an inviting, home-like environment can help to engage people with dementia in household and social activities.³⁶ Designing the physical space with this in mind will improve their quality of life.

Quality of life when a person reaches end-stage dementia is as important as during the earlier progression of the disease. A "good death" sees the person with dementia treated with dignity and respect. However, people with end-stage dementia do not always receive effective palliative care and their pain is not always managed properly.³⁷ Palliative and end-of-life care for people with dementia should address their physical, emotional, social, psychological and spiritual needs as well as those of their families. Care should be responsive to distressing symptoms, with an emphasis on promoting dignity and quality of life.

DELIVERABLES:

- 3.1** *Incorporate dementia friendly design into new and, where appropriate, existing residential care homes to improve quality of life for people with dementia.*
- 3.2** *Review and improve dementia-specific standards of care in residential settings, with the desired result of spreading those standards to all health-care settings.*
- 3.3** *Promote a palliative approach to end-of-life care for people with dementia.*
- 3.4** *Increase the capacity of the residential care sector to provide appropriate assessment and care for persons experiencing behavioural and psychological symptoms of dementia, including reducing the inappropriate use of antipsychotic drugs as treatment.*

33 BC Ministry of Health, Chronic Disease Information Registries, 2013/14, Alzheimer's Disease and Other Dementia Measures Report.

34 Fleming, R, Purandare, N (November 2010). *Long-term care for people with dementia: environmental design guidelines*. International Psychogeriatric 22(7): pp 1084-1096.

35 Chatha, D, Wilkinson, SB. (May 2012). Fraser Health alternative care model-dementia (ACM-D) manual.

36 Ibid.

37 Sampson, EL, Gould, V, Lee, D, et al. (March 2006). Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing* 35(2): pp 187-189.

PRIORITY 4: *Increase system supports and adoption of best practices in dementia care.*

GOAL: *Improve health-care professional and caregiver knowledge and ability to deliver safe, well-informed dementia care using best practices.*

As their disease progresses, people with dementia touch many parts of the health system, including primary care (medical care from a physician or other health care professional who is the patient's first contact with the health system), the acute sector (emergency departments and inpatient hospital care), home care (services provided in the patient's home) and residential care. A competent workforce is required in all settings. However, focus groups comprised of people with dementia and caregivers identified a lack of training and understanding of dementia in acute care and residential care, and expressed concern about the quality of care received.

Practicing health-care professionals and future practitioners need training on the diagnosis and management of dementia. Cultural competency training needs to be a component of this instruction to promote respectful and responsive care. Training and education that is evidence-based, person-centred and integrated between care settings and health professionals will support people with dementia to get the care they need.

Participating in a national dementia strategy will foster the adoption and spread of best practices, helping to improve care to those living with dementia.

DELIVERABLES:

- 4.1** *Increase and sustain consistent dementia training for health-care professionals and caregivers – including cultural competency training – in all care settings.*
- 4.2** *Work with educational institutions to increase dementia care competency among future health-care professionals.*
- 4.3** *Participate in the development of a national strategy that will promote the spread and adoption of best practices in dementia care.*



Conclusion

The Ministry of Health worked with health authorities, health-care professionals and other partners to refresh priorities and actions around dementia care and to build on the progress already achieved. Aligning with the ministry's *Setting Priorities for the B.C. Health System*, the guide provides a comprehensive approach to dementia care. It aims to improve the lives of those affected by dementia throughout the dementia journey.

The guide has concrete actions for the ministry, health authority staff and communities to include in their own planning processes to improve the lives of people living with dementia across the province. Implementation by health authorities includes ensuring work plans contain actions with targets and measures aligned to the ministry's strategic direction.

The person-centred approach will address issues at transition points along the dementia journey:

- ▶ At diagnosis: through early recognition and interventions to improve quality of life for people with dementia and their caregivers;
- ▶ During early progression of the disease: through improved home care services to support safety and quality of life while living at home, and reduce and/or delay hospital and residential care admissions;

- ▶ During changes in the living environment: through quality care in all care settings, with emphasis on residential care; and,
- ▶ At end of life: through improved palliative and end-of-life care that responds to peoples' beliefs and wishes.

