

BC Dementia Service Framework

A working document developed by the
Provincial Dementia Service Framework Working Group
September 2007

Contents

Acknowledgements	vii
1 Executive Summary	1
1. Executive Summary	3
2 Introduction	9
2. Introduction.....	11
3 About Dementia	15
3. About Dementia.....	17
3.1. What Is Dementia?	17
3.2. Values and Principles Guiding Dementia Care	20
3.2.1. Values.....	20
3.2.2. Principles.....	21
3.3. Rationale for Improving Dementia Care	22
3.3.1. The People Rationale	22
3.3.2. The Numbers Rationale.....	23
4 What Are Service Frameworks?	27
4. What Are Service Frameworks?	29
4.1. Organization of Service Frameworks	29
4.2. Why Are We Using the Service Framework Approach?.....	31
4.3. Relationship to Other Planning Frameworks.....	31
4.3.1. Population Health Planning.....	32
4.3.2. The Expanded Chronic Care Model.....	32
4.3.3. The Service Framework	32
5 About the Dementia Service Framework	35
5. About the Dementia Service Framework.....	37
5.1. Scope of the Dementia Service Framework	37
5.2. The Development of the Dementia Service Framework.....	37
5.2.1. Applying the Service Framework to Dementia.....	37
5.2.2. Guiding Principles for Development of the Dementia Service Framework.....	38

5.2.3. Key Initiatives Used to Complete the Service Framework	39
5.2.4. Performance Indicators	41
5.3. Using Levels of Evidence and Strength of Recommendations.....	42
5.4. Education for All	43
6 Dementia Service Framework	45
6. Dementia Service Framework	47
6.1. Priority Recommendations	48
6.2. Goals and Themes.....	55
6.3. Gaps and Related Recommendations	58
6.4. Dementia Service Framework Recommendations.....	66
Staying Healthy – Individual	70
Staying Healthy – Care Provider	74
Staying Healthy – Support Systems	78
Staying Healthy – Health Care Environment	82
Living with Dementia – Individual.....	85
Living with Dementia – Care Providers	89
Living with Dementia – Support Systems	96
Living with Dementia – Health Care Environment	101
Getting Better from Periods of Episodic Decline – Individual.....	104
Getting Better from Periods of Episodic Decline – Care Providers	106
Getting Better from Periods of Episodic Decline – Support Systems	110
Getting Better from Periods of Episodic Decline – Health Care Environment.....	115
Coping with End of Life – Individual.....	117
Coping with End of Life – Care Providers	120
Coping with End of Life – Support Systems	124
Coping with End of Life – Health Care Environment	127
7 Document Reference Library	131
7. Document Reference Library.....	132
Appendices	135
Appendix A: Your Stories.....	136
Appendix B: Expanded Chronic Care Model.....	149
Appendix C: Translation of Initiative-Specific Recommendations into Service Framework Recommendations	151
Appendix D: Indicators	153
Glossary	157

List of Tables

Table 1. Predicting the number of dementia cases.....	23
Table 2. Total costs of care for dementia (individuals >65 only)	24
Table 3. Generic service framework	30
Table 4. Levels of health care	30
Table 5. Levels of health status.....	31
Table 6. Levels of health status adapted to the dementia journey	38
Table 7. Priority recommendations.....	49

Table 8. Staying healthy themes55
Table 9. Living with dementia themes.....56
Table 10. Getting better from periods of episodic decline themes57
Table 11. End-of-life themes57
Table 12. Dementia Service Framework Matrix.....69

List of Figures

Figure 1. Projected increase in the number of dementia cases24
Figure 2. Process for translation of recommendations into the service framework (SF).....152

Acknowledgements

The following individuals participated either as contributors to the source documents and initiatives that were include in the Dementia Service Framework and/or actively participated in the development of the service framework.

Dementia Service Framework Working Group

Chris Rauscher (Chair)	Marianne McLennan, VIHA
Penny Lane,* Consulting Team Lead	Sherry Masters,* CARMHA, SFU
Jillian Oickle,* Primary Health Care, MOH	Elliot Goldner, CARMHA, SFU
Shana Ooms, Primary Health Care, MOH	Jaye Routledge, Impact BC
Gerrit van der Leer, MOH	Kathleen Friesen,* FH
Rosemary Rawnsley, ASBC	Elisabeth Antifeau,* IH
Paddy O'Reilly, Impact BC	Laurianne Jodouin, MOH (HCC)
Lorea Ytterberg,* NH	Shannon Berg, VCH
David Gayton, FHA	Bonnie Lillies, VCH
Martha Donnelly, UBC	Barbara Lindsay,* ASBC
Belinda Boyd,* VCH	Gary Ockenden,* Consulting Team
Mary Catherine Collins,* VIHA	Catriona Park,* Consulting Team

* Members who also participated as members of the Core Working Group

Initiative-Specific Teams

Vancouver Island Health Authority

Dr. Marilyn Bater
Marianne McLennan
Mark Blanford
Dr. Michael Cooper

Northern Health Authority

Lorea Ytterberg
Tim Rowe (by phone)
MaryLou Harrigan, Centre for Personhood
Lori Amdam

Vancouver Coastal Health Authority

Sue Davies
Henry Lee
Betty Sinclair
Belinda Boyd
Shannon Berg
Kathy Jack
Laurie Webster
Lia Kiessling
Candace Howcroft

Interior Health Authority

Elisabeth Antifeau
Heather Coulter
Patty Crozier
Dr. Elaine French
Dr. Alan Gow
Esther Krahn
Ann Ungaro

Fraser Health Authority

Dr. Pamela Thornton
Kathleen Friesen
Brenda Bailey
Dr. Tracy Lyster
Dr. Terry Isomura
Dr. David Gayton
Gina Gaspard
Dr. Peter O'Connor
Sue Melnychuk
Marnelle Roberts

Centre for Applied Research in Mental Health and Addiction

Penny McCourt, CARMHA
Sherry Masters/Keith Reynolds, CARMHA
Matthew Queree, CARMHA
Allan Cho, CARMHA
Katrina Bell, CARMHA
Dr Ladislav Volicer School of Aging Studies, University of Florida
Dr. Kiran Rabheru, Geriatric Psychiatrist in Vancouver Coastal Health Authority
Dr. Jean Kozak, Centre for Healthy Aging, Providence Health Care
Louise Stern, School of Social Work, University of British Columbia
Laurianne Jodouin, MOH
Donna Lommer, IHA
Marianne McLennan, VIHA
Judy Lett, NH
Dr. Romaine Gallagher, UBC
Dr. Brian Plain, VIHA

Alzheimer Society of British Columbia

Nicole Bertrand	Muriel Stanley	Judy Bourne
Barbara Lindsay	Marianne Luther	Katherine Guilbride
Dr. Kiran Rabheru	Marc LaBrecque	Jan Robson
Lynn Jackson	Bernice Ma	Joan Bird
Chris Smith	Avalon Tournier	Jani Cardinal
Rosemary Rawnsley	Jillian Armit	Jane Hope
Kathy Kennedy	Vivian Lam	Linda Hoskin
Kern Windwraith	Angela Johnston	Laurie Myres
Linda Forrest	Kerri Sutherland	Teresa Steeves
Betty Sinclair	Kerry McPhedran	Phyllis Dyck
	Gail Whitney	Terri Maynard
		Sheila Smith

BC Geriatric Mental Health Education Initiative (GMHEI)

Elisabeth Antifeau, IH	Lorna McNeil, VIHA
Shannon Berg, VCH	Ann Marie Monahan, VIHA
Mary Catherine Collins, VIHA	Darryl Oakley, IH
Dr. Martha Donnelly, UBC	Ilse Patterson, VCH
Veronica Doyle, VIHA	Rosemary Rawnsley, ASBC
Andrea Felzmann,	Dr. Stefan Schovanek, VIHA
Dorrie Ferster, FH	Sandra Somers, VIHA
Dr. Elaine French, IH	Anita Wahl, FH
Kathleen Friesen, FH	Dr. Carol Ward, IH
Dawn Hemingway, UBC	Laura Watts
Joan Hibbard, GPEP	Lorea Ytterberg, NH
Barbara Lindsay, ASBC	
Lisa McFarling, VCH	

Cognitive Impairment in the Elderly Working Group

Dr. Chris Rauscher, Chair, VCH and MOH
 Dr. Douglas C. Drummond, Prince George
 Marcia Carr, FH
 Darlene Arenson, MOH
 Dr. Martha Donnelly, UBC
 Dr. Lynn Beattie, UBC
 Dr. Duncan Robertson, Victoria
 Dr. Shamim Jetha, Vancouver
 Dr. Sherrill J. Purves, North Vancouver
 Jillian Oickle, MOH
 Shana Ooms, MOH

Transforming Dementia Care – Planning Committee

Barbara Lindsay, ASBC
 Dr. Martha Donnelly, UBC
 Marcia Carr, FH
 Penny Lane, IH
 Dr. Gloria Gutman, SFU
 Shana Ooms, MOH

Building Bridges (BCMA) – Steering Committee

Dr. Duncan Robertson

Dr. Lynn Beattie

Dr. Romyne Gallagher

Dr. David Gayton

Dr. Chris Rauscher

Executive Summary

Is It Dementia? – Your Story

“Looking back, I think I probably knew that something was wrong. The signs were there ... the memory lapses, the confusion, the angry outbursts. I guess there’s knowing, and then there’s knowing ...

“For a while, I had been feeling sort of fuzzy in my head. I was having trouble remembering things. Some days I was okay, but other days I would dial a phone number and forget who I was phoning. Or I’d be taking notes at a meeting and would lose track of the discussion.”

*(Story taken from the Vancouver Coastal Health website.
See [Appendix A](#) for entire story.)*

1. Executive Summary

The Dementia Service Framework (DSF) is a provincial initiative bringing together the work of those involved in receiving, planning, and delivering care and services to improve outcomes for people at risk for dementia, people with dementia, and their caregivers.

Service frameworks are an exciting new approach for health system planning in British Columbia. They are a “person-centred approach to improving health outcomes across the conventional boundaries of the health system.” The recommendations captured within a service framework present a high-level picture of optimal care that people should expect to see based upon evidence from the literature and upon best practices drawn from experts, including health care providers and patients. Because our knowledge base continues to grow and expand, service frameworks are viewed as “living documents,” evolving over time to include new research findings for improving care.

Dementia is a term applied to a group of signs and symptoms seen in a variety of diseases affecting the brain. For the most part, it is a chronic or progressive disease of older people resulting in impairment of higher brain functions such as memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgment, and executive function to a degree sufficient to affect daily activities.

Demographic trends indicate that British Columbia, along with the rest of Canada, is experiencing significant population aging. The chance of developing dementia increases significantly with age; population aging is therefore correlated with increases in the number of people affected by dementia. It is estimated that in 2006 \$1.39 billion was spent in BC on direct care related to dementia. These costs are projected to increase to \$1.97 billion by 2016 (in 2006 dollars). This cost estimate does not include acute care costs and the costs to individuals with dementia and their families.

The extent of the economic burden created by a high prevalence of dementia reinforces the need for a system-wide approach to ensuring that individuals with dementia and their families receive optimal care, drawn from best practice. It also points to the need for upstream activity to help prevent dementia and also help those who are at risk for or diagnosed with the condition remain healthy for as long as possible.

Currently there are some significant barriers to the provision of optimal dementia care in British Columbia. We have identified seven barriers or gaps:

- There is a gap in the system’s capacity and ability to address the clinical and support needs of people with dementia and their families/caregivers.

- There is a gap in the number of health care providers with expertise in elder and dementia care for people with dementia and their families/caregivers.
- There is a gap in the knowledge of health care providers about dementia as a chronic condition and about best practices in dementia care.
- There is a gap in policy that mitigates the impact of dementia on the people with dementia and their families/caregivers, and on the communities they live in.
- There is a gap in the recognition of the role of families and caregivers as partners on the care team.
- There is a gap in the capacity and ability of the acute care setting to meet the needs of people with dementia.
- There is a gap in the formal integration, collaboration, and communication across care settings, between health care providers, and across health authorities.

The Dementia Service Framework has been developed in order to close these gaps. The framework is comprehensive in its scope. Target populations include the general population of the province, caregivers and families of people living with dementia, people at risk for cognitive impairment and dementia, and people living with dementia at all stages of the journey, including end of life. The recommendations generated address the full continuum of brain health across the life span and are directed to all stakeholders.

A cross-section of stakeholders was involved in the development of this service framework. Representatives from the Ministry of Health, all five geographic health authorities in BC, the Alzheimer Society of BC, the Centre for Applied Research in Mental Health and Addiction, and Impact BC participated as members of the Dementia Service Framework Working Group, providing overall guidance and input. (See [Acknowledgements](#) for a complete list of the people who participated.)

The recommendations in the service framework are evidenced-based, including the experience of people living with dementia and clinical experts, and are targeted for action by four levels of care: individuals with dementia and their caregivers, care providers, support systems, and the health care environment. Overall, there are 130 recommendations contained within the service framework. Taken together, they provide system-wide direction for improving dementia care in BC. A subset of 54 recommendations has been identified for priority actions. These are further divided into priority actions for each of the four levels of care.

You can take action to close the seven gaps and improve services and care for people living with dementia by taking responsibility for implementing the recommendations contained in this service framework.

If you are an *interested member of the public*, an *individual at risk* for dementia, *living with dementia*, or a *caregiver* of a person with dementia, you can:

- Seek information to understand brain health, the risk factors associated with dementia, and the lifestyle choices you can make to reduce your risk
- Become knowledgeable about the early signs of cognitive impairment and ask your primary care provider for information and help in obtaining an early diagnosis of mild cognitive impairment or dementia
- Learn how to be an active partner in your care by seeking information about dementia, the care and life decisions that you will need to be planning for, and how to be an effective advocate for your care or your family member's care
- Talk about the values and beliefs that you want to be guiding decisions in the future about your care and treatment decisions

In this document, you will find background information on why these actions are important. You will also find links to resources that will help you take the first steps towards improving the care you receive. Go to [“Staying Healthy – Individual”](#) to get started and find out what you can do.

If you are a *provider of care* to individuals at risk for dementia, people living with dementia, and their caregiver, you can:

- Access information, education, and training on dementia to understand how to:
 - Advise clients about brain health and the risk factors for dementia
 - Identify cognitive impairment
 - Incorporate evidenced practice into your assessment, diagnosis, care, and treatment plans
 - Offer consistent information to people with dementia and their caregivers
- Take responsibility for ensuring that people with dementia and their caregivers and families are supported through transitions associated with the dementia journey.
- Engage people with dementia and their families and caregivers as active partners in care.

In this document, you will find specific information regarding the knowledge you need to support and care for persons with dementia and their families, as well as links to resources that will help you get started. Go to [“Staying Healthy – Care Provider”](#) for the specific actions you can take to improve dementia care.

If you are a *decision maker* within the health care system or in an agency that provides support to people living with dementia and their caregivers, you can:

- Provide education and information on brain health to the general public
- Build capacity within your organization to provide primary prevention and risk reduction for cognitive impairment

- Build capacity within your organization to identify at an early stage individuals with cognitive impairment and support accurate diagnosis by health care providers
- Ensure that families and caregivers are respected and valued
- Support communication, coordination, and collaboration among care providers and between care providers and families
- Build formal partnerships between agencies to address policy needs, research, and services
- Build capacity within your organization to ensure that adequate and knowledgeable staff are available for dementia care in the future
- Support access to education on dementia and dementia care by all groups involved
- Develop dementia-appropriate care environments, including acute care
- Engage in system planning to support people living with dementia through transitions and periods of episodic decline and end of life
- Support staff through professional development in improving their knowledge of dementia and dementia care

More information on how you can start taking action can be found by going to [“Staying Healthy – Support Systems”](#).

If you are a *policy maker*, you can improve the system of care for people living with dementia and their families and communities by:

- Supporting the development of a research agenda on dementia and best practice in dementia care and services
- Developing a dementia lens for the review of all policy to ensure that there are benefits for people impacted by dementia and that no unintended consequences of the policy further penalize this population
- Engaging in policy strategies that reduce the stigma associated with dementia in our society
- Improve the knowledge level of health care providers about dementia through improvements in education and continuing education curriculum
- Plan for and foster innovation in models of service delivery that are evaluated and, as appropriate, support their spread across the system

Go to [“Staying Healthy – Health Care Environment”](#) for more information on how you can make a difference.

A final word ...

As part of the development of the service framework, we conducted an external review of a near-final draft of the document. Over 100 individuals involved with dementia care and research were asked to review the document and respond to a series of questions. We were told that this framework is “a solid piece of work” and that, if implemented, there would be significant improvements in the care and outcomes for people living with dementia in BC. The respondents were able to identify opportunities and readiness in the system today to begin planning for and implementing many of the recommendations. Specifically, there is readiness and support for the development of a Provincial Dementia Education Framework that would contribute significantly to addressing many of the recommendations in the Dementia Service Framework. A number of barriers were also identified, but many of these barriers can be addressed through collaborative action by all stakeholders.

“It [the Dementia Service Framework] is brilliant, and from what I can gather it appears that a person who has dementia and their family, and the service people required to assist the person with dementia, will in effect work hand in hand to ensure that a person with dementia [will] never be lost due to lack of assistance advice and service.”

Living with Dementia – Your Story

“At first, I refused to accept I had dementia. I was furious! Why me? I’m too young – only 67! Those doctors didn’t know what they are talking about!

“I had a million excuses for what was going on. I badly wanted to believe in a different explanation for my symptoms. I was angry, then confused, then scared ... it was a very difficult period for me and my family. I became quite depressed. Life seemed so hopeless, so unfair!”

*(Story taken from the Vancouver Coastal Health website.
See [Appendix A](#) for entire story.)*

2. Introduction

VISION: "People living with dementia will lead full lives, through a shared passion for action by all stakeholders."

The Dementia Service Framework (DSF) is a provincial initiative bringing together the work of those involved in receiving, planning, and delivering care and services to improve outcomes for people at risk for dementia, people with dementia, and their caregivers.

Dementia is a disturbance of the brain that affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgment, and executive function, and is usually associated with chronic or progressive diseases such as Alzheimer's, cerebrovascular disease, and other diseases that affect the brain. A diagnosis of dementia has a significant impact not just on people with the disease but also on their families and their communities. The prevalence of dementia increases significantly with age; therefore population aging, as is occurring in British Columbia, is correlated with significant increases in the number of people with dementia. Yet there is hope. Through early recognition and diagnosis, anticipatory planning for life and health care decisions, and a more informed and appropriately responsive health care system, we can improve the dementia journey.

Service frameworks are a relatively new concept in BC and have developed out of the provincial work on Chronic Disease Prevention and Management and the development of Physician Best Practice Guidelines for specific chronic diseases. As Physician Guidelines for chronic conditions have been developed, there has been recognition that physician practice is only one component in the system of care, and that the guidelines will be more effective when implemented within the context of broader system redesign. In 2004, dementia was added to the list of chronic diseases in BC. Between 2005 and 2007, Cognitive Impairment Guidelines were developed (still in draft), and in the fall of 2006, work began on the development of the Dementia Service Framework.

A diverse group of stakeholders has been involved in the development of this service framework, including:

- The Ministry of Health
- All five geographic health authorities in BC
- The Alzheimer Society of BC
- The Centre for Applied Research in Mental Health and Addiction (CARMHA)
- Impact BC

In addition, many participants representing people living the experience of dementia, clinicians, researchers, administrators, and policy makers have been involved as members of cross-jurisdictional working groups or initiative-specific teams, and through provision of feedback on the service framework as it developed.

The objectives of the BC Dementia Service Framework are to:

- Develop a comprehensive set of practice recommendations that will direct the action of all levels of care based on evidence and the experience of people living with dementia
- Support the health authorities and agencies involved in providing dementia care and services in planning, prioritizing, and implementing system improvements

The DSF is a summary of evidence-based recommendations that, if implemented, will improve the outcomes for people at risk for dementia, people living with dementia, and their caregivers. Examples of actions that will lead to improved outcomes include increasing knowledge about the importance of brain health, engaging in activities that reduce the risk of cognitive impairment, linking people to services earlier, anticipatory life and care planning, and improving the dementia knowledge of care providers. The outcomes that will result include earlier recognition and diagnosis, delay in the onset and progress of the dementia, and improved quality of life and safety for those affected. Individuals with dementia and those who care for them will find their independence and ability to self-manage their care enhanced, along with a lessening of the burden on the caregiver.

