THE PROVINCIAL
Dementia Action Plan
FOR BRITISH COLUMBIA

Priorities and Actions
for Health System
and Service Redesign

Ministry of Health
November 2012
Acknowledgements

This action plan has been developed with input and expertise from a variety of clinical, research and policy experts. We are very grateful for their enthusiastic support of this work, their vision, expertise and time as the plan evolved.

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Glossary of Terms

**Active Partners in Care** – People with a health condition and their caregivers who are knowledgeable about health promotion and about their disease. They have the skills and confidence to engage actively with the health care team.

**Dementia** – A chronic, progressive disease of the brain that affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgment, and executive function.¹

**End of Life and End-of-Life Care** – The period marked by disability or disease that is progressively worse until death; also considered the final stage of life. Care provided during this time may also be called hospice care, comfort care, supportive care, palliative care or symptom management.² End-of-life care is associated with advanced, potentially fatal illnesses, and focuses on comfort, quality of life, respect for personal health care treatment decisions, support for the family, psychological and spiritual concerns.³

**Mild Cognitive Impairment (MCI)** – A transition phase of cognitive decline that can occur in some individuals between the cognitive changes associated with normal aging and cognitive losses identified in the early stages of various dementias. Losses are evidenced by self and/or informants along with deficits on objective cognitive tasks, and/or evidence of decline over time detected by neuropsychological testing.

**Person-Centred Approach**⁴ – An approach to the management of a health condition that incorporates biological, psychological, sociological and functional perspectives. This approach recognizes that these perspectives all interact to determine an individual’s experience of the condition.

**Transitions** – People living with dementia and their caregivers often refer to the significant transitions associated with the disease. Transitions are periods of key changes to the daily life and care needs of the person and their caregiver, as the disease causes deteriorations in function, changes in memory and behaviour and may decrease quality of life.

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¹ Adapted from the Dementia Service Framework, Ministry of Health (2007).
³ Adapted from definition outlined by the National Institute of Medicine (1999).
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Executive Summary

The Provincial Dementia Action Plan is intended to demonstrate government’s continued commitment to people with dementia and their families, and underlines the significance of dementia as a contributor to frailty and the loss of independence, particularly for seniors. The action plan outlines provinewide priorities for improved dementia care through health system and service redesign work currently underway in British Columbia. It is intended to support collaborative action over the next two years by individuals, health professionals, health authorities, and community organizations to achieve quality care and support for people with dementia, from prevention through to end of life.

The Ministry of Health has committed to a system-wide plan for innovation and strategic change to ensure the health system delivers quality services that meet families’ needs in a manner that is sustainable in the long term and organized around the following four goals:

1. Effective health promotion, prevention and self-management to improve the health and wellness of British Columbians;
2. British Columbians have the majority of their health needs met by high quality primary and community based health care and support services;
3. Access to high quality hospital services when needed; and
4. Improved innovation, productivity and efficiency in the delivery of health services.

The action plan reflects this system-wide innovation and change focus, with a goal to increase individual, community and health service capacity to provide early, appropriate and effective care and support to assist people with dementia to remain at home and in their communities to the greatest extent possible. Throughout the course of the disease, improvements in dementia care can make a positive impact on health outcomes, reduce the need for emergency department or hospital care, as well as reduce or delay the need for placement in a residential care facility.

In February, 2012, the Minister of Health released a new strategic document, entitled Improving Care for BC Seniors: An Action Plan. This senior focused plan addresses many of the concerns heard from seniors and their families about the need for accessible information, improved protections and streamlining of policies and regulations to provide more flexibility and responsiveness in the system of care for seniors. The Provincial Dementia Action Plan provides important areas of focus to inform this work for those with dementia and their families.

A diagnosis of dementia is life altering; the changes to memory, behaviour and functional abilities profoundly affect the lives of people with the disease and their relationships with family and friends. Understanding the impact of dementia and how best to assist and care for individuals and their families living with dementia are key to improved quality of life and health outcomes for people wherever they live.

Many British Columbians are, and will be, affected by dementia. They may be experiencing dementia themselves, or are caregivers supporting family members, friends, or coworkers with dementia in its early, middle or late stages. Although specific study results

5 Ministry of Health, Revised Health Service Plan 2011/12 – 2013/14
differ somewhat, all researchers agree that the prevalence of dementia is increasing. Current estimates suggest that between 60,000 and 70,000 British Columbians have dementia. Although dementia is not a normal part of aging, the risk of developing dementia does increase with age. Consequently, the impact of dementia will continue to grow as the proportion of seniors in British Columbia’s population increases over the next ten to fifteen years.