Actions in the guide will also increase public awareness and system supports. Education that reduces stigma in the community and strengthens health-care provider knowledge will help those affected by dementia to get the appropriate care and support they need earlier. In addition, increased public awareness of ways to promote brain health at all ages will help to reduce the risk of developing certain types of dementia.

In collaboration with stakeholders, the Province will continue to raise awareness of what it means to live with dementia. It will work to meet the challenges related to the increasing number of those affected. Government is committed to helping those with dementia, their families and their caregivers live with continued meaning, enjoyment and quality of life.



Glossary

ADVANCE CARE PLANNING: A process by which a capable adult considers their beliefs, values, and wishes for personal care and health care in advance of a time when they may be incapable of deciding for themselves. The advance care planning process includes ongoing conversations with close family/friend(s) and health care providers and is an essential element to ensuring health care treatments align with personal values and goals.

BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA: Behavioural and psychological symptoms of dementia include, but are not limited to, agitation, depression, apathy, repetitive questioning, psychosis, reactive behaviours, sleep problems and wandering. One or more of these symptoms will affect nearly all people with dementia over the course of their illness. These symptoms are among the most complex, stressful and costly aspects of care. They can lead to poor patient health outcomes, health-care problems and income loss for family caregivers.³⁸

CAREGIVER: Refers to family members, friends and/or neighbours who provide unpaid care to people with dementia.

COGNITIVE CHANGES: Changes in the brain (e.g., memory, attention, planning, decision making, language) that are noticeable by the person experiencing them or to other people who know them well. The impact of the changes can be major (severe enough to interfere with daily life) or mild (not severe enough to interfere with daily life).

DEMENTIA: A broad term applied to a group of signs and symptoms seen in a variety of diseases affecting the brain. Dementia affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgement and executive function (a mental process that helps us plan, organize, remember instructions and focus our attention).³⁹

Dementia is not itself a disease but is caused by a variety of diseases, including Alzheimer's disease. The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) now uses the term "major neurocognitive disorder" instead of "dementia." As well, the DSM-5 recognizes a less severe type of cognitive impairment, "mild neurocognitive disorder."

DEMENTIA JOURNEY: Refers to the journey people with dementia, their families and caregivers take as they progress through the stages of dementia to end of life.

END-OF-LIFE CARE: Care that is an important part of palliative care and usually refers to the care of a person living with a progressive condition during the last part of their life from the point at which it has become clear that the person is in a progressive state of decline.⁴⁰

MAJOR NEUROCOGNITIVE DISORDER: The term now used by the Diagnostic and Statistical Manual of Mental Disorders instead of "dementia."

38 The BMJ 2015;350:h369

39 Adapted from the *Dementia Service Framework*, Ministry of Health (2007).

40 Adapted from AVERT (United Kingdom) definition. www.avert.org/palliative-care.htm

PALLIATIVE CARE: An approach that improves the quality of life of people facing a life-threatening illness, and their families, through the prevention and relief of suffering by means of early identification, assessment, treatment of pain and other problems (physical, psychosocial and spiritual).⁴¹

PERSON-CENTRED DEMENTIA CARE

Care that is centred on:

- a. the whole person
- b. remaining abilities, emotions and cognitive abilities
- c. the person within the context of family, marriage, culture, ethnicity and gender; and,

Care that is centred within a wide society and its values.⁴²

RESIDENTIAL CARE SERVICES: Occur in facilities that provide a secure, supervised physical environment, accommodation and care to clients who cannot have their care needs met at home or in an assisted living residence.⁴³

RESPIRE: Short-term services that allow the client's principal caregiver a period of relief or provide the client with a period of supported care to increase independence.⁴⁴

WANDERING: Movement that is associated with confusion or disorientation when the person with dementia is at risk for becoming lost. Wandering is not the same as pacing, which is a common behaviour in dementia.