At a systems level, the DSF promotes collaborative, supportive, respectful partnerships between those with dementia, their caregivers, and the interdisciplinary care team. As consistent, evidence-based practice becomes embedded into the processes and structures of agencies and organizations responsible for care and service delivery, there will be improved integration, coordination, and communication of care across all services, across all sectors, and among all health care providers. This will result in improved use of health and social resources related to the care of people affected by dementia.

What is the purpose of a service framework?¹

- To guide recommended care across disciplines and sectors
 - To provide a whole-system view of an illness, disability, or health issue
 - To address the patient's journey through the health system over the course of an illness
 - To describe services needed by people living with the disease across the continuum of care and by different care providers
 - To outline the best care and services for patients and families, and show how providers, administrators, and planners can support the best care
 - To identify best practice based on evidence from clinical research and patient/provider experience
 - To improve patient outcomes, facilitate quality care, and promote optimal use of health services and health system sustainability
-

¹ Preface to “Service Frameworks in British Columbia” (BC Ministry of Health, January 2007).

Care at Home – Your Story

“Every day is a marathon. So much to do, so many demands on my time. Caring for my mother with Alzheimer’s ... my father ... my husband and children ... on top of full-time work. At times I feel completely overwhelmed, and I wonder how much longer I can keep it all up.

“When my parents moved in, our family life was turned upside down. They could no longer live safely in their own home. Several times my mother wandered off and got lost, and my father was frantic. Twice she forgot to turn off the iron. She wasn’t remembering to eat. So it was necessary for my parents to move in with us.”

*(Story taken from the Vancouver Coastal Health website.
See [Appendix A](#) for entire story.)*

3. About Dementia

This section begins with an overview of dementia, including its symptoms, forms, stages, and transitions.^{1,2,3} The values and principle statements that should ideally underpin dementia care are also presented, as is the rationale for making change in the way care is delivered for people with dementia and their families.

3.1. What Is Dementia?

“Dementia is a general term identifying specific cognitive impairment stemming from a range of diseases.”

Dementia is a term applied to a group of signs and symptoms seen in a variety of diseases affecting the brain. For the most part, it is a chronic or progressive disease of older people resulting in impairment of higher brain functions such as memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgment, and executive function to a degree sufficient to affect daily activities. Consciousness is not clouded (as in delirium); however, the impairments of cognitive functioning are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

People with early dementia may exhibit some of the following symptoms:

- Problems remembering recent events
- Difficulty performing familiar tasks or learning new ones
- Changes in mood, personality, and behaviour
- Impaired judgment and reasoning
- Difficulty finding words, finishing thoughts, or following directions

Although the chance of developing dementia increases with age, dementia is not a normal part of aging. Overall, 8% of people over the age of 65 have dementia, but this varies from 1-2% of the population at age 65 to about 35% of the population over the age of 85.

¹ Either as cited or as described in the “Interior Health Phased Dementia Pathway” (Interior Health Authority, BC, 2006), online: <http://www.interiorhealth.ca/NR/rdonlyres/E2299B8D-DD63-4F1E-9E0C-2340A81A5018/4042/MCIPathwaydescription.pdf>.

² As cited in the “Draft Dementia Framework for South Australia: 2004-2009,” online: <http://www.dfc.sa.gov.au/document/publications/dementiaframework>.

³ “Transforming Dementia Care in BC: Addressing Gaps and Improving Care – Let’s Get Creative!” (Alzheimer Society of BC, 2005), online: <http://www.alzheimerbc.org/documents/AlzheimerDementiaFinalReport.pdf>.

There are different forms of dementia. The most common are described below.

Alzheimer's Disease

A progressive disease of the brain featuring memory loss and at least one of the following cognitive disturbances:

- 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)
- Disturbance in executive functions such as planning, organizing, sequencing, and abstracting

Vascular Dementia

This is 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's 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 Lobe Dementia

This is 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.

Alcohol-Related Dementia

This dementia is caused when damage to brain cells occurs from excessive consumption of alcohol.

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's disease and vascular dementia.

Alzheimer's disease is the most common form of dementia; approximately 60% of all people who have dementia have Alzheimer's disease. After that, estimates vary, with vascular dementia accounting for approximately 5-10% and dementia with Lewy bodies accounting for about 5% of all dementias. Mixed dementias account for approximately 20-30% of all dementias.

A related condition is called "mild cognitive impairment." Mild cognitive impairment (MCI) is frequently described as 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. The cognitive losses are evidenced by either self and/or informant (e.g., family, caregiver) report along with deficits on objective cognitive tasks, and/or evidence of decline over time detected by neuropsychological testing. Ten to fifteen percent of people each year who are diagnosed with MCI will progress to dementia when followed over a five-year period.

Because dementia is a progressive degenerative condition, people who have dementia tend to move through clinical *stages* as they progress through their disease. These stages have been defined based on tests for mental competency. As dementia progresses, significant change to the person's personality and mood can 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. Caregivers will experience stress because of 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, and concentration skills. This decline in functioning 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 skills, and living skills. Due to these losses, the person cannot be left unsupervised and requires total assistance in all activities of daily living. There is a total dependence on the caregivers, who are at risk for all of the impacts identified above. Severe dementias include the end of life care for the person with dementia.

People living with dementia and their caregivers often refer to the significant *transitions* associated with the disease rather than the clinical stages described above. The transitions are typically key changes for the person and their caregiver as the disease causes deteriorations in function (cognitive and physical) that trigger significant life and care-planning decisions and a decrease in quality of life. Typical *transition* points are the receipt of the diagnosis of dementia, the need to make decisions that are linked to a loss of independence (e.g., loss of ability to drive), changes in living environment (e.g., a need to move in with a family member), and decisions about residential and end of life care. These points of transition are often the times when additional support from health care and other support services is required by the people living with dementia and their caregivers.

3.2. Values and Principles Guiding Dementia Care

Excellence in dementia care is strongly related to a values- and principles-based approach in planning and service provision because dementia is a condition for which there is no cure. Dementia impacts all aspects of a person's life: relationships, vocation, life planning, cognitive, mental and emotional, and physical. People living with the disease and their caregivers are the experts on what quality of life means to them, and how they are functioning in their normal environment, and they are often the first to notice changes in function throughout all stages of the disease. International, national, and provincial work has been done to define the values and principles that should inform the planning and delivery of care and services to people living with dementia and their caregivers. The values and principle statements underpinning the BC Dementia Service Framework have been drawn from these documents, and are integral to the recommendations that are made in this service framework. The reference documents include:

- National Framework for Action on Dementia, 2005 Consultation Paper, Australian Health Ministers Conference
- Submission from Alzheimer's Australia Vic Consumer Reference Group to the National Framework for Action on Dementia, 2005 Consultation Paper
- IH Dementia Strategy (adapted from Alzheimer Society of Canada), 2005
- Guidelines for Elderly Mental Health Care Planning for Best Practices for Health Authorities, February 2002, British Columbia Ministry of Health Services

3.2.1. Values

Self-Determination

Each person living with dementia has the right to self-determination, including the right to participate in and plan for their care and make life decisions. The diagnosis of dementia does not remove the obligation of others to engage them in decision making or to respect their personhood and their choices.

Value and Respect

The needs and experiences of each person experiencing and involved with dementia are unique and deserving of respect and value for the person's intrinsic worth as an individual. This includes persons living with dementia, their caregivers, their families, and their support systems.

Compassion

People living with dementia and their caregivers will receive concern, compassion, empathy, and understanding from all providers for the journey they travel, the choices they face, and the losses they will experience.

Integrity

All providers and contributors to care and services will exhibit trustworthiness, honesty, reliability, and loyalty in their interactions with persons with dementia, caregivers, and family members.

3.2.2. Principles***Person-Centred Care***

Dementia is a progressive, deteriorative, and terminal disease. People living with dementia and their caregivers will have different capacities in making the life and care choices that will be a part of the journey. Therefore, both care providers and services that are flexible and adaptive to the changing needs of individuals and their caregiver over time will be based on respect for the person, their needs, their values, and their choices.

Consultation with Caregivers

The majority of elderly people with dementia are cared for at home by their families and support system. Caregivers are an integral part of the support system for the person with dementia and therefore are integral members of the care team. All decisions affecting persons with dementia and their caregivers will be made in consultation with those caregivers.

Person-Centred System Design

The service delivery system will make service and care decisions that are received by the person with dementia and the caregiver to be designed for the purpose of supporting their journey and needs. This will include transparency in the development of policies that affect the receiver of care and services.

Provider Competency

All providers, planners, and policy decision makers whose decisions contribute to the care and services of people living with dementia will have the appropriate skills, knowledge, and competency to provide evidenced-based practice, care, and services.

3.3. Rationale for Improving Dementia Care

As has been noted, the purpose of creating the Dementia Service Framework is to present a high-level picture of optimal care that people should expect based upon evidence drawn from both the literature and the expert opinion of patients, families, professionals, and care providers. There are two main (and related) reasons why identification and implementation of optimal care are important:

- **The People Rationale** – the significant issues and challenges people with dementia and their caregivers experience with the current approach to dementia care in British Columbia
- **The Numbers Rationale** – the demographic imperative facing BC and the rising economic burden associated with increasing numbers of dementia cases

3.3.1. The People Rationale

On April 4, 2005, a conference entitled *Transforming Dementia Care in BC: Addressing Gaps and Improving Care* was held in Vancouver, BC. The conference brought together health care practitioners and decision makers from around the province and provided the first real opportunity for a collective dialogue on how to transform dementia care in BC.

The conference opened with presentations by people with dementia, family caregivers of people with dementia, and health care providers.

The similarity of the needs of each of these groups was striking. Each representative stated the need for:

- Health care workers to receive additional training specific to caring for people with dementia
- Improved continuity of care through permanent client assignment and increased staffing levels
- An interdisciplinary, person-centred approach to care that includes the person with dementia, family, and frontline staff as active members of the care team

In addition, participants at the conference identified the following system gaps in dementia care:

- Disparities in services available between rural and urban communities
- Lack of accessibility to the whole spectrum of care, from pre-diagnosis to post-diagnosis
- Lack of acute care dementia-friendly environments
- Planners who lack a “dementia policy lens”
- Lack of continuity of care

- Lack of collaboration among health care providers
- No provincial education framework
- Lack of inter-health authority connectedness
- Lack of appropriate care environments and facilities that specialize in dementia care
- Need for improved and increased resources for caregivers in the community

Conference participants recommended as a priority the development of a comprehensive province-wide system guideline (a service framework), including intersectoral and interdisciplinary recommendations to strengthen dementia care in BC. It was also strongly recommended that this guideline be embedded within a chronic disease management approach and articulate a clear philosophy of care. The goal is a transformed system to support all people affected by dementia.

3.3.2. The Numbers Rationale

Demographic trends indicate that British Columbia, along with the rest of Canada, is experiencing significant population aging. The chance of developing dementia increases significantly with age; therefore, population aging is correlated with increases in the number of people affected with dementia.

The Centre for Applied Research in Mental Health and Addiction (CARMHA) at Simon Fraser University has done modelling to project the number of dementia cases British Columbia may expect to see over the next 20 years (Table 1).⁴

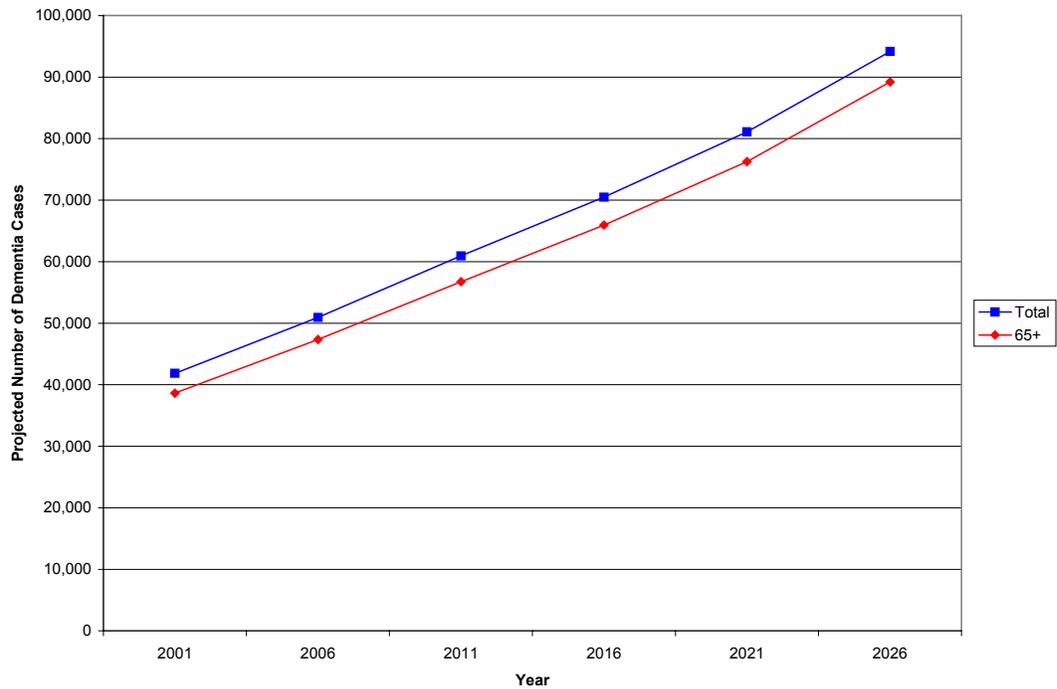
Table 1. Predicting the number of dementia cases

Year	Age								Total	>65
	<60	60-64	65-69	70-74	75-79	80-84	85-89	>90		
2001	2,020	1,204	2,135	3,859	6,332	8,446	9,378	8,487	41,861	38,637
2006	2,091	1,502	2,351	4,015	6,825	10,138	11,591	12,422	50,936	47,342
2011	2,154	2,036	2,960	4,466	7,204	11,066	13,895	17,152	60,933	56,743
2016	2,215	2,314	4,004	5,628	8,055	11,736	15,275	21,269	70,496	65,967
2021	2,255	2,580	4,546	7,598	10,161	13,219	16,330	24,396	81,085	76,250
2026	2,288	2,648	5,063	8,625	13,701	16,692	18,509	26,635	94,160	89,224

As shown in [Figure 1](#), the number of cases rises dramatically and is almost entirely due to the age 65+ group.

⁴ “Dementia Projections for British Columbia” (Centre for Applied Research in Mental Health and Addiction, Simon Fraser University, September 2006).

Figure 1. Projected increase in the number of dementia cases



The economic burden accompanying this rise in cases will be profound and can be characterized in terms of **direct costs**, **indirect costs**, and **non-financial costs**.

3.3.2.1. Direct Costs

The direct health care costs are staggering, as shown in CARMHA’s costing model (Table 2).⁵

Table 2. Total costs of care for dementia (individuals >65 only)

Year	Community care	Long-term care	Drugs	Diagnosis	Total
2001	87,000,000	1,021,000,000	4,000,000	3,000,000	1,116,000,000
2006	104,000,000	1,280,000,000	5,000,000	3,000,000	1,393,000,000
2011	123,000,000	1,560,000,000	6,000,000	4,000,000	1,694,000,000
2016	143,000,000	1,815,000,000	7,000,000	5,000,000	1,970,000,000
2021	167,000,000	2,077,000,000	8,000,000	6,000,000	2,257,000,000
2026	198,000,000	2,404,000,000	10,000,000	7,000,000	2,618,000,000

Costs are all in 2006 dollars.

⁵ “Dementia Projections for British Columbia” (Centre for Applied Research in Mental Health and Addiction, Simon Fraser University, September 2006).

Note that this is the cost attributed to treating dementia only. Most of these individuals will also require other medical care.

3.3.2.2. Indirect Costs

Indirect financial costs tend to be borne primarily by people with dementia and those who care for them. These include:⁶

- The value of all care provided or purchased by family and other caregivers
- The income forfeited by people with dementia and their families and caregivers, due to absenteeism and early retirement
- The costs of equipment and devices that are required to help cope with the illness
- Transfer costs such as welfare and disability payments

3.3.2.3. Non-Financial Costs

Non-financial costs are also very important – the pain, suffering, and premature death that result from dementia. Although more difficult to measure, these can be analyzed in terms of Disability Adjusted Life Years (DALYs), which is a combination of:

- The years of life lost (YLL) due to premature death – the mortality burden
- The years of healthy life lost due to disability (YLD) – the morbidity burden⁷

In Australia in 2002, the burden of disease attributable to dementia was estimated as 117,083 DALYs. Morbidity was the major source of the burden (85,651 YLDs were 73% of the total), while mortality accounted for 31,432 YLLs, or 27%. Females bore 62% of the overall burden of disease. The same proportion was borne by people aged over 75.

The extent of the economic burden described here reinforces the need for a system-wide approach to ensuring that individuals with dementia and their families receive optimal care, drawn from best practice. It also points to the need for upstream activity to help prevent dementia and also help those who are at risk for or diagnosed with the condition to remain healthy for as long as possible. The service framework is the ideal vehicle for reorienting the entire system in these directions.

⁶ As analyzed in *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia* (Canberra: Alzheimer's Australia, March 2003).

⁷ Ibid.

What Are Service Frameworks?

Making Decisions about Care – Your Story

“My sister is on the phone, calling from the reserve. I’ve never heard her sound so exhausted and depressed. She apparently had a fight today to get my mother to take her medication. Mom knocked the pills out of her hand, sending them flying all over the floor. And there was an earlier scene when my mother kicked at the door, shouting that she was being held prisoner. My sister had installed a special doorknob cover to stop Mom from going outside and wandering off again, because two days ago it took hours to find her in the pouring rain.

“I’m not sure how much longer I can do this,” said Sis. “I really want to do what’s best for Mom, but I’m going crazy trying to cope.”

*(Story taken from the Vancouver Coastal Health website.
See [Appendix A](#) for entire story.)*

4. What Are Service Frameworks?

The service framework approach, a new approach for health system planning, was conceived in the spring of 2005. In British Columbia, service frameworks represent a “person-centred approach to improving health outcomes across the conventional boundaries of the health system.” They present a high-level picture of optimal care that people should expect to see based upon evidence from the literature and upon best practices drawn from experts, including health professionals, care providers, and patients. Service frameworks do not attempt to prescribe how care would be provided, as this needs to be determined locally according to local priorities and capacity. Rather, service frameworks offer a menu of priority action-oriented recommendations that allow all stakeholders to define how they will contribute to improved services and better outcomes. In applying service frameworks to chronic diseases, there will be many recommendations that are common to more than one chronic disease.¹

4.1. Organization of Service Frameworks

Service frameworks are organized into a matrix. Levels of health status are listed along one axis, looking at care across the spectrum of health and illness. Levels of health care are on the other axis, looking at the responsibilities of the various partners in health. [Table 3](#) provides an overview of how the service framework is conceptualized. One interesting aspect of the service framework matrix has been how it has been embraced by a wide group of stakeholders who can see where they “fit” and how they might work with others to improve/maintain the health of individuals and populations.

¹ Preface to “Service Frameworks in British Columbia” (BC Ministry of Health, January 2007).

Table 3. Generic service framework

		LEVELS OF HEALTH STATUS			
		Staying Healthy	Getting Better	Living with Illness	End of Life
LEVELS OF HEALTH CARE	Individual	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>
	Care Provider	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>
	Support Systems	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>
	Health Care Environment	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>	<i>Goals and Recommendations</i>

Tables 4 and 5 provide working definitions for each of the levels of health care and levels of health status in a generic service framework. In a working service framework, these definitions are used to focus the recommendations for the best fit and the optimum impact.

Table 4. Levels of health care

Levels of health care

Individual is the level where care is experienced. It includes the patient's role in health care and managing disease, as well as the impact of illness on family.

Care providers refers to those individuals who actually provide care, including physicians, allied health professionals, and caregivers such as friends and volunteers. It also includes providers from the community at large and sectors other than health, such as social services and non-profit organizations.

Support systems are the health and community organizations that house and support health care providers, as well as the tools and resources required.

Health care environment refers to the broader context that influences and shapes organizational and care-provider action, such as government policy, laws, rules, payment schemes, accreditation, and professional training.