This action plan is based on collaborative work undertaken between the ministry, clinical experts, physician leaders, community organizations, people with dementia and their caregivers over the past five years. As the health system moves forward in implementing a more integrated and responsive system of care, supporting people with dementia and their caregivers are a priority population to ensure that individuals receive quality care and support in all care settings through to end of life.

British Columbia is committed to improving the health system and quality of care for people who have dementia and their families. The Provincial Dementia Action Plan for British Columbia provides a common road map to continue building on investments in clinical innovations and new approaches to service delivery actively underway across the province.

6 Medical Service Economic Analysis, Health System Planning Division, Ministry of Health, Dementia (age 45+ years only) January 17, 2011, project 2010_372. Centre for Applied Research in Mental Health and Addictions, Simon Fraser University, 2006
Introduction

A diagnosis of dementia is life altering. The changes to memory, behaviour and ability to carry out activities of daily living profoundly affect the lives of people with dementia, their family and friends as the disease runs its course. Understanding dementia and the role we can all play to support and care for those living with it are important to support a better quality of life and the best possible outcomes for those with dementia and their families.

Many British Columbians are affected by dementia. There are many different types of dementia, each with its own unique characteristics and patterns. Like many progressive, degenerative conditions, dementia has an impact not just on the person with the disease, but also their caregivers, supporting family members, friends and co-workers. And, like many chronic conditions, there is much that can be done at each stage of the disease to improve that experience and achieve more positive outcomes.

In 2007, a wide variety of stakeholders with expertise in dementia and dementia care came together to draft a framework, outlining a full range of potential strategies to improve brain health, help reduce the incidence of dementia, and support people who have dementia through all stages of the disease. This collaborative work identified a number of gaps in the system of dementia care, and with $1 million in funding from government, supported seven pilot projects to demonstrate strategies intended to improve dementia care across the full continuum. Once evaluated, the work from these initiatives and the 2007 framework was used to inform the development of this action plan.

While regional health authorities, clinical experts and physician leaders across the province have continued to collaborate to develop and improve evidence-based clinical guidelines, educational resources and interdisciplinary care teams to better meet the needs of people with dementia, government has provided significant funding commitments to support long term improvements in dementia care, including:

- $15 million to the Pacific Alzheimer Research Foundation to support research on prevention or arrest of Alzheimer disease and related dementias.8
- $34 million in drug coverage to the Alzheimer’s Drug Therapy Initiative (Oct 2007 to July 2012) to gather and examine clinical evidence on the safety and effectiveness of cholinesterase inhibitors, a group of medications for people with mild to moderate Alzheimer’s disease.9
- $25 million to the Brain Research Centre at UBC Hospital to support the development of the Djavad Mowafaghian Centre for Brain Health. This is a new facility that will bring together, for the first time, all the multidisciplinary areas of brain health under one roof to support the development of new treatments for illnesses and injuries of the brain.10

8 www.parf.ca/4478.html
9 www.health.gov.bc.ca/pharmacare/adti/index.html
10 http://www.brain.ubc.ca/index.php]
This action plan demonstrates British Columbia’s continued commitment to people with dementia, and underlines the significance of dementia as a contributor to frailty and the loss of independence, particularly for seniors. The action plan outlines provincewide priorities for improved dementia care over the next two years through the health system and service redesign work currently underway. It is intended to support collaborative action by individuals, health professionals, health authorities, and community organizations to provide quality care for people with dementia, from early diagnosis through to end of life. The strategies outlined in this document build on innovation and leading practices to improve access to quality care, while fostering sustainability of B.C.’s publicly funded health care system.

**A Vision for Integrated, Whole-Person Care in the Community**

The Ministry of Health has committed to a system-wide plan for innovation and strategic change to ensure the health system delivers quality services that meet families’ needs in a manner that is sustainable in the long term, organized around four goals:

1. Effective health promotion, prevention and self-management to improve the health and wellness of British Columbians;
2. British Columbians have the majority of their health needs met by high quality primary and community based health care and support services;
3. Access to high quality hospital services when needed; and
4. Improved innovation, productivity and efficiency in the delivery of health services.11

This action plan reflects this system-wide innovation and change focus, with a goal to increase individual, community and health service capacity to provide early, appropriate and effective care and support to assist people with dementia to remain at home and in their communities to the greatest extent possible. Throughout the course of the disease, improvements in dementia care can make a positive impact on the lives of individuals with dementia and their caregivers, reduce the need for emergency department or hospital care, as well as reduce or delay the need for placement in a residential care facility.