41 Adapted from the World Health Organization definition. www.who.int/cancer/palliative/definition/en/

42 Adapted from The Canadian Alzheimer Disease Review (April 2003). *Person-centred Dementia Care: A Vision to be Refined*.

43 Adapted from definition in the *BC Home and Community Care Policy Manual*, Chapter 8 (2014).

44 Ibid.

Appendix A – Status of Dementia Action Plan (2012) Commitments

ACTIONS	STATUS
PRIORITY: Support Prevention and Early Intervention	
Include information on brain health as an important element of healthy aging in all health promotion information – online (SeniorsBC.ca) and in print (BC Seniors Guide).	COMPLETE SeniorsBC.ca and BC Seniors Guide
Support the expansion of community support programs, such as the Alzheimer Society’s First Link. Together with physicians, refer people with dementia and their families to these services as early as possible	COMPLETE Ministry of Health funding for First Link
Provide increased access to information on managing the condition and daily lives, including abuse prevention information online and in print.	COMPLETE Protection from Elder Abuse/Neglect HealthLink BC Seniors Abuse and Information Line
Promote advance care planning to support people with mild cognitive impairment and their families to plan ahead for future personal and health-care decisions	COMPLETE My Voice Advance Care Planning Guide Speak Up BC Advance Care Planning Resources
PRIORITY: Ensure Quality Person-Centred Dementia Care	
Implement evidence-based interdisciplinary dementia education, information, tools and resources for family physicians, clinicians and care providers.	COMPLETE Behavioural and Psychological Symptoms of Dementia (BPSD) Algorithm Purchase of P.I.E.C.E.S.™ Canada License
Develop and implement clinical guidelines for the effective use of medications to assist with the behavioural and psychological symptoms of dementia. Work to reduce the use of antipsychotic medications across all settings wherever possible.	COMPLETE Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care Call for Less Antipsychotics in Residential Care (CLEAR)
Provide people with dementia and their caregivers with an identified care co-ordinator linked to an integrated health-care team, which includes family physicians, caregivers and community health services.	IN PROGRESS
Ensure provincial end-of-life care strategies and priorities include the unique needs of people with dementia.	IN PROGRESS
PRIORITY: Strengthen System Capacity and Accountability	
Increase the flexibility and number of options in housing and care models to provide a broader range of living environments with supportive care for those who cannot live independently	IN PROGRESS
Work with health authorities to ensure hospitals and emergency departments have strategies for seniors’ care that reflect best practice, and address the needs of people with dementia and their caregivers	COMPLETE 48/6 Model of Care
Identify evidence-informed measures of quality dementia care and incorporate these in integrated health services planning and quality improvement activities, beginning with residential care services	IN PROGRESS
Support research to improve outcomes for people with dementia and their families in all care settings	COMPLETE BC Alzheimers Research Award Centre for Brain Health

2012 Achievements

The 2012 dementia action plan identified three priorities and corresponding actions. The plan provided a whole-system approach to improving care and support for individuals with dementia and their families. This section lists accomplishments to date.

PRIORITY 1: Support Prevention and Early Intervention

GOAL: Increase awareness of self-care strategies for brain health and increase access to early support and information to manage the physical, behavioural and psychological symptoms of dementia.

WHAT WE ACCOMPLISHED:

- ▶ Updated HealthLink BC, SeniorsBC, and Home and Community Care websites and print resources with information on brain health, planning for healthy aging and living with dementia.
 - » Information about dementia and a wide range of other related topics is available on HealthLink BC, including information about the condition and specific types of dementia, behaviour changes, caregiver support and living with dementia.
 - » Seniors BC (www.seniorsbc.ca) and the Ministry of Health's Home and Community Care (www.gov.bc.ca/hcc) websites offer user-friendly navigation, updated information and enhanced ability to search for relevant information.
- ▶ The British Columbia Seniors' Guide has been translated from English into French, Chinese and Punjabi. The new guide includes updated information about brain health, physical activity and wellness, how to access health services, information on the First Link® program and a range of other useful topics.
- ▶ The Ministry of Health developed and distributed an Elder Abuse Information Kit to increase awareness about elder abuse. The kit helps older adults learn how to prevent abuse, recognize abuse when it happens, know how to respond and know where to find assistance. The resource was sent to over 600 seniors, ethno cultural and First Nations organizations provincewide, and is available in English, French, Traditional Chinese and Punjabi.
- ▶ Government has provided \$13.4 million to the Alzheimer Society of B.C. for First Link® since 2007. First Link® provides connections to learning, services and support to over 12,500 individuals diagnosed with dementia and their families throughout British Columbia.
- ▶ In April 2012, the ministry released *My Voice: Expressing My Wishes for Future Health Care Treatment*⁴⁵ a comprehensive advance care planning guide and workbook to help people prepare for their future health care. An online B.C. workbook, *Speak Up BC*, is also available. Advance care planning information, tips, brochures, videos and the My Voice guide (English, Punjabi, and Simplified Chinese Versions) are available at www.gov.bc.ca/advancecare.

45 www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf

PRIORITY 2: *Ensure Quality Person-Centred Dementia Care*

GOAL: *Improve health-care providers' knowledge and capacity to deliver timely, safe, person-centred care to individuals and their caregivers through evidence based information and interdisciplinary care team approaches across all care settings.*

WHAT WE ACCOMPLISHED:

- ▶ The *Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care*⁴⁶ was developed to support improved quality of care for people with dementia in residential care. The guideline focuses on the use of non-pharmacological interventions and the appropriate use of antipsychotic drugs in residential care settings. It offers evidence-based guidance to assist physicians, nurses, health-care professionals, family members and people with dementia in assessment, care planning and care decision making. An accompanying algorithm provides a practical, user friendly online decision support tool for health-care professionals and caregivers to support assessment, problem solving, care planning and evaluation. The online algorithm helps health-care professionals and caregivers provide dementia care that best meets the needs of the person receiving care.
- ▶ Health-care professionals in residential care are being trained with a dementia care program developed by P.I.E.C.E.S.TM Canada (**P**hysical, **I**ntellectual, **E**motional health, **C**apabilities, **E**nvironment, **S**ocial self)⁴⁷ through a joint project between the Ministry of Health and health authorities. P.I.E.C.E.S.TM provides a systematic framework for detection, assessment and care planning using a person-centred approach. As more individuals are trained in P.I.E.C.E.S.TM and related dementia care educational programs,

public and contracted residential care sites in British Columbia will be better equipped to provide individualized, appropriate and evidence-based care to people who are experiencing the complex behavioural and psychological symptoms associated with dementia.

PRIORITY 3: *Strengthen System Capacity and Accountability*

GOAL: *Provide high-quality assessment and treatment services and access to flexible community care services and care options for individuals with dementia to reduce or delay the need for admission to residential care services.*

WHAT WE ACCOMPLISHED:

- ▶ The 48/6 Model of Care for hospitalized seniors is being used in hospitals and all acute inpatient care settings. The 48/6 model focuses on screening and assessment in six key care areas. Inter-professional teams develop and implement a personalized care plan within 48 hours of the decision to admit a senior, based on screening and assessment, and in collaboration with the senior. The 48/6 approach was developed by geriatric experts and representatives in each health authority, along with the Ministry of Health and the British Columbia Patient Safety & Quality Council, to address essential needs early in a senior's admission. The goal is to reduce the risk of functional decline and to support independence.
- ▶ In December 2013, a new \$7.5-million fund to advance British Columbia's research into Alzheimer's disease was announced, with funding provided by the B.C. Government, Brain Canada, Michael Smith Foundation for Health Research, Genome B.C. and the Pacific Alzheimer's Research Foundation. Research is vital to preventing, treating and finding a cure for

46 www.health.gov.bc.ca/library/publications/year/2012/bpsd-guideline.pdf

47 www.piecescanada.com

Alzheimer's disease. The funding supports a new British Columbia Alzheimer's Research Award, which will contribute to international efforts to find a treatment or cure for the disease.