Table 5. Levels of health status

Levels of health status

Staying healthy involves achieving and maintaining optimal health and wellness.

Getting better refers to improving health through an exacerbation or acute event, or moving to a better plateau in a chronic condition.

Living with disease involves minimizing deterioration of health and successfully managing a long-term condition.

Coping with end of life involves relieving suffering and improving quality of life as well as maintaining health and wellness of family/caregivers.

4.2. Why Are We Using the Service Framework Approach?

Although there has been an established process for developing physician guidelines, including for chronic diseases management, through the Guidelines and Protocols Advisory Committee (GPAC), there is widespread expressed interest in looking at systems improvement in a broader framework. In addition, there was interest in looking at the systems from the “person” perspective. The service framework approach being used in the United Kingdom and Australia was seen as supporting these directions and was adapted for BC.

Three service frameworks are being developed in BC: for chronic obstructive pulmonary disease (COPD), arthritis and osteoporosis, and dementia. In spring 2005, the COPD Service Framework was commissioned through the Interior Health Authority, Central Okanagan. The final draft of the COPD Service Framework document was completed in August 2006, and is now being implemented. Today, work is well underway on the Arthritis and Osteoporosis Service Framework through The Arthritis Society of BC and Osteoporosis Canada, BC Division. Progress is also being made on the Dementia Service Framework through the Provincial Dementia Steering Committee in partnership with the Alzheimer Society of BC.

4.3. Relationship to Other Planning Frameworks

As noted previously, service frameworks represent a relatively new approach for health system planning for chronic diseases in BC. Alongside this approach, two important approaches/models have been at the forefront over the past few years in this arena and need to be reconciled with the service framework approach: population health planning and the Expanded Chronic Care Model.

4.3.1. Population Health Planning

Population health is an approach to health planning that aims to improve the health of an entire population.² One major step in achieving this aim is to reduce health inequities among population groups. Population health seeks to step beyond the focus of mainstream medicine and public health by addressing a broad range of factors that impact health on a population level, such as environment, social structure, resource distribution, etc. An important theme in population health is importance of the social determinants of health and the relatively minor impact that medicine and health care have on improving health overall.

The population health approach recognizes that health is a capacity or resource rather than a state, a definition that corresponds more to the notion of being able to pursue one's goals, to acquire skills and education, and to grow. This broader notion of health recognizes the range of social, economic, and physical environmental factors that contribute to health. The best articulation of this concept of health is “the capacity of people to adapt to, respond to, or control life's challenges and changes.”³

4.3.2. The Expanded Chronic Care Model

The Chronic Care Model is a planning framework for managing chronic health conditions (see [Appendix B](#)). In British Columbia, the model has been modified and renamed the Expanded Chronic Care Model in order to integrate population health promotion. The model involves two overlapping realms – the community and the health care system – each containing a number of elements. Strengthening and maximizing the efficiency of each of these elements creates environments where “informed activated patients” interact with “prepared, proactive practice teams.” This in turn results in improved population health outcomes and improved functional and clinical outcomes.

4.3.3. The Service Framework

The service framework builds on both of these approaches. Service frameworks incorporate the population health approach. They generate recommendations for actions at different levels of the system, and include recommendations that consider the broader determinants of health. It is intended that the recommendations will be implemented through the Expanded Chronic Care Model, which utilizes a change approach that includes:

- Partnership with services and agencies that address the broader determinants of health, such as social issues, living and working conditions, transportation, education, and socio-economic status

² For more information on population health, see <http://www.phac-aspc.gc.ca/ph-sp/phdd/approach/index.html>.

³ C.J. Frankish et al., *Health Impact Assessment as a Tool for Population Health Promotion and Public Policy* (Vancouver: Institute of Health Promotion Research, University of British Columbia, 1996).

- Service improvements through an emphasis on the Plan-Do-Study-Act quality improvement approach (PDSA)
- Collaborative working relationships between care providers
- Alignment of care with patient-centred goals and facilitation of decision making by patients and caregivers to meet those goals
- Recognition of the diversity of different communities/regions and their need to structure and deliver care in ways that reflect unique community circumstances and capacity

About the Dementia Service Framework

Remaining at Home – Your Story

“There are difficult, challenging days with my mother-in-law that leave us physically and emotionally drained. But there are also magical times, moments of joy and shared love, and those I wouldn’t miss for the world.

“I know that not everyone is able to make the decision that we made, nor would they want to. My wife and I certainly chewed over the options and grappled with our decision to care for my mother-in-law at home. Could we properly look after an elderly woman with advanced dementia?”

*(Story taken from the Vancouver Coastal Health website.
See [Appendix A](#) for the entire story.)*

5. About the Dementia Service Framework

5.1. Scope of the Dementia Service Framework

The Dementia Service Framework is comprehensive in its scope. The target populations include the general population of the province, caregivers and families of people living with dementia, people at risk for cognitive impairment and dementia, and people living with dementia at all stages of the journey, including end of life. The recommendations address the full continuum of brain health across the life span and are directed to all stakeholders.

5.2. The Development of the Dementia Service Framework

A cross-section of stakeholders was involved in the development of this service framework. Representatives from the Ministry of Health, all five health authorities in BC, the Alzheimer Society of BC, the Centre for Applied Research in Mental Health and Addiction, and Impact BC all participated as members of the Dementia Service Framework Working Group, providing overall guidance and input. The work began with the development of the Way Forward Document for Dementia.

A smaller subset of the Dementia Service Framework Working Group, the Core Working Group, was formed to take on many of the tasks associated with the service framework development. The Core Working Group also included the external consulting team assigned to the project. Additionally, initiative-specific teams were formed to aid in the translation of existing resources and work into the service framework. A consulting team provided the project management, facilitation, and writing support for the work.

5.2.1. Applying the Service Framework to Dementia

Due to the nature of dementia and its impact on both the person with dementia and that person's support network, the application of the service framework approach to dementia has required a number of adaptations and key decision points. These adaptations and key decisions are relevant to how the dementia service framework is interpreted and applied and may be different from other service frameworks. Key adaptations and decisions include:

- Interpreting the “Staying Healthy” level of health status to include the diagnosis of dementia
- The inclusion of recommendations that reflect the role of the caregiver as both receiver and provider of care
- Reordering the “Living with Dementia” and “Getting Better” levels of health status within the framework (see [Table 6](#))

- Relabelling “Getting Better” as “Getting Better from Periods of Episodic Decline” (see Table 6)
- Using work already done with in the province (rather than starting with an extensive review of the literature as sources of evidence-based practice)
- Using the Strength of Recommendation Taxonomy (SORT)¹ technique to evaluate the levels of evidence for the recommendations
- Developing goal statements specific for dementia within each of the levels of health status

Table 6. Levels of health status adapted to the dementia journey

Level of health status	Involves ...
Staying Healthy	Achieving and maintaining optimal health and wellness
Living with Disease	Minimizing deterioration of health and successfully managing a long-term condition
Getting Better from Periods of Episodic Decline	Improving health through a transition or acute event, or moving to a better plateau in a chronic condition; includes care received in the acute care setting
Coping with End of Life	Relieving suffering and improving quality of life as well as maintaining health and wellness of family/caregivers

5.2.2. Guiding Principles for Development of the Dementia Service Framework

The following principles² were developed as a guide for the development of the Dementia Service Framework:

- Partnerships and collaborative approaches will characterize the working relationships between stakeholders.
- The recommendations in the service framework will encourage appropriate responses to the health condition of the person with dementia.
- Existing work in British Columbia on dementia care is presumed to be based on evidence, and therefore will be used to populate the service framework.
- Support will be provided for action in care and service delivery that is both achievable and reasonable.

¹ M.H. Ebell et al., “Simplifying the Language of Evidence to Improve Patient Care: Strength of Recommendation Taxonomy: A Patient Centered Approach to Grading Evidence in the Medical Literature,” *Journal of Family Practice* 53 (February 2004): 2.

² Guiding principles are statements that capture values, beliefs, and ideas that guide both the development of and the decision-making processes of the service framework. Principles are not the same as goals; rather, they are absolute statements of what should be.

- Equity, transparency, improved health outcomes and the use of the best available evidence will be reflected in the recommendations.
- Information will be comprehensive and will be provided in clear and consistent messaging for individuals, care providers, organizations, and policy makers.
- Holistic, person-centred, person-directed, interdisciplinary, community-based care and services will be supported.
- Continuous improvement will be integrated into the work, resulting in a document that is living and changing with the evidence over time.
- The full spectrum of health determinants will be considered to achieve population-level improvements in health status and reduce health inequities.
- The Expanded Chronic Care Model is an integral component of the service framework development.
- Sustainability elements and key enablers (e.g., education) will be incorporated into the development of the service framework.

5.2.3. Key Initiatives Used to Complete the Service Framework

Eleven existing initiatives were identified as being the key building blocks for information to complete the service framework:

- **Northern Health Clinical Practice Guidelines, 2005**
NH has developed clinical practice guidelines (CPGs) related to dementia, depression, and delirium (October 2005). The guidelines address standards of care, nursing assessment, tools available, interventions, and evaluation. A comprehensive bibliography is also included.
- **Vancouver Island Health Authority Service Framework for Dementia Care, (in draft, October 2006)**
VIHA has developed a framework for dementia care that will be used as the basis for consultation within the health authority before an authority-wide dementia care plan is finalized.
- **Vancouver Coastal Health and Alzheimer Society of BC Client Journey Website, 2006**
VCH has developed a website – <http://www.vch.ca/dementia/> – designed to link individuals to helpful resources and information about dementia. The site is based on six stories drawn from actual experiences with the dementia journey. Each of the stories illustrates a different stage of dementia.

The stories are drawn from dozens of interviews and discussions with real people with dementia as well as their families, caregivers, and health providers. The reader is encouraged to move the computer cursor over the words, and the website prompts will direct them to relevant resources and information.

- **Interior Health Phased Dementia Pathways, 2006**
Interior Health's Phased Dementia Pathway Project (<http://www.interiorhealth.ca/Health+Services/Senior+Care/Dementia/>) was undertaken to identify and develop dementia "best practices" (evidence-informed practice) aimed at addressing the "clinical pinch-points" or special care needs and issues that arise for the person with dementia, caregivers, and clinicians. The Phased Dementia Pathway describes the unique physical, mental, emotional, and social needs of the person with dementia and caregivers across the spectrum of cognitive change from earliest diagnosis to the end of life. The pathway also guides the development of interdisciplinary clinical practice recommendations, and provides nurses, social workers, occupational and physiotherapists, mental health clinicians, and other health care professionals with the direction and knowledge needed to address these clinical issues at any point in the disease course.
- **Fraser Health Framework for Dementia Care, September 2006**
This comprehensive report was developed with input from a wide range of stakeholders. The report describes a standardized, person-centred approach to improving health outcomes for people living with dementia across the health authority.
- **Guidelines and Protocols Advisory Committee (a Joint Partnership of Medical Services Division of the Ministry of Health and the British Columbia Medical Association) – Recognition, Diagnosis and Management of Cognitive Impairment in the Elderly, DRAFT Guideline, October 2006**
This guideline summarizes current recommendations for recognition, diagnosis, and longitudinal management of cognitive impairment and dementia in the elderly. Where the guideline refers to "people affected by dementia," this indicates not only the person with dementia but also the people in their "network of support." The primary care objectives are to encourage early recognition and assessment of cognitive impairment and to support general practitioners in the development of a comprehensive care plan that includes the identification of community resources for the people affected by dementia.
- **Geriatric Mental Health Education Initiative (GMHEI) (in progress)**
The GMHEI is a provincial interdisciplinary group whose purpose is to promote, facilitate, and support dementia and other geriatric mental health education for stakeholders across British Columbia. Formed in 2004, its membership includes health care practitioners from each BC health authority, the Alzheimer Society of BC, and other allied professional groups. This group reviewed the service framework recommendations from the perspective of the evidence supporting best practice in dementia education.
- **Alzheimer Society Initiatives (in progress)**
The Alzheimer Society – <http://www.alzheimerbc.org/> – is the leading not-for-profit health organization working nationwide to improve the quality of life for Canadians affected by Alzheimer's disease and advance the search for the cause

and cure. The Alzheimer Society provides support, information, and education to people with Alzheimer's disease, families, physicians, and health care providers.

- **British Columbia Medical Association Building Bridges, May 2004**
The British Columbia Medical Association (BCMA) is a voluntary association of British Columbia's medical doctors. The BCMA offers recommendations about legislation and regulations affecting health care and the practice of medicine. The association is also an advocate for the health issues that concern the citizens of British Columbia. To this end, in 2004 they released a discussion paper calling upon the government to develop a collaborative plan to manage dementia care in BC (http://www.bcma.org/public/patient_advocacy/DementiaStrategyPaper.htm).
- **Report from "Transforming Dementia Care in BC," April 2005**
This conference brought together people diagnosed with dementia, family caregivers, and medical and non-medical service providers from across disciplines and sectors related to dementia care and support. The stated goal was to build momentum for transforming dementia care in BC.
- **CARMHA Review of Research in End of Life Dementia Care (conducted in Fall 2006)**
The Centre for Applied Research in Mental Health and Addiction is a research centre within the Faculty of Health Sciences at Simon Fraser University. Its mandate is to conduct research that can be applied to enhance the effectiveness, efficiency, and quality of mental health and addiction services in British Columbia. Research activities often address innovative approaches to the development, implementation, and dissemination and evaluation of health promotion activities, preventive strategies, and treatment services, particularly those that can be applied at a system-wide, population level. (For example, see <http://www.carmha.ca/publications/index.cfm?fuseaction=publications.showOnePublication&contentID=4>.)

Each of the key initiatives was translated into the service framework over the course of the project. For more on the process, see [Appendix C](#).

5.2.4. Performance Indicators

Performance indicators are described as a component of service frameworks in "A Guide to the Development of Service Frameworks in British Columbia" (Draft for Discussion, April 3, 2006):

Where possible, indicators to assess the quality of care should be included in the service framework. Performance indicators identify the most appropriate criteria to measure care improvement ... It should be emphasized that indicators must be actionable: that is, they must have immediate meaning at the level of the individual and health provider.

Indicators will become more specific with the implementation of the Dementia Service Framework recommendations and as implementation takes place at the local service delivery level. Both quantitative and qualitative indicators will have value in

assessing the outcomes of care resulting from service and system improvements. Potential quantitative indicators for use with the Dementia Service Framework have been identified for the individual and care provider levels of care. These can be found in [Appendix D](#).

5.3. Using Levels of Evidence and Strength of Recommendations

Assessing the evidence supporting a recommendation is a key strength of the service framework approach to planning. The DSF Working Group identified early in the process that the research evidence with regard to dementia care is currently a developing body of knowledge, and that the majority of the evidence is derived from expert opinion.

The DSF Working Group agreed to the use of the Strength of Recommendation Taxonomy (SORT) to assess the level of evidence of the source documents in the Dementia Service Framework for two reasons:

- It was the tool applied to the Interior Health Phased Dementia Pathway work and therefore provided for consistency in approach.
- It is the tool that emphasizes client outcomes that matter to clients, including helping them live longer or better lives; reducing morbidity, mortality, or symptoms; and providing improved quality of life and lower cost of health care services. (For more evidence on the SORT, see http://www.jfponline.com/pdf%2F5302%2F5302JFP_AppliedEvidence1.pdf.)

Within the SORT, levels of evidence are ranked “1,” “2,” and “3” based on the validity (quality) of each of the individual quantitative studies used to develop a recommendation, where:

- 1 = Good-quality client-oriented evidence
- 2 = Limited-quality client-oriented evidence
- 3 = Other evidence (this includes expert evidence)

Within the DSF, the majority of the evidence underlying the recommendations has been assessed as “3.”

Once the levels of evidence have been assessed, the strength of recommendations are determined based on grading the quantity and consistency of the entire body of evidence used to develop a recommendation. The ranking for the strength of recommendation is:

- A = Consistent and good-quality client-oriented evidence
- B = Inconsistent or limited-quality client-oriented evidence
- C = Evidence lacking, more research needed; based on expert consensus/usual practice

The majority of the recommendations within the DSF have been assigned a “C” ranking. It is important to note that a finding of inconsistent or limited-quality client-oriented evidence (B or C) does not indicate evidence of ineffectiveness, but rather reflects the fact that this is an area of developing research and that there is currently not enough information to make an A-level recommendation. An outcome of developing the Dementia Service Framework is the strong support in the recommendations for developing a research agenda that would strengthen the evidence for practice.

5.4. Education for All

Education is an important component of the Dementia Service Framework. Sustainable and evidence-informed education is vital given the characteristics of the population being served. The very nature of dementia as a chronic disease leaves the person with dementia vulnerable. There is an extra weight on professionals to be goal-directed and person-centred when assisting individuals living with dementia to understand and choose between options. In addition, individuals living with dementia are often less likely to evaluate the information and options presented by professionals, leaving a greater onus on professionals to ensure that they are up to date in the information and interventions they are providing to such individuals. A further issue is that dementia crosses the majority of other chronic diseases as a symptom or co-morbidity, so there are few or no health professionals and physicians who do not require some level of expertise in dealing with dementia.

Due to these factors, in order to integrate the Dementia Service Framework into general practice by health professionals, physicians, and people with dementia/families, administrators, and policy makers, education must be a core component of the framework, and integrated throughout. If education is treated as a “one-time” activity, use of the framework will not be sustainable, and will be unlikely to have uptake in all sectors.

The **principles** for integrating education as a core component of the framework include:

- Education will be viewed as interdisciplinary, including the family and/or the person with dementia. Therefore, educational curriculum/content should be developed to suit an interdisciplinary audience, and be adaptable to one-on-one delivery, specific professions, group delivery, etc.
- Education will be competency-based and include common, complementary, and collaborative competencies.³
- The core education must allow for cultural sensitivity, and be adaptable to specific cultures.

³ H. Barr, *Interprofessional Education Today, Yesterday, and Tomorrow. A Review Commissioned by the Learning and Teaching Support Network for Health Sciences and Practice* (London: UK Centre for the Advancement of Interprofessional Education, 2003), 18-19.

- Education must follow adult learning principles (e.g., multiple modalities, practice-based, case-based, just in time).
- A sustainability plan to ensure that the educational curriculum and content is continuously updated with evidence-informed materials must be built into the implementation plan for the Dementia Service Framework.
- Content must be consistent across sectors, professions, etc., but the language and delivery method will vary according to the audience (e.g., keeping jargon to a minimum for people with dementia and their families).
- The balance of the weight in deciding on content for educational programs must fall on what increases the quality of life and maintains function for the person with dementia and caregivers.
- Evaluation of education as a core component of the Dementia Service Framework must be included in the evaluation plan for the framework.

Because competency in dealing with dementia is required of most health professionals and physicians, the Dementia Service Framework, with education as a core component, must be widely accessible and flexible, depending upon the needs of the individual using it. Curriculum will need to be kept current as well as evidence-informed.

Dementia Service Framework

Moving to Residential Care – Your Story

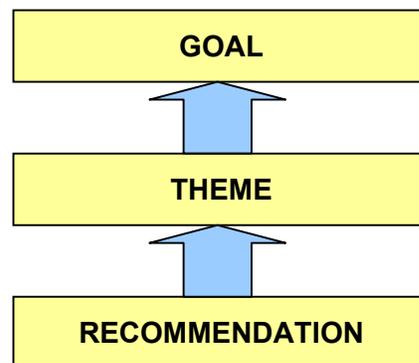
“Brenda: Tuesdays are my day to drive down to visit my parents here at the residential care home. I usually stay all day and spend the night with my son and his family in town before heading back up the coast.

“I wish I lived closer and it wasn’t such a major effort to get here, but the staff at the care facility include me as part of the extended ‘team’ in my parents’ care. They try to schedule any case meetings for Tuesdays, and we’re also in touch by phone a lot. They know that I want to take an active role in the decisions that affect my parents’ care. I think it’s important that I stay on top of things.”

*(Story taken from the Vancouver Coastal Health website.
See [Appendix A](#) for the entire story.)*

6. Dementia Service Framework

This section provides the full text of the Dementia Service Framework recommendations. To help the reader navigate through the recommendations, the section “5.2.1, [Applying the Service Framework to Dementia](#),” is a primer on the underlying assumptions that helped to form the recommendations. Generally the logic flow within the recommendation matrix is from the recommendations that are specific to a level of care and level of health status, to the themes, and then to the goals.