In February, 2012, the Minister of Health released a new strategic document, entitled *Improving Care for BC Seniors: An Action Plan*. This senior focused plan addresses many of the concerns heard from seniors and their families about the need for accessible information, improved protections and streamlining of policies and regulations to provide more flexibility and responsiveness in the system of care for seniors. The *Provincial Dementia Action Plan* provides important supporting direction to inform this work for those with dementia and their families.

11 Ministry of Health, Revised Health Service Plan 2011/12 – 2013/14
Dementia in British Columbia

Dementia is a broad term used to describe the symptoms of a number of illnesses which cause a loss of memory, judgment, and reasoning, as well as changes in behaviour and mood. These changes result in a progressive decline in a person’s ability to function at work, in social relationships, or to perform regular daily activities.

Types of Dementia

There are many different types of dementia, although some are far more common than others. Some of the more common types are outlined below.

Alzheimer disease (AD): A progressive disease of the brain featuring memory loss and at least one of the following cognitive disturbances that significantly affects activities of daily living:

- Language disturbances (aphasia);
- An impaired ability to carry out motor activities despite intact motor function (apraxia);
- A failure to recognize or identify objects despite intact sensory function (agnosia); and
- Disturbance in executive functions such as planning, organizing, sequencing, and abstracting.

Vascular Dementia: A dementia that is a result of brain cell death that occurs when blood circulation is cut off to parts of the brain. This may be the result of a single stroke or multiple strokes, or more diffusely as the result of small vessel disease.

Dementia with Lewy Bodies: This disease often has features of both Alzheimer disease and Parkinson's disease. Microscopic 'Lewy bodies' are found in affected parts of the brain. Common symptoms include visual hallucinations, fluctuations in alertness and attention, and a tendency to fall.

Frontal Temporal-Lobe Dementia: A dementia that primarily affects the frontal lobes of the brain and results in early impairment in the control of personal, social and interpersonal conduct: loss of insight; emotional level blunting; and language deficits.

Other Dementias: These include dementias associated with Creutzfeldt-Jakob disease, Huntington’s disease, Parkinson’s disease, brain injury, HIV/AIDS, Down syndrome, developmental disabilities, and mental illnesses.

Mixed Dementias: People may show features of more than one type of dementia. For example, many people, especially the very old, appear to have a mix of Alzheimer disease and Vascular Dementia.

12 www.alzheimer.ca/english/disease/whatisit-intro.htm
13 www.alzheimer.ca/english/disease/dementias-vascular.htm
14 www.lbda.org/category/3437&cfid=9708013&cftoken=94894883/what-is-lbd.htm
15 www.ftd-picks.org/frontotemporal-dementias/ftd-overview
16 www.alzheimer.ca/english/disease/dementias-creutzfeldt.htm
17 www.alzheimer.ca/english/disease/dementias-vascular.htm
Alzheimer disease is the most common form of dementia—approximately 64 per cent of all Canadians who have dementia have Alzheimer disease.\textsuperscript{18} Vascular dementia is the second leading form of dementia, accounting for up to 20 per cent of all cases.\textsuperscript{19} Researchers estimate that approximately 2–5 per cent of all dementia cases are frontal lobe dementia.\textsuperscript{20} Lewy body dementia can occur by itself, or together with Alzheimer disease or Parkinson's. It accounts for 5–15 per cent of all dementias.\textsuperscript{21}

A related condition, called mild cognitive impairment, is frequently described as a transition phase of cognitive decline that can occur in some people between the cognitive changes associated with normal aging and cognitive losses in the early stages of various dementias.

**Stages of Dementia**

Dementia is a progressive degenerative condition, and consequently people who have dementia tend to move through clinical stages that each present distinct challenges for both the person with dementia and their caregivers. As dementia progresses, significant change to the person’s personality and mood may occur. Health clinicians generally refer to three commonly accepted stages of dementia: mild, moderate, and severe.

**Mild:** The person who has mild dementia is still able to function somewhat independently. However, memory loss and thinking impairment are present, often with mild word-finding difficulties. Caregivers may report stress due to the functional changes in the person with dementia.

**Moderate:** The person who is in a moderate stage of dementia will experience further decreases in memory, thinking, language and concentration skills. This results in an increased need for supervision and assistance. In this stage there can also be changes in behaviour and a potential for wandering. The caregiver is at risk for stress, depression, general health deterioration, and loss of productivity at work.

**Severe:** The person who is in the severe stage of dementia experiences a considerable loss of memory, language, and living skills. As a result, they cannot be left unsupervised and require assistance in all activities of daily living. A high level of dependence on the caregiver can increase the risks to the caregiver's health and ability to continue to manage care at home. Severe dementia often requires admission to a residential care facility, and may indicate the need for end-of-life-care.