- ▶ On Feb. 27, 2014, the Djavad Mowafaghian Centre for Brain Health opened in Vancouver, uniting research and patient care under one roof. As a partnership between the University of British Columbia and Vancouver Coastal Health, the centre will accelerate research and discovery in neuroscience, psychiatry and neurology – translating new knowledge into better treatment and prevention strategies.

Much was accomplished within each priority of the 2012 *Provincial Dementia Action Plan for British Columbia*. This success was due to the collaboration between the Ministry of Health, clinical experts, health authorities and partners in dementia care improvement, as well as better integration of primary and community care services.

The Ministry of Health released *Improving Care for B.C. Seniors: An Action Plan in February 2012*.⁴⁸ The plan included concrete actions targeted at addressing concerns expressed by seniors, their families and care providers about seniors' care in British Columbia. It was informed by the findings and recommendations of the British Columbia Ombudsperson's report, *The Best of Care: Getting it Right for Seniors in British Columbia (Part 2)*.⁴⁹

Along with other strategies such as *Healthy Minds, Healthy People: A Ten-year Plan to Address Mental Health and Substance Use in British Columbia*⁵⁰ and *The Provincial End-of-Life Care Action Plan for British Columbia*,⁵¹ we have built a solid foundation for system-wide change. Renewed overall leadership

and integration of these programs and strategies has led to better alignment of actions and policy improvements, shared learnings and increased momentum to sustain change.

We have also benefitted from the concerted efforts of our partners in care. In order to continue to move ahead with health system and health care culture change, it is important that our communities and partner organizations are engaged and empowered to make differences that meet the needs of the people they serve and represent.

We have witnessed a range of activities from our partners and organizations involved in the lives of people with dementia, including:

- ▶ The British Columbia Care Providers Association's knowledge exchange *Care to Chat* speaker series which brings in experts and leaders to speak to the continuing care sector and other stakeholders about emerging topics relevant to seniors care. Their session titled "Debunking the Myths and Misconceptions of B.C.'s Continuing Care Sector" included a look at whether the vast majority of seniors moving into care were living with dementia.
- ▶ The British Columbia Care Providers Association's *Best Practices Guide for Safely Reducing Anti-Psychotic Drug Use in Residential Care*⁵² shares stories of excellence from residential care settings across the province.
- ▶ The British Columbia Patient Safety & Quality Council's Call for Less Antipsychotics in Residential Care (CLeAR) is a quality improvement project designed to support interested teams from

48 <http://www2.gov.bc.ca/assets/gov/people/seniors/about-seniorsbc/pdf/seniorsactionplan.pdf>

49 www.bcombudsperson.ca/images/pdf/seniors/Seniors_Report_Volume_2.pdf

50 www.health.gov.bc.ca/library/publications/year/2010/healthy_minds_healthy_people.pdf

51 www.health.gov.bc.ca/library/publications/year/2013/end-of-life-care-action-plan.pdf

52 www.bccare.ca/wp-content/uploads/Anti-Psychotics-Guide-hr-06-05-13.pdf

residential care facilities in British Columbia in their efforts to manage the behavioural and psychological symptoms of dementia and reduce the inappropriate use of antipsychotics.

- ▶ The Alzheimer Society of B.C.'s website www.alzheimerbc.org offers a wandering package toolkit with information on wandering and locating devices, an identification kit and tips for police. Tools, education and information provide help for municipalities, professionals, corporations and the public to develop dementia-friendly communities. As well, the Alzheimer Society of Canada has partnered with the Canadian MedicAlert Foundation to improve the MedicAlert® Safely Home® program, which is designed to help identify the person who is lost and assist in a safe return home.

Local governments across British Columbia have taken steps to make their communities more age friendly, with support from the Province and the Union of British Columbia Municipalities. For example, the City of Vancouver developed *The Age-Friendly Action Plan: A Safe, Inclusive and Engaging City for Seniors*,⁵³ which includes dementia awareness training and information and active programming for people with dementia.