There are over 100 recommendations in the Dementia Service Framework. Some readers may want to peruse all the recommendations, while others may prefer to take one of the four navigational approaches described in the sections that follow:

- **Working from Priority Recommendations** – Some readers may prefer to begin by reading the priority recommendations as identified by the Dementia Service Framework Working Group.
- **Working from the Goals and Themes** – Some readers may prefer to initially see the conceptual links between the goals and themes within each level of health status and level of care before examining the individual recommendations within each theme that will help achieve the goals.
- **Working from Gaps and Related Recommendations** – Some readers may want to start by learning about the gaps that currently exist in the system – and then reviewing the recommendations that address those gaps.
- **Working from the Recommendations** – Some readers may prefer to start with the full set of recommendations.

Helpful hints

The Dementia Service Framework is a tool and a resource for people who have a role to play in improving dementia care in BC. Each person who reviews the DSF will recognize a number of recommendations that are relevant to their role and their ability to effect change within the health care system. The language and terminology used throughout the recommendations are intended to be inclusive of all possible roles and to spark action for improvement. As the reader examines the recommendations, the following points may assist in interpretation and understanding:

- Consider names or labels for groups that have been assigned an action in the broadest of terms. For example, “agencies and organizations” refers to any group that has a role to play in improving the support system within which care providers interact with each other and with persons with dementia and their families; and “government” refers to any or all levels of government that create policy, legislation, and regulation that impact the life and care of people living with dementia.
 - Stakeholders at each level of care (individual, care providers, support systems, and health care environment) can look to the recommendations to inform their own actions and priority-setting processes to impact change locally while other recommendations are being considered provincially.
 - The location of a recommendation within the levels of health status is intended to reflect best fit for directing and supporting change. A conscious decision has been made not to overly replicate recommendations within the service framework in order to reduce duplication. This does not mean, however, that a recommendation could not be adapted to achieve the goals of another level of health status and level of care.
 - Generally, attempts have been made to ensure that recommendations at each level of care reinforce the recommendations at the other levels of care; for example, that policy is recommended that supports the recommendations targeted to the individual and care provider levels.
-

6.1. Priority Recommendations

While the service framework is intended to be implemented in its entirety, it is important to provide some direction as to where to begin. The DSF Working Group completed a priority-setting process, reviewing each of the recommendations against the following criteria:

- Does the recommendation address one or more of the seven identified gaps?
- To what extent is the system ready to act upon the recommendation?
- How many of the original dementia initiatives supported this recommendation?
- What is the potential impact of this recommendation on individuals?
- Is this recommendation a key precursor for others?

Although there was an intent to develop a short list of priority recommendations, in the end it was recognized that different perspectives will result in different sets of priorities. Almost all of the recommendations were seen as being important because

when taken together they provide a whole-system approach to improvement, and there are different levels of readiness within and across the system to act. The 54 priority recommendations that resulted from the DSFWG priority-setting process are presented in [Table 7](#).

Table 7. Priority recommendations

Number	Recommendation	Theme
Priority Recommendations for Individuals		
SH-I-1	All BC residents, including those diagnosed with dementia, will seek information and programs that will raise their awareness with regard to brain health and adopt behaviours to help them reduce their risk for dementia and all other chronic diseases.	<i>Promoting brain health across the life course</i>
SH-I-3	All individuals will recognize the importance of following up on subtle cognitive changes with their primary care provider.	<i>Early detection and diagnosis of dementia</i>
SH-I-5	People with dementia and their caregivers will understand the importance and value of seeking and receiving an early diagnosis, and the benefits of disclosing the diagnosis to others. They will understand their responsibility to advocate for a correct diagnosis (e.g., if the diagnosis of dementia does not seem correct) and their responsibility for learning how to communicate the diagnosis.	<i>Early detection and diagnosis of dementia</i>
SH-I-6	People at risk for and diagnosed with dementia and their caregivers will connect with the Alzheimer Society First Link program where it exists, or call the Alzheimer Society for information, support, and education.	<i>Activated partners in care</i>
SH-I-7	People diagnosed with dementia and their caregivers will: <ul style="list-style-type: none"> • Seek information about dementia and dementia care (Internet resources, books, videos, pamphlets, research articles, conference materials, etc.) • Learn about and adapt strategies that support the person with dementia to live as normally and independently as possible • Seek information about care decisions that will be required as the dementia progresses, including medications, non-pharmacological interventions, end-of-life decision making, and support resources • Seek information and assistance with enduring powers of attorney, representation agreements, and wills to enable future life and care planning 	<i>Activated partners in care</i>
LW-I-2	People with dementia and their caregivers will request information and support on programs developed specifically to meet their needs in mild, moderate, severe, and end-of-life stages of dementia.	<i>Activated partners in care</i>
LW-I-3	People with increased risk for dementia (e.g., mild cognitive impairment), people diagnosed with dementia, and their caregivers will build their skills for self-advocacy and problem solving and become confident and activated persons who are involved in their own care, maintaining as much control as possible in their own lives, including through the transitions that are a part of the disease.	<i>Activated partners in care</i>

Number	Recommendation	Theme
LW-I-4	People with dementia and their caregivers will learn about and adapt strategies that support the person with dementia to live as normally and independently as possible.	<i>Activated partners in care</i>
GB-I-1	Families and caregivers for people with dementia will notice changes in cognition, behaviour, mood, or function and report these to their physician or specialist team (e.g., mental health) for further investigation and follow-up as required. They will expect their memory complaints to be taken seriously, assessed and reported to their physician, or referred to a specialist team (e.g., mental health).	<i>Activated partners in care</i>
GB-I-2	The families and caregivers of people with dementia will ensure that the correct information and support are in place in order to act as substitute decision-makers for health care decisions.	<i>Activated partners in care</i>
EOL-I-1	Families and caregivers will advocate for the appropriate care and treatment for the person with dementia. This will include decisions about where the person with dementia will receive the best care at the end of life and that the location is aligned with the person's expressed values and beliefs. This is particularly important when the person with dementia can no longer communicate verbally.	<i>Activated partners in care</i>
EOL-I-4	Families and caregivers of people with dementia will ensure that a person's values, beliefs, concerns, and wishes have been discussed (and are in writing) and are being used to guide decision making when the individual is no longer able to speak for himself or herself.	<i>Applying advance life and care decisions</i>
EOL-I-5	Families and caregivers will seek information about all the risks and benefits of any medical intervention being considered for the person with dementia at the end of life.	<i>Applying advance life and care decisions</i>
Priority Recommendations for Care Providers		
SH-CP-3	Physicians will assess individuals with suspected dementia, differentiate between conditions, and make an accurate diagnosis. They will also work collaboratively with specialists and other health providers as needed to provide individuals with an accurate diagnosis as soon as possible.	<i>Early diagnosis based on thorough assessment</i>
LW-CP-1	All health care providers will avail themselves of up-to-date training, education, and information specific to caring for people with dementia. Ongoing mentoring and clinical support should support them where applicable. Care providers will be knowledgeable about behaviours in later stages of dementia and be skilled in coping with these behaviours in a manner that respects and preserves the dignity of the person with dementia.	<i>Education</i>
LW-CP-2	Health care providers will offer consistent education and information to people with dementia and their caregivers – in order to strengthen awareness and to increase transition support. Information will be geared towards helping people understand the course of dementia and will include information on accessing health system and agency services.	<i>Education</i>
LW-CP-3	While building on general skills and competencies for supporting this population, community health workers will be trained to understand the particular challenges of working with this population.	<i>Education</i>

Number	Recommendation	Theme
LW-CP-5	Health care providers will support people with dementia and their caregivers based on the best-known practices. These supports will help people with dementia and their caregivers plan for the future and attain the best treatments and supports available.	<i>Comprehensive and continuous care</i>
LW-CP-6	Health care providers in all sectors will provide support to the caregivers of people with dementia.	<i>Comprehensive and continuous care</i>
LW-CP-14	Care providers will use creative strategies to determine the reason for, or meaning of, agitated, “dementia-related” behaviours.	<i>Behaviour management</i>
GB-CP-1	Health care providers (all professions) in all settings will access current information and education that support them in providing optimal care during periodic episodes of decline and during transitions. They will be knowledgeable about the common conditions that cause episodic decline and about Dementia Care Pathways related to episodic decline.	<i>Education</i>
GB-CP-2	Health care providers will recognize the importance of communication with families and caregivers when a person with dementia is transferred from one care transition to another.	<i>Support for the caregiver</i>
GB-CP-6	Health care providers will support individuals with dementia in periods of decline or transition with appropriate care plans.	<i>Easing transitions</i>
EOL-CP-2	Health care providers in palliative care programs will quickly assess for and treat all symptoms associated with end of life, including pain, nausea, and fatigue.	<i>Providing appropriate care and interventions</i>
EOL-CP-3	Health care providers will recognize, respect, and provide adequate support to families and caregivers and include them as active partners of the team.	<i>Families and caregivers as partners</i>
<i>Priority Recommendations for Support Systems</i>		
SH-SS-1	Agencies and organizations that provide services to people with dementia will provide British Columbians with public information and education about: <ul style="list-style-type: none"> • Its never being too late to make lifestyle changes that reduce known dementia risk • Promoting healthy brains and healthy aging, even when memory loss is evident • Preventing cognitive impairment (“Heart Smart = Brain Smart”) 	<i>Providing information on brain health across the life course</i>
SH-SS-2	Agencies and organizations that provide services to people with dementia will invest in health promotion and chronic disease prevention work, including dementia prevention.	<i>Building capacity for primary prevention and risk reduction</i>

Number	Recommendation	Theme
SH-SS-3	<p>Agencies and organizations in which physicians, nurses, and other health professionals work (including those that work in clinics and emergency rooms) will:</p> <ul style="list-style-type: none"> • Provide interdisciplinary education to address key areas of knowledge on promoting brain health and the early detection of dementia • Provide the infrastructure and support to translate this knowledge into practice • Implement systems to monitor the knowledge transfer into practice 	<i>Building capacity for early identification and diagnosis</i>
SH-SS-4	<p>People with dementia and their caregivers can expect that agencies and organizations provide physicians who work with dementia patients adequate assistance (e.g., clinical guidelines, education) to reach a diagnosis and to find an appropriate manner and methodology to disclose the diagnosis to the patient and/or caregiver.</p>	<i>Building capacity for early identification and diagnosis</i>
SH-SS-5	<p>Agencies and organizations will ensure that people with mild cognitive impairment or dementia, and their families and caregivers throughout British Columbia, find programs that support them, and they will facilitate this by improving the exchange of information between care providers and between care providers and families.</p>	<i>Supporting communication, coordination, collaboration</i>
SH-SS-6	<p>Agencies and organizations, including the Alzheimer Society of BC, researchers, policy makers, and regional health authorities, will work collaboratively through formalized partnerships.</p>	<i>Supporting communication, coordination, collaboration</i>
SH-SS-7	<p>Agencies and organizations will develop human resource plans, policies, and procedures that address the recruitment and retention of clinicians with the knowledge, skills, and abilities to prevent, diagnose, treat, and support people with dementia and their families, and that reflect service models that support effective uses of human resources available.</p>	<i>Building human resource capacity</i>
LW-SS-1	<p>Agencies and organizations will ensure access to education on dementia and dementia care throughout the province for the following groups of people:</p> <ul style="list-style-type: none"> • The general public • Individuals living with dementia • Family caregivers of people with dementia • Care providers of people with dementia, including those working in acute care settings, assisted-living environments, long-term care settings, adult day programs, and the community 	<i>Supporting access to dementia education</i>
LW-SS-3	<p>Agencies and organizations will provide an array of flexible support services to support caregivers and enable people with dementia to stay at home as long as possible, such as access to enhanced resources/services during periods of crisis and transition.</p>	<i>Providing comprehensive and coordinated care</i>
LW-SS-8	<p>Organizations and agencies (including government and health authorities) will develop incentives to improve the linkages between family physicians/primary care providers, specialized geriatric providers, care managers, and other care providers and coordinators.</p>	<i>Providing comprehensive and coordinated care</i>

Number	Recommendation	Theme
LW-SS-9	All residential care facilities will be designed (taking into account the whole building) as a dementia care friendly environment, making due allowance for appropriate subenvironments for individuals with other complex care needs who are cognitively intact.	<i>Creating dementia-appropriate residential care</i>
LW-SS-11	Health organizations and agencies will establish ongoing linkages and partnerships with other community-based agencies and organizations (e.g., the Alzheimer Society and its volunteers, municipalities, parks and recreation associations, seniors' associations) to create an ongoing and collaborative understanding of community needs with regard to dementia and to model and mentor in providing dementia-friendly services.	<i>Building community capacity through partnership and planning</i>
LW-SS-13	Organizations and agencies (including the Ministry of Health and health authorities) will work with the physician system to improve the data collection and sharing of aggregate data on dementia. This would include the development of a minimum data set for dementia patients.	<i>Building community capacity through partnership and planning</i>
GB-SS-1	Agencies and organizations will support their staff in all settings to provide interdisciplinary, comprehensive dementia care through access to comprehensive information, training and education on prevention, early recognition and management of episodes of decline, and the impact of the dementia and episodic decline on persons with dementia and their caregivers.	<i>Supporting access to education</i>
GB-SS-3	Agencies and organizations responsible for the provision of acute care services will ensure that the acute care environment (i.e., culture, setting, processes, and practice) is sensitive and appropriate for people with dementia and their caregivers. Individuals with dementia and their caregivers expect that acute care environments will be adapted and accommodated to the needs of the person with dementia.	<i>Dementia-sensitive acute care</i>
GB-SS-6	Organizations and agencies will provide continuous services and support for clients and caregivers during periods of episodic decline (e.g., home care support and respite care). They should ensure that organizational structures, policies and procedures, and guidelines for best practice dementia and geriatric care are in place to support comprehensive integrated care. They should ensure that service delivery approaches, including staffing levels and time allotted, meet the diverse and extensive client needs during periods of transition.	<i>System planning</i>
EOL-SS-1	Agencies and organizations will initiate system changes to ensure that the end-of-life care and support needs of individuals with dementia and their families and caregivers are met.	<i>Respecting and valuing families and caregivers</i>
EOL-SS-2	Agencies and organizations will provide all their staff with current information and education regarding end-of-life care for dementia.	<i>Supporting professional development and education</i>
EOL-SS-4	Agencies and organizations will support care providers in addressing ethical issues, and when ethical conflicts arise, provide access to ethics experts for consultation.	<i>Progressive practice framework</i>
EOL-SS-5	Agencies and organizations will have programs developed specifically to meet the end-of-life needs of people with dementia.	<i>Planning and organizing services</i>

Number	Recommendation	Theme
<i>Priority Recommendations for the Health Care Environment</i>		
SH-HCE-5	Policy makers will develop a dementia research agenda that addresses gaps in dementia research, including prevention and risk reduction of dementia, practices that support the caregiver, and end-of-life palliative care for dementia.	<i>Supporting a dementia research agenda</i>
SH-HCE-8	Government and policy makers will ensure that legislation and policy provide the legal tools for families to plan for future health, personal, and financial care in advance, with a well-understood, accessible, and person-centred default process for those who are unable to plan in advance.	<i>Creating dementia-sensitive policy</i>
LW-HCE-1	Public and private sector policy makers will collaborate to ensure that the entire community is an assistive environment, accepting and supportive of its members living with dementia, and enabling them to function as well as possible in the community. This will include educating the general public on dementia to decrease fear and ageist values and attitudes.	<i>Reducing the stigma associated with dementia</i>
LW-HCE-2	Institutions with a role in the education and continuing education of health care providers will <i>ensure</i> a coordinated and improved geriatric content in schools of medicine, nursing, rehabilitation, pharmacy, social work, home support, and other relevant training curriculum.	<i>Improving knowledge about dementia</i>
LW-HCE-3	Policy makers will ensure that policy on financial assistance to compensate or offset expenses incurred by people living with dementia, their caregivers, and families of people with dementia is evaluated and adjusted accordingly.	<i>Creating dementia-sensitive policy</i>
LW-HCE-4	Government will ensure that provincial policy supports access to a range of affordable and accessible community-based services to support the needs of people with dementia and their caregivers through all stages and transitions of dementia.	<i>Creating dementia-sensitive policy</i>
LW-HCE-8	Government will support the development of innovative models of service delivery for people living with dementia. Policy makers will ensure that there is ongoing provincial-level evaluation of dementia care programs and services and that policy and plans are adjusted accordingly.	<i>Planning for improvements in dementia care</i>
EOL-HCE-5	Government will ensure that employment policies support the involvement of family at the end of life, such that family members are able to take compassionate leave from work.	<i>Creating dementia-sensitive policy</i>
EOL-HCE-6	Government will ensure that appropriate policy and education is developed to: (1) identify best practice in end-of-life decision making, and (2) support the health care provider and the family in making decisions that respect the advance care plans of persons with dementia.	<i>Creating dementia-sensitive policy</i>

6.2. Goals and Themes

To ensure alignment of the recommendations within the DSF, goal statements have been articulated for each of the levels of health status. A summary overview of the goals and the themes that support these goals is provided in the following sections.

Staying Healthy Goals

- To promote an awareness of the importance of brain health across the life course for all, reducing the likelihood of disease and/or delaying its progression
- To ensure that there is early recognition of a change in an individual that leads to early detection

Table 8. Staying healthy themes

Level of care	Themes
Individual	<ul style="list-style-type: none"> • Promoting brain health across the life course • Early identification of risk for dementia • Early detection and diagnosis of dementia • Activated partners in care • Future life and care planning
Care Provider	<ul style="list-style-type: none"> • Support for self-management • Early recognition and screening • Early diagnosis based on thorough assessment • Supporting individuals and their caregivers post-diagnosis • Personal professional development (continuing education)
Support Systems	<ul style="list-style-type: none"> • Providing information on brain health across the life course • Building capacity for primary prevention and risk reduction • Building capacity for early identification and diagnosis • Supporting communication, coordination, collaboration • Building human resource capacity
Health Care Environment	<ul style="list-style-type: none"> • Addressing the broader determinants of health across the life course • Reducing the stigma associated with dementia • Supporting a dementia research agenda • Improving knowledge about dementia • Creating dementia-sensitive policy

Living with Dementia Goals

- To promote and support the quality of life for people living with dementia
- To promote and support the quality of life for caregivers of people living with dementia

Table 9. Living with dementia themes

Level of care	Themes
Individual	<ul style="list-style-type: none"> • Future life and care planning • Activated partners in care • Self-advocacy to further knowledge of the lived dementia experience
Care Provider	<ul style="list-style-type: none"> • Education • Respect and dignity • Comprehensive and continuous care • Behaviour management • Research
Support Systems	<ul style="list-style-type: none"> • Supporting access to dementia education • Sustaining human resource capacity • Providing comprehensive and coordinated care • Creating dementia-appropriate residential care • Building community capacity through partnership and planning • Accessible services
Health Care Environment	<ul style="list-style-type: none"> • Reducing the stigma associated with dementia • Improving knowledge about dementia • Creating dementia-sensitive policy • Planning for improvements in dementia care • Supporting a dementia research agenda

Getting Better from Periods of Episodic Decline Goals

- To promote optimal health for people living with dementia as they experience periods of decline in health
- To promote optimal support for caregivers of those living with dementia during times when those they care for experience episodic decline in health
- To ensure that intervention, active planning, and supportive action are there for the person with dementia and caregiver for successful transitions in care

Table 10. Getting better from periods of episodic decline themes

Level of care	Themes
Individual	<ul style="list-style-type: none"> • Activated partners in care • Advance life and care planning
Care Provider	<ul style="list-style-type: none"> • Education to increase the ability to support transitions through episodic decline • Support for the caregiver • Acute events and behaviour management • Easing transitions
Support Systems	<ul style="list-style-type: none"> • Supporting access to education • Respect and support for the caregiver (during periods of episodic decline) • Dementia-sensitive acute care • Providing comprehensive and coordinated care • System planning
Health Care Environment	<ul style="list-style-type: none"> • Planning for improvements in dementia care • Improving knowledge about dementia

Coping with End of Life Goals

- To ensure that people with dementia move to the end of their life with dignity
- To ensure that caregivers of people with dementia are supported through and after the end-of-life stage of the dementia journey

Table 11. End-of-life themes

Level of care	Themes
Individual	<ul style="list-style-type: none"> • Activated partners in care • Applying planned life and care decisions • Self-advocacy
Care Provider	<ul style="list-style-type: none"> • Providing appropriate care and interventions • Families and caregivers as partners • Personal professional development
Support Systems	<ul style="list-style-type: none"> • Respecting and valuing families and caregivers • Supporting professional development and education • Progressive practice framework • Planning and organizing services • Appropriate built environment
Health Care Environment	<ul style="list-style-type: none"> • Planning for improvements in dementia care • Creating dementia-sensitive policy • Improving knowledge about dementia end-of-life care • Supporting a dementia research agenda

6.3. Gaps and Related Recommendations

An analysis of current gaps in the system of dementia care in BC has been completed. Seven critical gaps have been identified:

1. There is a gap in the system's capacity and ability to address the clinical and support needs of people with dementia and their families/caregivers.
2. There is a gap in the number of health care providers with expertise in elder and dementia care for people with dementia and their families/caregivers.
3. There is a gap in the knowledge of health care providers about dementia as a chronic condition and about best practices in dementia care.
4. There is a gap in policy that mitigates the impact of dementia on the people with dementia and their families/caregivers, and on the communities they live in.
5. There is a gap in the recognition of the role of families and caregivers as partners on the care team.
6. There is a gap in the capacity and ability of the acute care setting to meet the needs of people with dementia.
7. There is a gap in the formal integration, collaboration, and communication across care settings, between health care providers, and across health authorities.