\textsuperscript{18} www.alzheimer.ca/english/disease/dementias-intro.htm
\textsuperscript{19} www.alzheimer.ca/english/disease/dementias-vascular.htm
\textsuperscript{20} www.alzheimer.ca/english/disease/dementias-frontotemp.htm
\textsuperscript{21} www.alzheimer.ca/english/disease/dementias-lewy.htm
An Increasing Prevalence of Dementia

Despite the fact that the chance of developing dementia increases with age, dementia is not a normal part of aging. According to the Canadian Study of Health and Aging, the prevalence of dementia increases significantly after age 65 and is higher in people age 85 or more when compared to those between the ages of 65 – 84. Early onset dementia occurs in people under age 65 and may appear in persons as young as age 45 or even younger. The link between dementia and increasing age has significant implications for British Columbia as we plan for the needs of an aging population in the years ahead.

Although the numbers may vary between studies, researchers and health care analysts agree that the prevalence of dementia is increasing significantly as our population ages. In British Columbia, current estimates of the numbers of people with dementia vary between 60,000 and 70,000. As the numbers of seniors grows, particularly those seniors aged 85 and older, the impact of dementia will continue to increase.

The Importance of Caregivers

A recent study by the Canadian Institute for Health Information examined the health and functional status of persons over age 65 with dementia. These individuals were studied to evaluate the factors that most contributed to their need for admission to a residential care facility and their utilization of health care resources.

Although B.C. residents were not part of the study group, the findings provide important information to inform priorities for community health services. Ninety-nine per cent of those studied who received care at home had an available caregiver, compared to only 26 per cent who lived in a residential care facility. With an available caregiver, many seniors with dementia and health instability were still able to be cared for at home, while those without a caregiver were often admitted to residential care facilities at earlier stages of dementia and with less health instability.

These findings suggest that factors such as the availability of an able caregiver, and the caregiver’s capacity to cope with the person with dementia’s needs have a significant influence on the ability to support care at home, perhaps even to a greater degree than the status of the individual’s cognitive impairment.
**Addressing the Needs of People with Dementia and their Families**

People with dementia, their families, care providers, clinical experts and community organizations have provided important perspectives on the goals a provincial action plan should support. These include:

**For the person with dementia…**
- Community programs and services support people with dementia to maintain their ability to live independently at home;
- Depression, functional and behavioural changes are recognized and managed in a coordinated system of care; and
- Future and end-of-life care planning is addressed early, to provide the opportunity to plan ahead for changes in ability to manage daily activities, and for future health care treatment decisions.

**For families and caregivers…**
- Access to information and supportive community resources improves understanding and reduces stress as the disease progresses;
- Family members and other caregivers are able to support the person throughout the course of the disease; and
- Participation as an active partner in care supports their own physical and mental health, and the maintenance of personal and professional productivity.

**For the health care system…**
- Proactive community care supports early recognition, diagnosis, and treatment, resulting in better patient care and outcomes;
- Hospital care is informed by evidence and linked to the primary and community health team, reducing the length of stay in hospital and reducing avoidable emergency departments visits; and
- People with dementia are able to access a range of housing and supportive care options, reducing or delaying the need for placement in residential care facilities.

**For the community…**
- Better public education supports age friendly communities, and supports individuals to maintain higher levels of participation in the community;
- Health promotion and chronic disease prevention strategies improve the overall health of seniors; and
- Community organizations are linked to health services planning, and collaborate to improve the availability of appropriate services in each community.
A Shift to Integrated Primary and Community Care

The primary point of contact with the health care system for most people is their family physician, who helps them understand and manage their health conditions. For those with a chronic, progressive health condition, community based health services and other community supports may be needed, including those provided by the Alzheimer Society, community centres and volunteer groups. Studies show that the best results are achieved when the health care team works collaboratively, with the patient and their family actively participating as partners in care.26

For this reason, the ministry, in partnership with the BC Medical Association, is supporting a major shift in health service delivery through integrated primary and community care. In communities across the province, family physicians, through local societies called Divisions of Family Practice, are partnering with health authorities, community groups and patients to redesign health service delivery, with a goal of improving the quality of care for patients with chronic and complex health conditions through a coordinated, team based approach.27

A key goal of this more integrated approach to care is to expand the capacity of community based health services to support chronic and complex conditions, reduce the need for avoidable hospital and emergency department visits, and reduce or delay the need for admission to a residential care facility. This is a significant departure from a more siloed approach to health care services that can make it difficult for families to access the supports they need, and often results in care providers working in isolation from one another.28