53 vancouver.ca/files/cov/age-friendly-action-plan.pdf

Appendix B – Guide to Dementia Care Deliverables, Implementation Leads

PRIORITY 1: Increase public awareness and early recognition of cognitive changes.	
	LEAD
1.1 Increase understanding of dementia and continue to expand community information and support programs (e.g., dementia-friendly communities) for people with dementia and their caregivers.	Ministry of Health
1.2 Increase awareness of healthy behaviours associated with risk reduction for certain types of dementia, and promote brain health for all ages while targeting midlife individuals.	Ministry of Health
1.3 Increase the ability of health-care professionals to detect and diagnose cognitive changes, provide appropriate and culturally sensitive treatment, and link people with dementia and their families to information and community supports such as First Link®.	Ministry of Health
1.4 Support and promote early advance care planning for people with major cognitive changes and their caregivers.	Health Authority
PRIORITY 2: Support people with dementia to live safely at home for as long as possible, including caregiver support.	
	LEAD
2.1 Review, modify and/or expand home care services, including flexible respite programs and supports for people with dementia and their caregivers.	Health Authority
2.2 Review and enhance workplace policies for people with dementia and caregivers.	Ministry of Health
2.3 Develop and implement a strategy to address wandering that spans from prevention through to the safe return of the individual.	Ministry of Health
2.4 Develop a care pathway for the identification, management and care of people with dementia, starting with diagnosis and including transitions in care.	Ministry of Health develop & Health Authorities implement
PRIORITY 3: Improve quality of dementia care in residential care including palliative and end-of-life care.	
	LEAD
3.1 Incorporate dementia friendly design into new and, where appropriate, existing residential care homes to improve quality of life for those with dementia.	Health Authority
3.2 Review and improve dementia-specific standards of care in residential settings, with the desired result of spreading those standards to all health care settings.	Ministry of Health develop & Health Authorities implement
3.3 Promote a palliative approach to end-of-life care for people with dementia.	Health Authority
3.4 Increase the capacity of the residential care sector to provide appropriate assessment and care for persons experiencing behavioural and psychological symptoms of dementia, including reducing the inappropriate use of antipsychotic drugs as treatment.	Health Authority
PRIORITY 4: Increase system supports and adoption of best practices in dementia care.	
	LEAD
4.1 Increase and sustain consistent dementia training for health-care professionals and caregivers – including cultural competency training – in all care settings.	Ministry of Health and Health Authority
4.2 Work with educational institutions to increase dementia care competency among future health-care professionals.	Ministry of Health
4.3 Participate in the development of a national strategy that will promote the spread and adoption of best practices in dementia care.	Ministry of Health

Appendix C – Guide to Dementia Care Advisory Committee Members

The Ministry of Health wishes to thank members for their time, contribution and dedication toward improving the health and quality of care for people with dementia.

Debbie Andersen, Seniors' Health Promotion Directorate, Ministry of Health

Elisabeth Antifeau, Interior Health

Simon Barton, Acute and Provincial Services, Ministry of Health

Monica Blais, Seniors' Health Promotion Directorate, Ministry of Health

Lisa Chu, Fraser Health

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Fabio Feldman, Fraser Health

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Kelly Gunn, Northern Health

Maria Howard, Alzheimer Society of British Columbia

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Jennifer Kennedy, Northern Health

Christina Krause, B.C. Patient Safety & Quality Council

Barbara Lindsay, Alzheimer Society of British Columbia

Deborah Lorimer, Vancouver Coastal Health

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Sarah Metcalfe, Fraser Health

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Valerie Spurrell, Ridge Meadows Hospital

Jennifer Stewart, Alzheimer Society of British Columbia

Elizabeth Stanger, Vancouver Coastal Health

Dr. Carol Ward, Division of Geriatric Psychiatry, University of British Columbia; and Interior Health

Susanne Watson, Northern Health

Dr. Michael Wilkins-Ho, Vancouver Coastal Health

Gerrit Van Der Leer, Mental Health and Substance Use Policy and Program, Ministry of Health

James Watson, Quality Assurance, Ministry of Health

Janet Zaharia, Policy and Planning for End of Life and Dementia Care, Ministry of Health





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