The cumulative impact of these shortfalls on people with dementia, on their families and caregivers, and on the system itself is profound.

For the person with dementia ...

- Depression and functional changes go unrecognized and unmanaged.
- There is heavy reliance on family members and other caregivers as the “formal” system is ill equipped to cope.
- Future care and life planning is not addressed while the individual still has the cognitive abilities to do so.
- There is reduced quality of life as the disease progresses.

For families and caregivers ...

- Stress and worry about what might be wrong with their loved one, and then stress and worry when what is wrong is confirmed as dementia.
- There is deterioration in their mental and physical health, for example, depression.
- There are cross-generational effects as people struggle to balance the needs of their parents with the needs of their children.
- There are decreases in on-the-job productivity due to absenteeism and lack of focus.

For the health care system ...

- There is a lack of focus on proactive management of care.
- Emergency and hospital responses are suboptimal.
- There is inappropriate use of pharmacological interventions.
- There are delays in recognition, diagnosis, and treatment, meaning that individuals enter the system at more of a crisis point.

For the community ...

- People with dementia and their families/caregivers withdraw from important community roles.
- There is dependence on residential care rather than expansion of other housing options.
- Strain is placed on community agencies and volunteers trying to respond to the needs of people with dementia and their families/caregivers.
- There is a lack of dementia-sensitive policies, programming, and infrastructure.

The rest of this section provides a more detailed overview of each of the seven gaps. Key recommendations within the service framework that would address these gaps are identified.

Gap 1	Source
<p>There is a gap in the system’s capacity and ability to address the clinical and support needs of people with dementia and their families/caregivers.</p>	<p>BCMA FH VIHA TDC</p>

Recommendations addressing this gap

SH-SS-3, SH-SS-4, LW-SS-2, LW-SS-3, LW-SS-9, LW-SS-10, LW-SS-12, LW-SS-14, LW-HCE-4, LW-HCE-6, LW-HCE-8, GB-CP-6, GB-CP-8, GB-SS-1, GB-SS-5, GB-HCE-1, EOL-SS-1, EOL-SS-3, EOL-SS-5, EOL-SS-6, EOL-HCE-1

Description of the gap

The current system is challenged by a lack of understanding of the clinical needs of people with dementia and their families/caregivers. This most often includes the need for:

- Emotional support
- Education
- Information

- Physical care
- Future life and care planning
- Participation as activated partners in care

Across the system, there is a gap in the functions and processes related to dementia care:

- Promoting brain health across the life course
- Early identification of risk for dementia
- Early detection and accurate diagnosis
- A preventive, early-intervention focus to coordinated care management¹ (over time and across all care settings)
- Easing transitions
- Use of interdisciplinary teams with expertise in dementia care

There is also a lack of service delivery capacity and few appropriate care settings to support people with dementia and their families/caregivers:

- Home support capacity and delivery models
- Access to dementia-appropriate residential care
- Access to dementia-appropriate end of life care
- Access to respite care, home care, daycare programs, specialists, drugs, and family support and education
- Access to living options (i.e., those that fall between living at home and residential care)
- Adequate staffing in residential care settings to meet the needs
- Community-based services (e.g., counselling, support)
- Rehabilitation services to help the person with dementia regain or maintain function
- Dementia-appropriate acute care physical environments
- Appropriate community options for caring for the acute needs of people with dementia outside of the acute care and emergency environments
- Dementia-appropriate emergency care

¹ Shannon Berg, “Section 1.1: What Is Client-Directed Care Management?” In *HEAL 310: Client-Directed Care Management*, 2nd ed. (Kamloops, BC: Thompson Rivers University, 2005), 1-3. Definition adapted from Joel Kanter, “Care Management with Long-Term Patients: A Comprehensive Approach,” in *Handbook of Treatment for the Seriously Mentally Ill*, ed. S.M. Soreff (Seattle: Hogrefe and Huber, 1996).

As a result of these gaps, inadequate, inappropriate, and poor care and support are received by people living with dementia and their caregivers, creating a cycle of poor health outcomes, crisis intervention, and high utilization of inappropriate services.

Gap 2	Source
There is a gap in the number of health care providers with expertise in elder and dementia care for people with dementia and their families/caregivers.	BCMA DSFWG

Recommendations addressing this gap

[SH-SS-7](#), [LW-SS-2](#), [LW-HCE-7](#), [GB-HCE-2](#), [EOL-SS-2](#)

Description of the gap

There is a shortage, both current and projected for the future, of health human resources with expertise in elder and dementia care. This current and future lack of manpower is stressing all sectors of the health care system. Elder care has historically had difficulty attracting health providers, often because of a lack of emphasis on this population within the education programs, a stigma attached to working with the elderly, and a lack of attractive remuneration. This lack of manpower is seen in almost all disciplines, including nursing, medicine (geriatricians, family practitioners with a focus on geriatrics), and community health workers. As the manpower challenges become more acute, geriatric care will be faced with increased vacancies through retirements and a lack of replacement manpower at a time when the population is aging, creating an even greater capacity deficit.

Gap 3	Source
There is a gap in the knowledge of health care providers about dementia as a chronic condition and about best practices in dementia care.	BCMA VIHA DSFWG TDC

Recommendations addressing this gap

[SH-CP-7](#), [SH-SS-3](#), [SH-HCE-8](#), [SH-HCE-5](#), [SH-HCE-7](#), [LW-CP-1](#), [LW-HCE-2](#), [LW-HCE-9](#), [GB-CP-1](#), [GB-SS-1](#), [GB-HCE-2](#), [EOL-CP-1](#), [EOL-CP-5](#), [EOL-CP-6](#), [EOL-CP-7](#), [EOL-SS-2](#), [EOL-HCE-6](#), [EOL-HCE-7](#), [EOL-HCE-8](#)

Description of the gap

Health care professionals are provided with either no or minimal basic and continuing education on dementia. As result, most health professionals are unable to recognize dementia, adapt their practice and environment to the needs of people with dementia, or meet the ongoing care, support, and transition needs of persons with dementia and

their caregivers. The impact of this lack of knowledge for persons with dementia and the health care system can be:

- Inaccurate, missed, late, or no diagnosis of the dementia
- A loss of opportunity for risk reduction
- A lack of problem-solving and supportive skills
- A loss of opportunity for future care and life planning
- Inappropriate care and exacerbation of the dementia and other health conditions

Additionally, there is a lack of knowledge of the tools that are available to support persons with dementia and their caregivers in future care and life planning, such as enduring powers of attorney and representation agreements. As a result, advance care and life planning is often not encouraged or is not recognized by health care providers and critical transition and end-of-life decisions are made in a crisis, often resulting in poor decisions that negatively impact the quality of care received.

Health care providers also often lack access to best practice and evidence-based practice in dementia care, as well as the supports necessary to translate research and evidence into practice. Opportunities for interface between researchers and practitioners are needed.

Gap 4	Source
There is a gap in policy that mitigates the impact of dementia on the people with dementia and their families/caregivers, and on the communities they live in.	BCMA TDC

Recommendations addressing this gap

[SH-SS-2](#), [SH-HCE-1](#), [SH-HCE-2](#), [SH-HCE-3](#), [SH-HCE-4](#), [SH-HCE-6](#), [SH-HCE-7](#), [SH-HCE-9](#), [SH-HCE-10](#), [LW-SS-13](#), [LW-HCE-1](#), [LW-HCE-3](#), [LW-HCE-4](#), [LW-HCE-9](#), [GB-SS-6](#), [EOL-HCE-2](#), [EOL-HCE-5](#), [EOL-HCE-9](#)

Description of the gap

Dementia is having and will continue to have a significant impact on caregivers, communities, and the health care system. Dementia is a chronic, deteriorating, and terminal condition that is devastating for the person with dementia, burdensome to the family and support network, and potentially overwhelming to a health care system that is unprepared for its impact and significantly constrained in its ability to address the health care needs of the disease. The nature of the disease is unlike that of most other health conditions because as it progresses, it robs the individual of their ability to make decisions and engage directly in their own care, leads to a requirement for 24-hour supervision and monitoring, and eventually leads to 24-hour personal care.

Appropriate policy, whether at the organizational or government (federal, provincial, municipal, and regional) level is one of the foundational elements of a responsive health system. In the case of dementia, policy must be in place that recognizes and reflects the needs and impacts of dementia on the individual, caregivers, and communities. As the service framework has been developed, the outcomes of gaps in policy have consistently been identified as:

- A lack of awareness by the public about the risk factors for chronic disease and their own role in reducing their risk factors
- Constraints on the ability of caregivers, care providers, and agencies to deliver appropriate and evidence-based care

While the provincial government is taking steps to close the policy gap with the development of the Dementia Service Framework, there are still significant areas to be addressed by policy makers across the system:

- The need for public education on the risks for dementia and other chronic disease, the steps that can be taken to decrease the risk, the signs of early cognitive impairment, and the steps that should be taken
- Disincentives in the primary health care system to appropriately meet the needs of persons with dementia lead to missed or late diagnosis, inappropriate care planning, missed opportunities for future life and care planning, and overburdened caregivers. Examples of disincentives include reimbursement fee schedules that do not reimburse for the amount of time required to work with a person living with dementia or the time spent in interdisciplinary team conferences.
- An unbalanced focus in the system on episodic curative or crisis needs rather than deteriorating chronic conditions. Currently, services are primarily addressing crises as they arise and providers are often unable to shift their attention to the development of preventive strategies for persons with dementia and caregivers. Planned anticipatory care that is primarily community-based will improve the quality of life for persons with dementia and their caregivers. However, the health care system is often unable to provide the continuity and proactive planning required, and the result is often resource-intensive crisis interventions with temporary solutions.
- The need for policy to support the collection of a minimal data set about dementia in order to determine and monitor the prevalence of dementia or the utilization of services by people living with the disease. This results in a lack of data to support evaluation and costing of services and outcomes, or for the development of a business case for system change.
- The need for a dementia policy lens for reviewing the impact of policies – both positive and negative – on people living with dementia. Without this policy lens, policies will continue to be developed that inadvertently penalize this population, because their needs are significantly different from the care and support needs of

other populations (e.g., assisted-living criteria, restrictions on home support services).

- The need for a cohesive research agenda that focuses on gaps in research related to dementia, such as research on the risks for and prevention of cognitive impairment, best practice models of dementia care service delivery (including the acute care setting), best practice in support to caregivers, and best practice in end-of-life care.

Gap 5	Source
There is a gap in the recognition of the role of families and caregivers as partners on the care team.	BCMA FH DSFWG TDC

Recommendations addressing this gap

SH-SS-5, LW-CP-2, LW-CP-5, LW-SS-4, LW-HCE-3, GP-CP-3, GP-CP-4, GB-SS-2, GB-SS-6, EOL-CP-3, EOL-HCE-5

Description of the gap

The family and caregiver are critical to the long-term support, care, and health of the person with dementia. The health care system is heavily dependent on the ability of the caregiver to care for the person with dementia, yet this is not recognized through any formal programs, plans, or policy. Currently, health care providers may spend time problem solving with and assessing the needs of the caregiver to support them in their role. This work is often not viewed as “legitimate” work by the agency, and therefore not captured and not resourced even though being a caregiver is known to increase the risk for stress depression and general health decline. Knowledgeable and well-supported caregivers will be the glue that holds the caregiving environment together. Without them, care crises will be prevalent and the cycle of inappropriate care will become the norm.

Gap 6	Source
There is a gap in the capacity and ability of the acute care setting to meet the needs of people with dementia.	TDC VIHA

Recommendations addressing this gap

[GB-CP-1](#), [GB-CP-6](#), [GB-CP-7](#), [GB-CP-8](#), [GB-SS-3](#)

Description of the gap

The acute care environment is often not appropriately responsive to the needs of the people with dementia or their caregivers, regardless of the stage of the dementia that is present. An exception to this would be in a purpose-designed geriatric medical unit or program. There can exist, in acute care, an attitude of ageism that sees the elderly as blockers to the flow of patients in and out of the emergency and the inpatient units. The fast-paced environment, the perpetual relocation of patients, the orientation to acute episodic and curative episodes, and lack of recognition of the needs of persons with dementia can significantly compromise the care of such persons in the acute care environment.

Additionally, there may be a lack of knowledge or a lack of a dementia-sensitive care approach by providers. Because the physical environment can be unsafe and overstimulating, the result can be inappropriate care results that cause further decline in the health and quality of life for patients with dementia. Families, caregivers, and other health care providers who know the patients and their needs may often find that they are ineffective in advocating for people with dementia.

As a result, patients with dementia have longer lengths of stay in acute care compared with cognitively intact patients, and the acute care stay will often trigger premature admission to residential care.

Gap 7	Source
There is a gap in the formal integration, collaboration, and communication across care settings, between health care providers, and across health authorities.	BCMA FH TDC VIHA

Recommendations addressing this gap

[SH-SS-5](#), [SH-SS-6](#), [LW-CP-10](#), [LW-SS-6](#), [LW-SS-8](#), [LW-SS-11](#), [GB-CP-2](#), [GB-CP-5](#), [GB-SS-4](#)

Description of the gap

The diagnosis of dementia can mean long-term involvement with all sectors of the health care system, including primary care physicians, specialists, community care,

mental health, acute care, emergency, residential care, and end-of-life care. Typically, the transfer of clinical information across care settings or between care providers is limited and often is dependent on informal networks or protocols. For people with dementia, a lack of awareness by care provider of their diagnosis and care plan can lead to inappropriate care and management of transitions. Because of the long-term care needs of persons with dementia, the impact of the lack of integration will likely have a cumulative detrimental effect.

The ability of the system to support accurate and relevant communication of clinical information for people with dementia could be a critical success factor or performance measure for the system – if information is well communicated for this population, it is likely to be well communicated for most other clients. Additionally, the ability of care providers across care settings to collaborate and proactively plan for the needs of persons with dementia could be a key indicator for almost all other client groups.

At a planning/policy level, there is also a need to work collaboratively across the health authorities (with other stakeholders) to create opportunities to learn from each other and advance best practice in dementia care. Again, this happens informally but requires greater emphasis in order to effect change. The service framework is one example of how that formal integration and collaboration can be achieved.

6.4. Dementia Service Framework Recommendations

The full service framework, including all the evidence and best practice–based recommendations for dementia care, provides a comprehensive picture of the steps that need to be taken to improve the system of care for people living with dementia and their caregivers. The first page of the service framework provides quick hyperlinked access to the sections of interest to the reader ([Table 12](#)). Within the body of the framework, the tables are organized as follows:

Staying Healthy – Individual

Identifies the level of health status and level of care

A quick visual orientation to the section of the matrix the reader is in

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care providers				
Support systems				
Health care environment				

Goals for the level of health status

Staying Healthy Goals

1. To promote an awareness of the importance of brain health for all across the life course, reducing the likelihood of disease and/or delaying its progression
2. To ensure that there is early recognition of a change in an individual that leads to early detection

Themes by which the recommendations are grouped



Themes for Individual Actions for Staying Healthy

- Promoting brain health across the life course
- Early identification of risk for dementia
- Early detection and diagnosis of dementia
- Activated partners in care
- Future life and care planning

Level of Health Status: Staying Healthy		Level of Care: Individual
Theme	Recommendations	
Promoting brain health across the life course	SH-I-1 All BC residents, including those diagnosed with dementia, will seek information and programs that will raise their awareness with regard to brain health <i>and</i> adopt behaviours to help them reduce their risk for dementia, and all other chronic diseases.	
	<p><i>Explanation:</i></p> <p>The decision to adopt healthy lifestyle behaviours across the life-course rests with all residents of BC. Dementia is a chronic disease and shares many of the risk factors associated with other chronic diseases.</p> <p>behaviours to minimize risk factors for dementia, and other chronic diseases, across the life course</p> <p>include:</p> <p>Sources (LOE): IH (3), TDC (3), FH (3), VIHA (3), VCH (3), ASBC (3)</p> <p>SOR: (3)</p>	

Recommendation number indicates the level of health status (SH), the level of care (I), and the number (1) reference for this “box”

Source initiatives contributing to the recommendations and LOE

Initiatives reviewed and used as sources

- ASBC Alzheimer Society of BC (Society Initiatives)
- BCMA BB British Columbia Medical Association Building Bridges
- CARMHA CARMHA Review of Research in End of Life Dementia Care, Fall 2006
- CI PG Guidelines and Protocols Advisory Committee – Recognition, Diagnosis and Management of Cognitive Impairment in the Elderly
- FH Fraser Health Framework for Dementia Care
- GMHEI Geriatric Mental Health Education Initiative
- IH Interior Health Phased Pathways
- NH Northern Health Clinical Practice Guidelines
- TDC Transforming Dementia Care in BC (April 2005 conference)
- VCH Vancouver Coastal Health Client Journey Website
- VIHA Vancouver Island Health Authority Service Framework for Dementia Care
- LOE Level of Evidence
- SOR Strength of Recommendations

Table 12 provides quick hyperlinked access to the various sections of the Dementia Service Framework.