Taking a population based approach to dementia involves looking at the full health continuum – from those who are well and would benefit from prevention and self-care strategies, to those with severe dementia who may require support for complex symptoms or end-of-life care. While the focus on integrated health care teams may be on those at the moderate to severe stages of dementia, strategies need to address all stages of the disease to fully support improved health outcomes.29

26 E. Suter, N.D. Oelke, C.E. Adair and G. Armitage, Ten Key Principles for Successful Health Systems Integration. www.longwoods.com/content/21092
27 Information regarding Divisions of Family Practice available at www.gpscbc.ca/family-practice-incentive/divisions-family-practice
Principles for Person-Centred Dementia Care

In developing priorities for dementia care within the context of this shift to a more population-based approach, and the ministry’s commitment to innovation and change, the priority actions were informed by the following key principles:

1. **Recognition of the link between dementia and frailty** – Dementia is a degenerative disease that contributes significantly to the frailty of individuals and their ability to live independently in the community, especially if alone.

2. **People with dementia and their families are a priority population for integrated primary and community care** – Given the link between dementia and frailty, the prevention, diagnosis and management of dementia through all its phases must be considered a core focus of integrated primary and community care.

3. **Information and early supports are critical components of dementia care** – People with dementia and their caregivers require easy access to information and supports from the community, physicians and other health care providers throughout the course of the disease.

4. **Patients and caregivers are active partners in care** – People with dementia and their caregivers must be included as partners in health care planning and treatment decisions.

These principles are assumed in each of the following priorities and actions.
The Provincial Dementia Action Plan for British Columbia

Priorities and recommended actions for dementia care in B.C.

The priorities and recommended actions that follow have their roots in the collaborative work done over the past five years with medical experts, clinicians, health authorities, care providers and community organizations, such as the Alzheimer Society of British Columbia. Many of these actions build on initiatives already in development, or underway as part of service innovation and the implementation of a population-based approach to care. In many cases, the work underway may be limited to a specific project or community, but has demonstrated successful outcomes that can be effectively spread across urban, rural and remote communities in the province. Each of the actions below is intended for province-wide implementation over the next two years.

**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.

**ACTIONS:**

- Include information on brain health as an important element of healthy aging in all health promotion information – both online (e.g., SeniorsBC.ca) and in print (e.g., BC Seniors Guide).
- Support the expansion of community support programs, such as the Alzheimer Society’s First Link® and, together with physicians, refer people with dementia and their families to these services as early as possible.
- Provide increased access to information on managing the condition and daily lives, including abuse prevention information through both web-based and print information.
- Promote advance care planning to support people with mild cognitive impairment and their families to plan ahead for future personal and health care decisions.

**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.

**ACTIONS:**

- Implement evidence-based interdisciplinary dementia education, information, tools and resources for family physicians, clinicians and care providers.
- Develop and implement clinical guidelines for the effective use of medications to assist with the behavioural and psychological symptoms of dementia, and work to reduce the use of antipsychotic medications across all settings wherever possible.
➢ Provide people with dementia and their caregivers with an identified care coordinator linked to an integrated health care team that includes family physicians, caregivers and community health services.

➢ Ensure provincial end-of-life care strategies and priorities include the unique needs of people 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.

**ACTIONS:**

➢ 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.

➢ Work with health authorities to ensure that hospitals and emergency departments have strategies for seniors’ care that reflect best practice, and address the needs of people with dementia and their caregivers.

➢ Identify evidence-informed measures of quality dementia care and incorporate these in integrated health services planning and quality improvement initiatives, beginning with residential care services.

➢ Support research to improve outcomes for people with dementia and their families in all care settings.
Summary and Conclusions

British Columbia is committed to improving the health system and the quality of care for people with dementia and their families. The Provincial Dementia Action Plan for British Columbia provides a common road map to build on investments in clinical innovations and to incorporate these into new approaches to service delivery actively underway across the province.

Although it is not possible to identify absolute strategies for prevention, we do know that there is a great deal that can be done to reduce the risk of developing chronic disease as we age, including dementia. We can work together to manage each person’s journey through dementia with a focus on quality of life, maintaining independence and participation in the community to the highest degree possible. It is also critically important that we support and maintain a culture of accountability and continuous improvement, so that we can continue to foster innovation in person-centred care in the years ahead.

Implementation of the Provincial Dementia Action Plan for British Columbia will support healthier aging and provide support for those with dementia, their family and friends, with a sustainable and responsive approach to care.