Table 12. Dementia Service Framework Matrix

Improvement Outcomes		Levels of Health Status			
		Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	End of Life
Levels of Health Care	Individual	Click for goals and recommendations			
	Care Provider	Click for goals and recommendations			
	Support Systems	Click for goals and recommendations			
	Health Care Environment	Click for goals and recommendations			

Staying Healthy – Individual

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Staying Healthy Goals

1. To promote an awareness of the importance of brain health for all across the life course, reducing the likelihood of disease and/or delaying its progression.
2. To ensure that there is early recognition of a change in an individual that leads to early detection



Themes for Individual Actions for Staying Healthy

- Promoting brain health across the life course
- Early identification of risk for dementia
- Early detection and diagnosis of dementia
- Activated partners in care
- Future life and care planning

Level of Health Status: Staying Healthy	Level of Care: Individual
Theme	Recommendations
<i>Promoting brain health across the life course</i>	<p>SH-I-1 – All BC residents, including those diagnosed with dementia, will seek information and programs that will raise their awareness with regard to brain health <i>and</i> adopt behaviours to help them reduce their risk for dementia and all other chronic diseases.</p> <p><i>Explanation:</i></p> <p>The decision to adopt healthy lifestyle behaviours across the life course rests with all residents of BC. Dementia is a chronic disease and shares many of the risk factors associated with other chronic diseases. Behaviours to minimize risk factors for dementia and other chronic diseases across the life course include:</p> <ul style="list-style-type: none"> • Controlling/reducing blood pressure and cholesterol • Not smoking • Eating a healthy diet • Regular exercise • Modest intake of alcohol • Reducing stress • Engaging in regular mental and social/leisure activities • Taking action to avoid head trauma (helmets, seat belts, etc.) • Developing and maintaining a social network <p>Sources (LOE): IH (3), TDC (3), FH (3), VIHA (3), VCH (3), ASBC (3)</p> <p>SOR: C</p>
<i>Early identification of risk for dementia</i>	<p>SH-I-2 – Individuals with familial history of dementia and/or the presence of vascular risk factors, obesity, or diabetes mellitus will seek and act on additional information about prevention and early screening for dementia (e.g., genetic counselling with appropriate support).</p> <p>Sources (LOE): IH (3), FH (3), ASBC (3)</p> <p>SOR: C</p>
<i>Early detection and diagnosis of dementia</i>	<p>SH-I-3 – All individuals will recognize the importance of following up on subtle cognitive changes with their primary care provider.</p> <p>Sources (LOE): IH (3), ASBC (3)</p> <p>SOR: C</p> <hr/> <p>SH-I-4 – Individuals and families and caregivers will seek educational resources about mild cognitive impairment when there are early signs of cognitive change.</p> <p><i>Resources:</i></p> <ul style="list-style-type: none"> • Definition of mild cognitive impairment • List of early warning signs <p>Sources (LOE): IH (3), ASBC (3)</p> <p>SOR: C</p>

Level of Health Status: Staying Healthy	Level of Care: Individual
Theme	Recommendations
	<p>SH-I-5 – People with dementia and their caregivers will understand the importance and value of seeking and receiving an early diagnosis, and the benefits of disclosing the diagnosis to others. They will understand their responsibility to advocate for a correct diagnosis (e.g., if the diagnosis of dementia does not seem correct) and their responsibility for learning how to communicate the diagnosis.</p> <p>Resources:</p> <ul style="list-style-type: none"> • Getting a Diagnosis <p>Sources (LOE): IH (3), VCH (3), ASBC (3)</p> <p>SOR: C</p>
<i>Activated partners in care</i>	<p>SH-I-6 – People at risk for and diagnosed with dementia and their caregivers will connect with the Alzheimer Society First Link program where it exists, or call the Alzheimer Society for information, support, and education.</p> <p>Resources:</p> <ul style="list-style-type: none"> • Alzheimer Society of BC <p>Sources (LOE): ASBC (3)</p> <p>SOR: C</p>
	<p>SH-I-7 – People diagnosed with dementia and their caregivers will:</p> <ul style="list-style-type: none"> • Seek information about dementia and dementia care (Internet resources, books, videos, pamphlets, research articles, conference materials, etc.) • Learn about and adapt strategies that support the person with dementia to live as normally and independently as possible • Seek information about care decisions that will be required as the dementia progresses, including medications, non-pharmacological interventions, end-of-life decision making, and support resources • Seek information and assistance with enduring powers of attorney, representation agreements, and wills to enable future life and care planning <p>Sources (LOE): IH (3), FH (3) VIHA (3), VCH (3), ASBC (3), TDC (3)</p> <p>SOR: C</p>
<i>Future life and care planning</i>	<p>SH-I-8 – People diagnosed with dementia and their caregivers will build a network of support and seek support as needed through the journey with dementia.</p> <p>Explanation:</p> <p>People with dementia who do not have a support network of family, friends, and caregivers will be advised to develop a personal support network to help them maintain their independence for as long as possible.</p> <p>Sources (LOE): IH (3), VCH (3), ASBC (3)</p> <p>SOR: C</p>

Level of Health Status: Staying Healthy	Level of Care: Individual
Theme	Recommendations
	<p>SH-I-9 – All individuals, but most particularly those diagnosed with dementia and their caregivers, will actively engage their loved ones in values and belief-based conversations and planning related to end-of-life decision making and review their life and care plans regularly to ensure that they will guide the decision making required in future years.</p> <p><i>Explanation:</i></p> <p>All individuals should ensure that their legal and financial affairs are in order, including an enduring power of attorney and advance health care directives and representation agreements. This also potentially includes the development of a short written “personhood profile” with information on personal elements of the individual’s life that can be presented when encountering the health care system.</p> <p><i>Resources:</i></p> <ul style="list-style-type: none"> • Representation agreements • Enduring power of attorney <p>Sources (LOE): TDC (3), IH (3), VIHA (3), VCH (3), NH (3), ASBC (3), CARMHA (2)</p> <p>SOR: C</p>
	<p>SH-I-10 – All individuals, most particularly those at risk for dementia, will make informed choices about participating in research or provide support to research into prevention and treatment of dementia.</p> <p><i>Explanation:</i></p> <p>Research into the prevention of dementia and the delay of onset is vitally important. Participants should be able to expect clear explanations about: potential risks and costs involved, consent to participate, the role of research, and what to expect as part of the research trial. Results should be communicated in a timely way.</p> <p>Sources (LOE): FH (3), ASBC (3)</p> <p>SOR: C</p>



Staying Healthy – Care Provider

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Staying Healthy Goals

1. To promote an awareness of the importance of brain health for all across the life course, reducing the likelihood of disease and/or delaying its progression.
2. To ensure that there is early recognition of a change in an individual that leads to early detection



- Themes for Care Providers Actions for Staying Healthy**
- Support for self-management
 - Early recognition and screening
 - Early diagnosis based on thorough assessment
 - Supporting individuals and their caregivers post-diagnosis
 - Personal professional development (continuing education)

Level of Health Status: Staying Healthy	Level of Care: Care Provider
Theme	Recommendations
<i>Support for self-management</i>	<p>SH-CP-1 – Health care providers will help people reduce their risk for chronic diseases, including dementia. Frontline staff will utilize “teachable moments” as opportunities for primary health promotion (e.g., <i>assess and promote</i> individual lifestyle behaviours that integrate physical, social, and intellectual activities with daily living).</p> <p>Explanation:</p> <p>Dementia is a chronic disease and shares many of the risk factors associated with other chronic diseases. All health care providers have a role to play in helping individuals reduce their risk for chronic diseases.</p> <p>Behaviours to minimize risk factors for dementia and other chronic diseases include:</p> <ul style="list-style-type: none"> • Controlling/reducing blood pressure and cholesterol • Not smoking • Eating a healthy diet • Regular exercise • Modest intake of alcohol (and not consuming alcohol for the purposes of preventing cognitive loss or dementia, because the safe use of alcohol is extremely complex and variable across populations and for individuals) • Reducing stress • Engaging in regular mental and social/leisure activities • Taking action to avoid head trauma (helmets, seat belts, etc.) <p>Sources (LOE): IH (3), FH (3), VIHA (3), ASBC (3)</p> <p>SOR: C</p>
<i>Early recognition and screening</i>	<p>SH-CP-2 – Health care professionals will take early signs of cognitive changes seriously and refer individuals for further investigation and diagnosis.</p> <p>Explanation:</p> <p>Often early signs of cognitive change are minimized. Interdisciplinary professionals will use “opportunistic recognition” of cognitive loss during routine care assessments as a means of promoting early detection and referral for follow-up investigation, rather than routine screening.</p> <p>Interdisciplinary health care providers will assist in early detection efforts by maintaining a high index of suspicion for early cognitive-related changes and relaying information about changes to other care providers (example: change in function, memory loss, language, mood, and behaviour).</p> <p>Health care providers will be knowledgeable about providing support for individuals with mild cognitive impairment.</p> <p>Sources (LOE): IH (3), ASBC (3), VCH (3)</p> <p>SOR: C</p>

Level of Health Status: Staying Healthy	Level of Care: Care Provider
Theme	Recommendations
<i>Early diagnosis based on thorough assessment</i>	<p>SH-CP-3 – Physicians will assess individuals with suspected dementia, differentiate between conditions, and make an accurate diagnosis. They will also work collaboratively with specialists and other health providers as needed to provide individuals with an accurate diagnosis as soon as possible.</p> <p>Explanation:</p> <p>Physicians are expected to:</p> <ul style="list-style-type: none"> • Differentiate, treat, and rule out remediable and/or contributory cause(s) of cognitive impairment (consider conditions causing delirium and also consider depression).² • Complete a comprehensive review of medication history (type, dosage, and compliance for both prescription and over-the-counter). Any medication may be implicated. • Assess patients for mild cognitive impairment (MCI) when other causes of impaired cognition have been excluded and the patient does not meet criteria for a diagnosis of dementia either because they lack a second sphere of cognitive impairment or because their deficits are not significantly affecting their daily living. People being assessed for MCI may expect their care provider to conduct additional assessments using the MoCA when their Standardized Mini Mental State Exam (SMMSE) score is in the “normal range” (24-30). • Consider referral to secondary services for the assessment of dementia in appropriate cases with diagnostic uncertainty or atypical features. • Provide a specific dementia subtype diagnosis, which will aid in treatment planning and counselling. <p>Resources:</p> <ul style="list-style-type: none"> • Guidelines and Protocols Advisory Committee (GPAC), Guidelines by Alphabetical Listing <p>Sources (LOE): CI PG (3), TDC (3), NH (3), ASBC (3)</p> <p>SOR: C</p> <hr/> <p>SH-CP-4 – Health care providers will be informed by principles, goals, and ethics of excellent dementia care and understand the importance of providing a diagnosis as soon as possible. The timing and extent of disclosure of the diagnosis will be supported by referral to other support resources as appropriate.</p> <p>Sources (LOE): CI PG (3), AS (3)</p> <p>SOR: C</p> <hr/> <p>SH-CP-5 – Health care providers are expected to encourage and support people with dementia and their caregivers during the process of diagnosis to address fear and reduce stress and to provide secondary prevention of other conditions (e.g., reduce risk of depression).</p> <p>Sources (LOE): VCH (3)</p> <p>SOR: C</p>

² Further detail for all recommendations derived from the GPAC CI Physician Guidelines can be found in the guidelines (<http://www.health.gov.bc.ca/gpac/alphabetical.html>).

Level of Health Status: Staying Healthy	Level of Care: Care Provider
Theme	Recommendations
<i>Supporting individuals and their caregivers post-diagnosis</i>	<p>SH-CP-6 – Health care providers will encourage and support people with dementia and their caregivers in initiating future life planning, such as:</p> <ul style="list-style-type: none"> • Assistance with advance directives • Driving assessments • Establishing an enduring power of attorney and representation agreement • Early identification of the person’s support network <p>Sources (LOE): BCMA BB (3), FH (3), VCH (3), ASBC (3)</p> <p>SOR: C</p>
<i>Personal professional development</i>	<p>SH-CP-7 – Health professionals in all settings will access education about the clinical management of mild cognitive impairments and dementia and put the knowledge into practice.</p> <p>Explanation:</p> <p>This will include education about:</p> <ul style="list-style-type: none"> • Early recognition of dementia or dementia risk (including MCI) • Early diagnosis of dementia • Dementia care <p>Education is informed by recent research and is expected to give particular emphasis to:</p> <ul style="list-style-type: none"> • Communicating effectively and respectfully with an individual who has a dementia by understanding their verbal, non-verbal, and behavioural cues • Perceiving and supporting the remaining capabilities of the person with dementia on a day-by-day basis so they can function as independently as possible • Helping the caregiver to establish and maintain an environment that contains a good balance of stimulation and support (or, in the case of adult day program or community centre staff, enhancing the program setting in the same way) • Helping the caregiver to deal with his/her own needs • Utilizing “teachable moments” within episodic health care as teaching opportunities for primary health promotion <p>Sources (LOE): TDC (3), IH (3), FH (3), VIHA (3), ASBC (3)</p> <p>SOR: C</p>



Staying Healthy – Support Systems

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Staying Healthy Goals

1. To promote an awareness of the importance of brain health for all across the life course, reducing the likelihood of disease and/or delaying its progression.
2. To ensure that there is early recognition of a change in an individual that leads to early detection.



Themes for Support Systems Actions for Staying Healthy

- Providing information on brain health across the life course
- Building capacity for primary prevention and risk reduction
- Building capacity for early identification and diagnosis
- Supporting communication, coordination, collaboration
- Building human resource capacity

Level of Health Status: Staying Healthy	Level of Care: Support Systems
Theme	Recommendations
<i>Providing information on brain health across the life course</i>	<p>SH-SS-1 – Agencies and organizations that provide services to people with dementia will provide British Columbians with public information and education about:</p> <ul style="list-style-type: none"> • Its never being too late to make lifestyle changes that reduce known dementia risk • Promoting healthy brains and healthy aging, even when memory loss is evident • Preventing cognitive impairment (“Heart Smart = Brain Smart”) <p>Explanation:</p> <p>Agencies and organizations are expected to integrate brain health into other health promotion work. This will include:</p> <ul style="list-style-type: none"> • Increasing public awareness about health-determining social and environmental conditions and monitoring those conditions for effect on health status • Making internal resources more readily available to groups working on health determinants • Supporting community organization, networks, and action on health determinants, through dedicated community development/health • Engaging in joint programming and policy development work • Developing and advocating statements on policy options that influence health determinants <p>Sources (LOE): VIHA (3), VCH (3), ASBC (3), FH (3), IH (3)</p> <p>SOR: C</p>
<i>Building capacity for primary prevention and risk reduction</i>	<p>SH-SS-2 – Agencies and organizations that provide services to people with dementia will invest in health promotion and chronic disease prevention work, including dementia prevention.</p> <p>Explanation:</p> <p>Agencies and organizations are expected to integrate brain health into chronic disease prevention work. This includes developing linkages between preventive programs that target common risk factors for chronic diseases such as heart and stroke, diabetes, and dementia, and between the health authority and community partners. (For example, enhance liaison between health authority and recreational centres, seniors’ centres, etc., to create social opportunities to reach isolated people with dementia (e.g., seniors, physically and mentally disabled). This will include:</p> <ul style="list-style-type: none"> • Treating dementia as a chronic disease requiring diagnosis and early treatment similar to other chronic diseases and according to chronic disease management guidelines • Using knowledge about lifelong learning, social engagement, and activity/task complexity, “building” brain reserve and integrating this in program planning and design of client activity programs (e.g., adult or mental health day programs, residential care activity programs, child care programs) • Taking seriously identifiable changes in memory, thinking, mood, or ability to problem-solve/function in everyday life • Making resources available for people struggling with cognitive problems, either before or after a diagnosis of dementia • Understanding the difference between dementia and other, non-progressive conditions that may resemble dementia • Seeking medical advice for further investigation <p>Sources (LOE): IH (3), ASBC (3)</p> <p>SOR: C</p>

Level of Health Status: Staying Healthy	Level of Care: Support Systems
Theme	Recommendations
<i>Building capacity for early identification and diagnosis</i>	<p>SH-SS-3 – Agencies and organizations in which physicians, nurses, and other health professionals work (including those that work in clinics and emergency rooms) will:</p> <ul style="list-style-type: none"> • Provide interdisciplinary education to address key areas of knowledge on promoting brain health and the early detection of dementia • Provide the infrastructure and support to translate this knowledge into practice • Implement systems to monitor the knowledge transfer into practice <p>Explanation: The education will include such topics as:</p> <ul style="list-style-type: none"> • The continuum of cognitive-related changes from normal aging to MCI to Alzheimer’s disease and the related dementias • The use of “opportunistic recognition” of cognitive loss (as opposed to population screening) as a means to promote early detection and referral for follow-up investigation • The need to listen to and assess the person with dementia and caregiver reports of cognitive, functional, behavioural, and/or emotional changes as first-line evidence towards developing an index of suspicion for cognitive change • Understanding that such cognitive-related changes may have multiple etiologies, some of which are reversible, and need to be ruled out by physicians • The fact that reporting and referral of concerns of such changes may aid earlier detection and improve brain health and quality of life (reversal of cognitive losses) for people with MCI and their caregivers • The importance of monitoring reported changes or difficulties over time to assess trends • The importance of not presuming or equating any cognitive loss with a dementing disorder (e.g., many other conditions such a physical illness, delirium, depression, anxiety, and medications may result in similar losses) • The importance of early advance planning of financial, legal, and personal/domestic affairs <p>Sources (LOE): TDC (3), IH (3), FH (3), VIHA (3), ASBC (3)</p> <p>SOR: C</p>
	<p>SH-SS-4 – People with dementia and their caregivers can expect that agencies and organizations provide physicians who work with dementia patients adequate assistance (e.g., clinical guidelines, education) to reach a diagnosis and to find an appropriate manner and methodology to disclose the diagnosis to the patient and/or caregiver.</p> <p>Explanation: This support will address the importance of:</p> <ul style="list-style-type: none"> • Understanding the clinical and ethical challenges associated with the early diagnosis and disclosure of mild cognitive impairment (MCI) and early-stage dementias • Providing persons with dementia and their caregivers with emotional support as well as education and information following the diagnosis of possible or probable mild cognitive impairment or early dementia • Connecting people with dementia and their caregivers to appropriate support and information services in the formal and informal health care system to assist them in adjusting to the diagnosis of MCI <p>Sources (LOE): BCMA BB (3), VIHA (3)</p> <p>SOR: C</p>

Level of Health Status: Staying Healthy		Level of Care: Support Systems
Theme	Recommendations	
<i>Supporting communication, coordination, collaboration</i>	<p>SH-SS-5 – Agencies and organizations will ensure that people with mild cognitive impairment or dementia, and their families and caregivers throughout British Columbia, find programs that support them, and they will facilitate this by improving the exchange of information between care providers and between care providers and families.</p> <p>Explanation:</p> <p>Communication about dementia and dementia care is essential between the family, specialist, primary care physicians, community care services, long-term care facilities, assisted living, mental health services, acute care, and other caregivers. Improved information technology and systems are important for supporting improvements in communication (e.g., the use of electronic health records is expected).</p> <p>Sources (LOE): TDC (3), FH (3), VIHA (3), ASBC (3), IH (3), NH (3)</p> <p>SOR: C</p>	
	<p>SH-SS-6 – Agencies and organizations, including the Alzheimer Society of BC, researchers, policy makers, and regional health authorities, will work collaboratively through formalized partnerships.</p> <p>Sources (LOE): TDC (3), FH (3), BCMA BB (3), VIHA (3), ASBC (3)</p> <p>SOR: C</p>	
<i>Building human resource capacity</i>	<p>SH-SS-7 – Agencies and organizations will develop human resource plans, policies, and procedures that address the recruitment and retention of clinicians with the knowledge, skills, and abilities to prevent, diagnose, treat, and support people with dementia and their families, and that reflect service models that support effective uses of human resources available.</p> <p>Sources (LOE): FH (3), VIHA (3)</p> <p>SOR: C</p>	



Staying Healthy – Health Care Environment

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Staying Healthy Goals

1. To promote an awareness of the importance of brain health for all across the life course, reducing the likelihood of disease and/or delaying its progression.
2. To ensure that there is early recognition of a change in an individual that leads to early detection.



- Themes for Health Care Environment Actions for Staying Healthy**
- Addressing the broader determinants of health across the life course
 - Reducing the stigma associated with dementia
 - Supporting a dementia research agenda
 - Improving knowledge about dementia
 - Creating dementia-sensitive policy

Level of Health Status: Staying Healthy	Level of Care: Health Care Environment
Theme	Recommendations
<i>Addressing the broader determinants of health across the life course</i>	<p>SH-HCE-1 – Government will address non-medical determinants of health that create risk for chronic disease.</p> <p>Explanation: This will include:</p> <ul style="list-style-type: none"> • Promoting public awareness about health-determining social and environmental conditions and monitoring those conditions for effect on health status • Supporting community organizations and action on health determinants • Developing policy options that influence health determinants <p>Sources (LOE): IH (3) SOR: C</p>
	<p>SH-HCE-2 – Government will promote and advocate to the public that healthy (self-care) activities (attention to diet, exercise, alcohol consumption, and drug abuse) will enhance wellness, improve quality of life, and reduce the risk of chronic diseases, including dementia.</p> <p>Explanation: This should include providing public information with the message that it is never too late to make lifestyle changes that reduce known dementia risk and promote healthy brains and healthy aging, even when memory loss is evident. This can be linked with similar health promotion activities in some cases.</p> <p>Sources (LOE): BCMA BB (3) SOR: C</p>
<i>Reducing the stigma associated with dementia</i>	<p>SH-HCE-3 – Government and policy makers will identify and approach dementia as a chronic disease.</p> <p>Sources (LOE): BCMA BB (3), ASBC (3), IH (3), VIHA (3), VCH (3), FH (3) SOR: C</p>
	<p>SH-HCE-4 – Policy makers will develop policy that considers the importance of physical and social environments that enable citizens with dementia and their caregivers to function as well as possible in the community. This includes ensuring that the entire community is an assistive environment, accepting and supportive of people living with dementia.</p> <p>Sources (LOE): VIHA (3) SOR: C</p>
<i>Supporting a dementia research agenda</i>	<p>SH-HCE-5 – Policy makers will develop a dementia research agenda that addresses gaps in dementia research, including prevention and risk reduction of dementia, practices that support the caregiver, and end-of-life palliative care for dementia.</p> <p>Explanation: The development of a dementia research agenda in British Columbia will be strengthened through communication and collaboration across organizations. Annual or semi-annual meetings among caregiver panel members, researchers, and regional health authorities will serve to bring together the perspectives of those living with the disease, care providers who work in the system, and senior decision makers.</p> <p>Sources (LOE): FH (3), CARMHA (3) SOR: C</p>

Level of Health Status: Staying Healthy	Level of Care: Health Care Environment
Theme	Recommendations
	<p>SH-HCE-6 – Government and policy makers will develop, fund, and implement a comprehensive study of the costs of dementia care.</p> <p><i>Explanation:</i></p> <p>There is very little information or evidence about the costs and impact of dementia care, making it difficult for clinicians and senior decision makers to make evidence-based decisions about the allocation and utilization of resources to best meet the needs of this population. The study should include an examination of individual, system, and societal costs of prevention and treatment and end-of-life care for dementia. The study should also include the impact on caregivers and anticipated drug costs. Appropriate stakeholders should be consulted.</p> <p>Sources (LOE): TDC (3)</p> <p>SOR: C</p>
<p><i>Improving knowledge about dementia</i></p>	<p>SH-HCE-7 – Institutions with a role in the education and continuing education of health care providers will ensure that all health care provider undergraduate, postgraduate, and continuing education programs in the province address the importance of early recognition of dementia and mild cognitive impairment.</p> <p>Sources (LOE): BCMA BB (3), ASBC (3), IH (3)</p> <p>SOR: C</p>
<p><i>Creating dementia-sensitive policy</i></p>	<p>SH-HCE-8 – Government and policy makers will ensure that legislation and policy provide the legal tools for families to plan for future health, personal, and financial care in advance, with a well-understood, accessible, and person-centred default process for those who are unable to plan in advance.</p> <p>Sources (LOE): NH (3), TDC (3), ASBC (3)</p> <p>SOR: C</p>
	<p>SH-HCE-9 – Policy makers will ensure that public policies that impact people living with dementia are developed from evidenced-based dementia knowledge or a dementia policy lens, and not simply financial and political frameworks.</p> <p><i>Explanation:</i></p> <p>Policy makers will require education and access to knowledgeable clinicians regarding evidence-based dementia practice. The development and use of a dementia policy lens (evidence-based criteria for reviewing the impact of policy on people living with dementia) will ensure that any potential ramifications on people with dementia are examined as policy is developed and exceptions or changes defined to accommodate this very vulnerable population.</p> <p>Sources (LOE): TDC (3), ASBC (3), GHMEI (3)</p> <p>SOR: C</p>
	<p>SH-HCE-10 – Policy makers will ensure that proper incentives and support structures regarding dementia care are in place for primary care physicians, health care providers, agencies, and those living with dementia.</p> <p>Sources (LOE): BCMA BB (3)</p> <p>SOR: C</p>

Note: Some Health Care Environment recommendations in the Living with, Getting Better, and End of Life sections are also applicable to this section.



Living with Dementia – Individual

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Living with Dementia Goals

1. To promote and support the quality of life for people living with dementia
2. To promote and support the quality of life for caregivers of people living with dementia



Themes for Individual Actions When Living with Dementia

- [Future life and care planning](#)
- [Activated partners in care](#)
- [Self-advocacy to further knowledge of the lived dementia experience](#)

Level of Health Status: Living with Dementia	Level of Care: Individual
Theme	Recommendations
<i>Future life and care planning</i>	<p>LW-I-1 – People with dementia and their caregivers will plan for their future and update and implement these plans as appropriate.</p> <p>Explanation:</p> <p>The following areas will be considered at the earliest appropriate time:</p> <ul style="list-style-type: none"> • Ensuring that a person’s concerns and wishes have been discussed with their personal support network, are in writing, and are being used to guide decision making when the person with dementia is no longer able to speak for himself or herself • Discussing values, beliefs, and wishes for future care • Executing legal documents setting out future plans for legal, financial, personal, and health care • Understanding the appropriate legislation governing decision making and substitute decision making, and effecting future care plans accordingly • Asking for support to discuss in advance the most sensitive approach to driving cessation and other difficult choices and how to determine when that might be necessary <p>Sources (LOE): TDC (3), ASBC (3), VCH (3), IH (3)</p> <p>SOR: C</p>
<i>Activated partners in care</i>	<p>LW-I-2 – People with dementia and their caregivers will request information and support on programs developed specifically to meet their needs in mild, moderate, severe, and end-of-life stages of dementia.</p> <p>Explanation:</p> <p>Dementia is a progressive condition, and therefore the person with dementia and caregiver will be prepared for the changes in the person’s physical and cognitive function as they occur. Examples of important information and support include:</p> <ul style="list-style-type: none"> • Education on dementia and dementia care – including its likely progression, coping strategies, and information on services coordination and support • Easy access to Internet resources, books, videos, pamphlets, research articles, and conference materials • Information about adapting strategies that support the person with dementia to live as normally and independently as possible • Support to learn self-advocacy skills • Preparation for the management of transitions as the disease progresses (e.g., both functional and setting transitions) <p>Sources (LOE): TDC (3), FH (3), ASBC (3), VCH (3), VIHA (3), IH (3)</p> <p>SOR: C</p>
	<p>LW-I-3 People with increased risk for dementia (e.g., mild cognitive impairment), people diagnosed with dementia, and their caregivers will build their skills for self-advocacy and problem solving and become confident and activated persons who are involved in their own care, maintaining as much control as possible in their own lives, including through the transitions that are a part of the disease.</p> <p>Sources (LOE): TDC (3), FH (3), VCH (3), IH (3), ASBC (3)</p> <p>SOR: C</p>

Level of Health Status: Living with Dementia	Level of Care: Individual
Theme	Recommendations
	<p>LW-I-4 – People with dementia and their caregivers will learn about and adapt strategies that support the person with dementia to live as normally and independently as possible.</p> <p>Explanation:</p> <p>This may include seeking support, information, and education about dementia, and participating in programs that enhance their resilience and ability to cope, such as those offered through the Alzheimer Society of BC (e.g., the family caregiver series).</p> <p>Sources (LOE): VCH (3), ASBC (3)</p> <p>SOR: C</p>
	<p>LW-I-5 – People with dementia and their families and caregivers <i>may choose to</i> develop or join a support network – a group of knowledgeable and committed people able to provide support as the disease progresses.</p> <p>Sources (LOE): ASBC (3)</p> <p>SOR: C</p>
	<p>LW-I-6 – People with dementia and their families and caregivers will take responsibility for staying as healthy as possible.</p> <p>Explanation:</p> <p>Throughout the progression of the dementia, there are strategies that individuals (both persons with dementia and their caregivers) can use to stay as healthy as possible. These include:</p> <ul style="list-style-type: none"> • Understanding their medications • Eating healthily • Not smoking • Exercising • Maintaining brain activity • Consuming a modest intake of alcohol • Controlling/reducing blood pressure, cholesterol and stress <p>Resources:</p> <ul style="list-style-type: none"> • IH tool kit • Canadian Network for Prevention of Elder Abuse • Canadian Centre for Elder Law Studies <p>Sources (LOE): VCH (3), IH (3)</p> <p>SOR: C</p>
	<p>LW-I-7 – Families and caregivers of people with dementia will be aware of information and supports pertaining to preventing abuse and neglect (care providers will provide support for this).</p> <p>Resources:</p> <ul style="list-style-type: none"> • Elder abuse and neglect information <p>Sources (LOE): ASBC (3), IH (3)</p> <p>SOR: C</p>

Level of Health Status: Living with Dementia		Level of Care: Individual
Theme	Recommendations	
<i>Self-advocacy to further knowledge of the lived dementia experience</i>	<p>LW-I-8 – People with increased risk for dementia (e.g., MCI), people diagnosed with dementia, and their caregivers will consider contributing to the knowledge of dementia by sharing their knowledge, voice, and lived experience as opportunities arise, e.g., through public forums, research, and education.</p> <p>Sources (LOE): FH (3)</p> <p>SOR: C</p>	



Living with Dementia – Care Providers

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Living with Dementia Goals

1. To promote and support the quality of life for people living with dementia
2. To promote and support the quality of life for caregivers of people living with dementia



Themes for Care Providers When Living with Dementia

- Education
- Respect and dignity
- Comprehensive and continuous care
- Behaviour management
- Research

Level of Health Status: Living with Dementia	Level of Care: Care Providers
Theme	Recommendations
<i>Education</i>	<p>LW-CP-1 – All health care providers will avail themselves of up-to-date training, education, and information specific to caring for people with dementia. Ongoing mentoring and clinical support should support them where applicable.</p> <p>Care providers will be knowledgeable about behaviours in later stages of dementia and be skilled in coping with these behaviours in a manner that respects and preserves the dignity of the person with dementia.</p> <p>Explanation:</p> <p>Examples of what might be emphasized in training include:</p> <ul style="list-style-type: none"> • Communicating effectively and respectfully with individuals who have dementia by understanding their verbal, non-verbal, and behavioural cues • Interacting with persons with dementia and their caregiver as full partners in their care • Perceiving and supporting the remaining capabilities of individuals with dementia on a day-to-day basis so they can function as independently as possible • Helping the caregiver to establish and maintain an environment that contains a good balance of stimulation and support • Helping the caregiver to deal with her/his own needs • Respectful and development-oriented approaches that model the attitude staff are expected to demonstrate towards individuals with dementia <p>Resources:</p> <ul style="list-style-type: none"> • GPEP website <p>Sources (LOE): VIHA (3), TDC (3), IH (3), VCH (3)</p> <p>SOR: C</p> <hr/> <p>LW-CP-2 – Health care providers will offer consistent education and information to people with dementia and their caregivers – in order to strengthen awareness and to increase transition support. Information will be geared towards helping people understand the course of dementia and will include information on accessing health system and agency services.</p> <p>Explanation:</p> <p>Health care providers will respectfully engage persons at risk for dementia (e.g., with MCI), persons with dementia, and their caregivers in the care process and support them through knowledge transfer, education, and information.</p> <p>There are many elements to consider in providing support and information. Health care providers should not assume that all elements have been dealt with by the family physician and should seek opportunities to reinforce the messages, to answer questions, and to refer the family to needed resources.</p> <p>Research indicates that giving small, frequent sources of information is better than providing a large amount of information at once. The type and amount of information needs to be uniquely tailored for individual people with dementia and caregiver-specific needs, and asking persons with dementia and their caregivers what they perceive their priorities to be is the right place to start. Health care providers should realize that caregivers may have different information and support needs and that these needs may change throughout the caregiving experience.</p> <p>The support by health care providers should include assessment, referral, and counselling support of advance planning needs.</p>

Level of Health Status: Living with Dementia	Level of Care: Care Providers
Theme	Recommendations
	<p>Health care providers will recognize the importance of communication with families and caregivers when a person with dementia is transferred from one care site to another.</p> <p>Health care providers should ask people with dementia and their caregivers if they have connected to the Alzheimer Society of BC, and offer them a connection, including to the First Link program where it exists.</p> <p><i>Resources:</i></p> <ul style="list-style-type: none"> • Guidelines and Protocols Advisory Committee: Cognitive Impairment in the Elderly – Recognition, Diagnosis and Management – Patient Guide <p>Sources (LOE): FH (3), ASBC (3), VCH (3), VIHA (3), IH (3), CI PG (3), TDC (3)</p> <p>SOR: C</p>
	<p>LW-CP-3 – While building on general skills and competencies for supporting this population, community health workers will be trained to understand the particular challenges of working with this population.</p> <p><i>Explanation:</i></p> <p>Roles and boundaries can sometimes become blurred and confusing because of issues around territoriality, control, attachment, autonomy, etc. Community health workers (and others working in the home) need training to address these issues. In addition, there is a need for training on safety issues and communication approaches.</p> <p>Sources (LOE): ASBC (3)</p> <p>SOR: C</p>
<p><i>Respect and dignity</i></p>	<p>LW-CP-4 – Health care providers will use a person-centred philosophy of care. The care team will include the person with dementia (when appropriate) and caregivers.</p> <p><i>Explanation:</i></p> <p>In addition to inclusion in the care team, health care providers will use care plans for patients identified as having dementia that include personal and social information (developed by the person with dementia and caregivers). This will enable staff to make the environment as calm, respectful, and personalized as possible. This information will be provided (with the patient’s consent and as appropriate) to all personnel who come in contact with the patient (including food service and cleaning staff).</p> <p>Sources (LOE): TDC (3), CI PG (3), ASBC (3), IH (3), NH (3), VCH (3), VIHA (3)</p> <p>SOR: C</p>
<p><i>Comprehensive and continuous care</i></p>	<p>LW-CP-5 – Health care providers will support people with dementia and their caregivers based on the best-known practices. These supports will help people with dementia and their caregivers plan for the future and attain the best treatments and supports available.</p> <p><i>Explanation:</i></p> <p>Important supports include:</p> <ul style="list-style-type: none"> • Developing concrete strategies for monitoring of care and health status • Providing ethical care (including disclosure of diagnosis) • Offering information on and support for self-management issues • Offering information and resources about adapting the home environment • Providing supportive care and offering information that will assist in making decisions (including advance care planning and nutrition throughout the disease process)

Level of Health Status: Living with Dementia	Level of Care: Care Providers
Theme	Recommendations
	<ul style="list-style-type: none"> • Providing appropriate pharmacologic management, including the latest developments in medication for people with mild to moderate dementia of the Alzheimer’s type – for example, consideration of a trial of treatment with acetyl cholinesterase inhibitors (AChEIs) • Offering information and access to non-pharmacological interventions • Ensuring access to transition planning support • Diagnosing, monitoring, and assisting to manage co-morbid conditions (including depression and delirium) • Providing information and support for secondary and tertiary prevention strategies • Ensuring that individuals with dementia have their psychosocial needs met • Assessing and monitoring for pain and advocating for the appropriate treatment (particularly important when the person with dementia can no longer communicate verbally) • Offering information and access to caregiver support • Counselling and support that addresses the losses for the person with dementia as the disease progresses • Counselling and support that addresses cross-generational issues created by the dementia (e.g., grandchildren) • Providing information and access to involvement with other services, including community care, mental health, and other specialty services • Providing people living with dementia and their caregivers who chose to live at home with specific supports, including flexible home support, education, respite flexibility, urgent and emergent respite, equipment, and strong support for family caregivers • Providing correct information and support in order to make substitute decisions for health care as appropriate • Awareness of the potential risks for self-neglect, and neglect and abuse by caregivers and others (financial or psychological abuse) • Knowledge of how to do the preliminary assessment for neglect and abuse and referral to a designated agency for further assessment and action • Providing good oral care to individuals with dementia (from CARMHA) • Ensuring that individuals with dementia receive an annual vaccination for influenza (subject to informed consent) • Providing information and understanding of the law of consent in BC and providing accurate information and appropriate support when substitute decisions are made • Understanding the legislation and professional responsibilities related to driving assessment and approved process leading to driving cessation, and support to caregivers when they are coping with issues related to driving cessation <p>Sources (LOE): TDC (3), ASBC (3), IH (3), VCH (3), CI PG (3)</p> <p>SOR: C</p>

Level of Health Status: Living with Dementia	Level of Care: Care Providers
Theme	Recommendations
	<p>LW-CP-6 – Health care providers in all sectors will provide support to the caregivers of people with dementia.</p> <p><i>Explanation:</i></p> <p>Dementia caregiving is highly complex and variable. Regardless of the type of dementia, individuals in the middle phase of dementia generally experience enough loss in cognitive ability that they are increasingly dependent on their caregivers for basic daily living help. The resulting caregiving can be both an uncertain and stressful experience (as well as a personal journey of discovery and unrealized potential).</p> <p>Health care providers will recognize and respect the role of caregivers, provide adequate support to caregivers, and will ask about the caregivers’ needs, coping strategies, support system, and burden. They will also offer respite for caregivers.</p> <p>Sources (LOE): IH (3), CARMHA (3)</p> <p>SOR: C</p>
	<p>LW-CP-7 – Health care providers will support the protection of all, while basing safety interventions on a least-restraint philosophy. Physical and chemical restraints exacerbate dementia-related behaviours and should be avoided except in circumstances of immediate risk to the person and/or others.</p> <p><i>Explanation:</i></p> <p>Health care providers will support people with dementia and/or their decision makers in making appropriate and individualized decisions based on the principle of “least invasive care choices or options” that provide balance between the safety needs of persons with dementia and their rights to personal autonomy, choice, and control. There should be ongoing monitoring to ensure that health status changes are noticed and responded to, with a focus on a therapeutic environment, creative strategies, and the outcomes for the person.</p> <p>Sources (LOE): NH (3), TDC (3), IH (3)</p> <p>SOR: C</p>
	<p>LW-CP-8 – Health care providers will offer counselling to individuals of all ages on how to minimize and address vascular risk factors and diabetes mellitus.</p> <p>Sources (LOE): FH (3), IH (3)</p> <p>SOR: C</p>
	<p>LW-CP-9 – Health care providers will be knowledgeable about, and committed to, meeting the needs of culturally diverse clients.</p> <p>Sources (LOE): TDC (3), FH (3), VCH (3)</p> <p>SOR: C</p>
	<p>LW-CP-10 – Health care providers will coordinate and share information among themselves (e.g., diagnosis, care management and pharmacotherapy guidelines, representation agreements, utilization reporting, and improved access to information).</p> <p>Sources (LOE): BCMA BB (3), VCH (3), IH (3)</p> <p>SOR: C</p>

Level of Health Status: Living with Dementia	Level of Care: Care Providers
Theme	Recommendations
	<p>LW-CP-11 – The general practice physician (or primary care practitioner or team) will incorporate a chronic disease management (CDM) approach that facilitates proactive care and support.</p> <p><i>Explanation:</i></p> <p>This specific approach is based on known good practice and is being adopted in British Columbia for a range of chronic conditions. The approach includes:</p> <ul style="list-style-type: none"> • Establishing a disease registry and recall system for patients for review in a timely manner • Reassessing patients at planned visits dedicated solely to the care of dementia • Using a clinical action plan to address dementia and co-morbid conditions • Establishing a relationship with the person with dementia and family/caregivers, and involving them as much as possible in setting goals and making decisions related to care and support <p>Sources (LOE): CI PG (3), VIHA (3)</p> <p>SOR: C</p>
	<p>LW-CP-12 – Health care providers will involve appropriate team members/specialty resources and will consider referral to required integrated services for the assessment of dementia in appropriate cases, such as:</p> <ul style="list-style-type: none"> • Management issues that are difficult to resolve • Risk of harm to self or others • Request of client, family, or caregivers <p>Sources (LOE): CI PG (3), IH (3)</p> <p>SOR: C</p>
	<p>LW-CP-13 – Health care providers will ensure that individuals with dementia receive appropriate pain assessment and adequate pain management.</p> <p><i>Explanation:</i></p> <p>Pain in advanced dementia is difficult to assess and requires a combination of patient report, caregiver report, and direct observations. Pain is often undetected and under-treated for those with dementia compared with those without. There are a variety of pain assessment tools but none that are definitive for non-communicative individuals with dementia.</p> <p>Sources (LOE): CARMHA (1)</p> <p>SOR: A</p>
Behaviour management	<p>LW-CP-14 – Care providers will use creative strategies to determine the reason for, or meaning of, agitated, “dementia-related” behaviours.</p> <p><i>Explanation:</i></p> <p>Care providers should be knowledgeable about the behaviours in later stages of dementia and be skilled in coping with these behaviours in a manner that respects and preserves the dignity of the person with dementia. This reduces distress for the person, and the use of psychotropic medications is decreased.</p> <p>When behavioural and psychological symptoms of dementia (BPSD) occur, health care providers <i>should establish</i> an understanding of the origins of the behaviours before developing a management strategy.</p> <p>Health care providers should recommend environmental and behavioural modifications as first-line management for the behavioural and psychological symptoms of dementia.</p>

Level of Health Status: Living with Dementia		Level of Care: Care Providers
Theme	Recommendations	
	<p>Sources (LOE): CI PG (3), IH (3), NH (3), FH (3), VCH (3)</p> <p>SOR: C</p>	
<i>Research</i>	<p>LW-CP-15 – Care providers will provide people with dementia and their caregivers with full and transparent information about the value, as well as the risks and costs, of participating in research.</p> <p>Sources (LOE): FH (3), ASBC (3)</p> <p>SOR: C</p>	



Living with Dementia – Support Systems

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Living with Dementia Goals

1. To promote and support the quality of life for people living with dementia
2. To promote and support the quality of life for caregivers of people living with dementia



- Themes for Support System Actions When Living with Dementia**
- Supporting access to dementia education
 - Sustaining human resource capacity
 - Providing comprehensive and coordinated care
 - Creating dementia-appropriate residential care
 - Building community capacity through partnership and planning
 - Accessible services

Level of Health Status: Living with Dementia	Level of Care: Support Systems
Theme	Recommendations
<i>Supporting access to dementia education</i>	<p>LW-SS-1 – Agencies and organizations will ensure access to education on dementia and dementia care throughout the province for the following groups of people:</p> <ul style="list-style-type: none"> • The general public • Individuals living with dementia • Caregivers of people with dementia • Care providers of people with dementia, including those working in acute care settings, assisted-living environments, long-term care settings, adult day programs, and the community <p><i>Explanation:</i> Education will strengthen awareness, provide information, and increase community and transition support for people with dementia and their caregivers.</p> <p>Sources (LOE): TDC (3), FH (3), IH (3)</p> <p>SOR: C</p>
<i>Sustaining human resource capacity</i>	<p>LW-SS-2 – Agencies and organizations will provide frontline staff with a range of supports for working with people with dementia and their caregivers (across all phases of the disease).</p> <p><i>Explanation:</i> These supports include:</p> <ul style="list-style-type: none"> • A work environment that supports providers in their clinical practice • Consistent access to adequate supervisory assistance and support • Access to resources to assist in meeting the needs of culturally diverse clients • Appropriate staffing levels and time allotted to meet diverse and extensive client needs • Continuity in care and consistent client assignment as appropriate to client need • Comprehensive, coordinated, and ongoing education available for all staff (including non-professional staff such as food and cleaning service workers). <i>See CARE PROVIDERS (pages 90 and 94 for detailed examples of required education).</i> <p>Sources (LOE): TDC (3), ASBC (3), VCH (3), VIHA (3), IH (3)</p> <p>SOR: C</p>

Level of Health Status: Living with Dementia	Level of Care: Support Systems
Theme	Recommendations
<i>Providing comprehensive and coordinated care</i>	<p>LW-SS-3 – Agencies and organizations will provide an array of flexible support services to support caregivers and enable people with dementia to stay at home as long as possible, such as access to enhanced resources/services during periods of crisis and transition.</p> <p>Explanation:</p> <p>Dementia and dementia care are characterized by periods of stability, crisis, and transitions. The following are important supports and services that should be available to support care, to avoid crises, and to smooth transitions:</p> <ul style="list-style-type: none"> • Counselling and support for caregivers • Flexible care options, including: extended home support hours (beyond the standard monthly hours limitation), overnight respite care, short-term residential care (respite), emergency support, enhanced day programs, and day hospital • Home support services available for tasks needed by people with dementia and their caregivers, such as cooking, cleaning, and shopping • Affordable and accessible options for instrumental activities of daily living such as shopping, banking, laundry, and housecleaning • Additional hours of home support for night care and for people with end-stage dementia • Ambulatory and inpatient options for assessment and treatment, where required • Accessible community geriatric services <p>Sources (LOE): FH (3), BCMA BB (3), TDC (3), IH (3), ASBC (3), VIHA (3), VCH (3)</p> <p>SOR: C</p> <hr/> <p>LW-SS-4 – Health organizations and agencies will implement policies that support the caregiver as a client with his or her own right to access care and services.</p> <p>Sources (LOE): IH (3)</p> <p>SOR: C</p> <hr/> <p>LW-SS-5 – Organizations and agencies will institute effective processes whereby people with dementia and their caregivers will have input and participation in the development of policies and programs relevant to their care.</p> <p>Sources (LOE): ASBC (3)</p> <p>SOR: C</p> <hr/> <p>LW-SS-6 – Organizations and agencies will provide a clinical information summary and a copy of current care plan (paper or electronic) for patients with dementia that is accessible to health care professionals across the health care system.</p> <p>Sources (LOE): BCMA BB (3)</p> <p>SOR: C</p> <hr/> <p>LW-SS-7 – Organizations and agencies will ensure that care providers refer people with dementia and their caregivers to the Alzheimer Society of BC for information, self-advocacy strategies, support, and education, with the expectation of the Society to provide that information, education, and support.</p> <p>Sources (LOE): ASBC (3), VCH (3), IH (3)</p> <p>SOR: C</p>

Level of Health Status: Living with Dementia	Level of Care: Support Systems
Theme	Recommendations
	<p>LW-SS-8 – Organizations and agencies (including government and health authorities) will develop incentives to improve the linkages between family physicians/primary care providers, specialized geriatric providers, care managers, and other care providers and coordinators.</p> <p>Sources (LOE): BCMA BB (3), IH (3)</p> <p>SOR: C</p>
<i>Creating dementia-appropriate residential care</i>	<p>LW-SS-9 – All residential care facilities will be designed (taking into account the whole building) as a dementia care friendly environment, making due allowance for appropriate subenvironments for individuals with other complex care needs who are cognitively intact.</p> <p>Explanation:</p> <p>Projected demographics indicate that the majority of people needing residential care will be people with dementia. These people and their caregivers should expect that agencies and organizations will ensure access to environments that are designed specifically to enable freedom and enhance independence for individuals with dementia.</p> <p>Sources (LOE): TDC (3), VIHA (3)</p> <p>SOR: C</p>
	<p>LW-SS-10 – Agencies and organizations will provide dementia-appropriate staffing levels and staff mix in residential facilities, to ensure time to meet diverse and extensive client needs.</p> <p>Explanation:</p> <p>This includes staffing levels and mix that support multidisciplinary assessment and reviews and ongoing care planning, and that ensure dedicated care leaders who are trained and focused on individualized care.</p> <p>Sources (LOE): TDC (3), FH (3), VIHA (3)</p> <p>SOR: C</p>
<i>Building community capacity through partnership and planning</i>	<p>LW-SS-11 – Health organizations and agencies will establish ongoing linkages and partnerships with other community-based agencies and organizations (e.g., the Alzheimer Society and its volunteers, municipalities, parks and recreation associations, seniors' associations) to create an ongoing and collaborative understanding of community needs with regard to dementia and to model and mentor in providing dementia-friendly services.</p> <p>Sources (LOE): VIHA (3), IH (3), FH (3), VCH (3)</p> <p>SOR: C</p> <p>LW-SS-12 – The Ministry of Health, in conjunction with health authorities, will evaluate planned and existing community resources available to support people living with dementia, based on the projected distribution of seniors. This information should be made available to the public.</p> <p>Explanation:</p> <p>Care options may include independent care; semi-dependent care, including home health and supportive housing; assisted living; complex care, including acute geriatric programs/beds; and options for very late stage dementia.</p> <p>Sources (LOE): BCMA BB (3), FH (3), ASBC (3)</p> <p>SOR: C</p>

Level of Health Status: Living with Dementia		Level of Care: Support Systems
Theme	Recommendations	
	<p>LW-SS-13 – Organizations and agencies (including the Ministry of Health and health authorities) will work with the physician system to improve the data collection and sharing of aggregate data on dementia. This would include the development of a minimum data set for dementia patients.</p> <p>Sources (LOE): BCMA BB (3)</p> <p>SOR: C</p>	
	<p>LW-SS-14 – Agencies and organizations responsible for services will follow guidelines that use a chronic disease management approach, have a strong commitment to a clear philosophy of person-centred care, and support and adjust programs according to evaluation of all elements of dementia care.</p> <p>Sources (LOE): TDC (3), FH (3), VIHA (3)</p> <p>SOR: C</p>	
<i>Accessible services</i>	<p>LW-SS-15 – Agencies and organizations responsible for planning and delivering dementia-specific programs and services will provide services that are at accessible locations in the community, e.g., near a hospital, near parking, no stairs.</p> <p>Sources (LOE): FH (3)</p> <p>SOR: C</p>	



Living with Dementia – Health Care Environment

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Living with Dementia Goals

1. To promote and support the quality of life for people living with dementia
2. To promote and support the quality of life for caregivers of people living with dementia



- Themes for Health Care Environment Actions When Living with Dementia**
- Reducing the stigma associated with dementia
 - Improving knowledge about dementia
 - Creating dementia-sensitive policy
 - Planning for improvements in dementia care
 - Supporting a dementia research agenda

Level of Health Status: Living with Dementia	Level of Care: Health Care Environment
Theme	Recommendations
<i>Reducing the stigma associated with dementia</i>	<p>LW-HCE-1 – Public and private sector policy makers will collaborate to ensure that the entire community is an assistive environment, accepting and supportive of its members living with dementia, and enabling them to function as well as possible in the community. This will include educating the general public on dementia to decrease fear and ageist values and attitudes.</p> <p>Sources (LOE): TDC (3), VIHA (3), IH (3)</p> <p>SOR: C</p>
<i>Improving knowledge about dementia</i>	<p>LW-HCE-2 – Institutions with a role in the education and continuing education of health care providers will <i>ensure</i> a coordinated and improved geriatric content in schools of medicine, nursing, rehabilitation, pharmacy, social work, home support, and other relevant training curriculum.</p> <p>Explanation: Appropriate training is one element of ensuring the appropriate care in the future for a growing number of individuals who will be living with dementia. In addition to training, there is a need to create a uniform policy about payments and incentives for practitioners in this field (including physicians).</p> <p>Sources (LOE): FH (3)</p> <p>SOR: C</p>
<i>Creating dementia-sensitive policy</i>	<p>LW-HCE-3 – Policy makers will ensure that policy on financial assistance to compensate or offset expenses incurred by people living with dementia, their caregivers, and families of people with dementia is evaluated and adjusted accordingly.</p> <p>Sources (LOE): TDC (3), FH (3)</p> <p>SOR: C</p> <hr/> <p>LW-HCE-4 – Government will ensure that provincial policy supports access to a range of affordable and accessible community-based services to support the needs of people with dementia and their caregivers through all stages and transitions of dementia.</p> <p>Explanation: Current policies often limit community-based services to priorities that do not align with need; therefore, current service models often do not adequately address the needs of persons with dementia or those of their caregivers. For example:</p> <ul style="list-style-type: none"> • The appropriate amount and type of home care services for the needs of persons with dementia and their caregivers are often not available • The assisted-living model does not appropriately meet the needs of people with dementia on key issues such as medication management, nutrition, safety, and supervision <p>Sources (LOE): TDC (3), ASBC (3), BCMA BB (3)</p> <p>SOR: C</p> <hr/> <p>LW-HCE-5 – Policy makers will evaluate access to anti-dementia medication to ensure that all people with dementia have equal access to anti-dementia medication.</p> <p>Explanation: In addition, BC physicians will be provided with ongoing information on dementia pharmacotherapy.</p> <p>Sources (LOE): TDC (3), CI PG (3), FH (3)</p> <p>SOR: C</p>

Level of Health Status: Living with Dementia	Level of Care: Health Care Environment
Theme	Recommendations
<i>Planning for improvements in dementia care</i>	<p>LW-HCE-6 – Policy makers will ensure that dementia care is provided in appropriate care environments and facilities.</p> <p>Explanation:</p> <p>Based on current demographic and disease projections, the various systems of facility care should be primarily designed with people with dementia in mind.</p> <p>This includes assisted-living facilities that are designed for people with dementia in the earlier stages. The prioritization policy mechanisms will ensure equitable access to long-term care facilities.</p> <p>All residential care facilities should be designed in full for dementia care, making allowance for appropriate subenvironments for individuals needing complex care.</p> <p>Sources (LOE): TDC (3), BCMA BB (3), VIHA (3)</p> <p>SOR: C</p> <hr/> <p>LW-HCE-7 – Government will develop a provincial human resource plan that addresses the recruitment and retention of health care providers with the knowledge, skills, and abilities to prevent, diagnose, treat, and support persons with dementia and their families.</p> <p>Sources (LOE): FH (3)</p> <p>SOR: C</p> <hr/> <p>LW-HCE-8 – Government will support the development of innovative models of service delivery for people living with dementia. Policy makers will ensure that there is ongoing provincial-level evaluation of dementia care programs and services and that policy and plans are adjusted accordingly.</p> <p>Explanation:</p> <p>In addition to broad provincial-level evaluation and improvement efforts, this could include each health authority’s implementation of a demonstration project with an innovative model (or models) of service for people living with dementia. Evaluation results can be shared and emerging best practices adopted and standards established.</p> <p>Sources (LOE): FH (3), VIHA (3)</p> <p>SOR: C</p>
<i>Supporting a dementia research agenda</i>	<p>LW-HCE-9 – Policy makers will develop, in conjunction with stakeholders, a dementia research agenda that includes research on best practice in care and services for supporting and caring for people living with dementia and their caregivers.</p> <p>Sources (LOE): FH (3)</p> <p>SOR: C</p>

Note: Some Health Care Environment recommendations in the Staying Healthy, Getting Better, and End of Life sections are also applicable to this section.

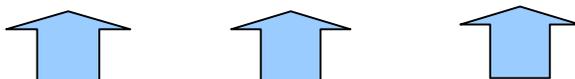


Getting Better from Periods of Episodic Decline – Individual

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Getting Better from Periods of Episodic Decline Goals

1. To promote optimal health for people living with dementia as they experience periods of decline in health
2. To promote optimal support for caregivers of those living with dementia during times when those they care for experience episodic decline in health
3. To ensure that intervention, active planning, and supportive action are there for the person with dementia and caregiver for successful transitions in care



Themes for Individual Actions When Getting Better from Periods of Episodic Decline

- [Activated partners in care](#)
- [Advance life and care planning](#)

Level of Health Status: Getting Better from Periods of Episodic Decline		Level of Care: Individual
Theme	Recommendations	
<i>Activated partners in care</i>	<p>GB-I-1 – Families and caregivers for people with dementia will notice changes in cognition, behaviour, mood, or function and report these to their physician or specialist team (e.g., mental health) for further investigation and follow-up as required. They will expect their memory complaints to be taken seriously, assessed and reported to their physician, or referred to a specialist team (e.g., mental health).</p> <p>Resources:</p> <ul style="list-style-type: none"> • IH Tool Kit <p>Sources (LOE): IH (3)</p> <p>SOR: C</p>	
	<p>GB-I-2 – The families and caregivers of people with dementia will ensure that the correct information and support are in place in order to act as substitute decision-makers for health care decisions.</p> <p>Sources (LOE): ASBC (3)</p> <p>SOR: C</p>	
<i>Advance life and care planning</i>	<p>GB-I-3 – People diagnosed with dementia and their caregivers will ensure that:</p> <ul style="list-style-type: none"> • The legal tools available are utilized to appoint and advise a substitute decision maker • The person’s concerns and wishes are in writing • Life and care plans are reviewed and updated • These wishes are being used to guide decision making when the person with dementia is no longer able to speak for himself or herself <p>Sources (LOE): TDC (3), VCH (3), ASBC (3)</p> <p>SOR: C</p>	



Getting Better from Periods of Episodic Decline – Care Providers

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Getting Better from Periods of Episodic Decline Goals

1. To promote optimal health for people living with dementia as they experience periods of decline in health
2. To promote optimal support for caregivers of those living with dementia during times when those they care for experience episodic decline in health
3. To ensure that intervention, active planning, and supportive action are there for the person with dementia and caregiver for successful transitions in care



Themes for Care Provider Actions When Getting Better from Periods of Episodic Decline

- Education to increase the ability to support transitions through episodic decline
- Support for the caregiver
- Acute events and behaviour management
- Easing transitions

Level of Health Status: Getting Better from Periods of Episodic Decline	Level of Care: Care Providers
Theme	Recommendations
<p><i>Education to increase the ability to support transitions through episodic decline</i></p>	<p>GB-CP-1 – Health care providers (all professions) in all settings will access current information and education that support them in providing optimal care during periodic episodes of decline and during transitions.</p> <p>They will be knowledgeable about the common conditions that cause episodic decline and about Dementia Care Pathways related to episodic decline.</p> <p><i>Explanation:</i></p> <p>The information will help health care providers strengthen their own awareness of the disease, increase their ability to support transitions for persons with dementia and their caregivers, and improve their ability to provide quality support and information to people with dementia and caregivers.</p> <p>Examples of information and education related to periods of episodic decline and transitions are:</p> <ul style="list-style-type: none"> • Recognizing the gravity of a change in state of health, which should lead to an assessment • Managing co-morbidities • Understanding the sensitivity needed due to the stress of moving between care settings • Utilizing the family’s knowledge of the person with dementia • Communicating effectively and respectfully with individuals who have a dementia by understanding their verbal, non-verbal, and behavioural cues • Perceiving and supporting the individuals’ remaining capabilities on a day-by-day basis so that they can function as independently as possible • Helping the caregiver establish and maintain an environment that contains a good balance of stimulation, support, and safety (or, in the case of adult day program or community centre staff, enhancing the program setting in the same way) • Helping the caregiver to deal with his/her own needs <p>Sources (LOE): TDC (3), FH (3), VIHA (3), IH (3), ASBC (3)</p> <p>SOR: C</p>
<p><i>Support for the caregiver</i></p>	<p>GB-CP-2 – Health care providers will recognize the importance of communication with families and caregivers when a person with dementia is transferred from one care transition to another.</p> <p>Sources (LOE): CI PG (3), VCH (3), VIHA (3), IH (3), ASBC (3)</p> <p>SOR: C</p>

Level of Health Status: Getting Better from Periods of Episodic Decline	Level of Care: Care Providers
Theme	Recommendations
	<p>GB-CP-3 – During periods of decline, health care providers will ask caregivers about their needs, coping strategies, support system, and burden. Health care providers will recognize, respect, and provide adequate support to the caregiver.</p> <p><i>Explanation:</i></p> <p>Planning and referral will be addressed and encouraged for:</p> <ul style="list-style-type: none"> • Respite support • Counselling and support to address issues such as the losses for persons with dementia, their support network as the dementia progresses, and cross-generational issues created by the dementia (e.g., grandchildren) <p>Health care providers will refer people at risk, people with dementia, and their caregivers to the Alzheimer Society of BC (if not already connected), for information, self-advocacy strategies, support, and education.</p> <p>Health care providers will refer people with dementia and their caregivers to the BC Nurseline for assistance with decisions during periods of episodic decline.</p> <p>The families and caregivers of people with dementia can expect that service providers will be attuned to the needs of people with dementia who live alone, monitoring their ability to manage and providing the requisite support as necessary.</p> <p>Sources (LOE): CI PG (3), TDC (3), IH (3), VCH (3), VIHA (3), ASBC (3), IH (3)</p> <p>SOR: C</p>
<p><i>Acute events and behaviour management</i></p>	<p>GB-CP-4 – Health care providers (in all settings) will support people with dementia and their caregivers, to prevent, recognize, and self-refer to assist in managing acute behavioural disturbances.</p> <p><i>Explanation:</i></p> <p>People with dementia who experience depression and/or delirium (and their caregivers) should expect interdisciplinary health care providers to be guided by practice recommendations concerning:</p> <ul style="list-style-type: none"> • Prevention • Early recognition • Screening • Assessment • Referral • Treatment • Support <p>Sources (LOE): BCMA BB (3), IH (3)</p> <p>SOR: C</p>
<p><i>Easing transitions</i></p>	<p>GB-CP-5 – Health care providers will work together to increase and improve communication between specialists, primary care physicians, and staff in community care services, long-term care facilities, assisted-living facilities, mental health services, adult day programs, and acute care, when working with persons with dementia who experience periods of episodic decline.</p> <p>Sources (LOE): TDC (3), BCMA BB (3), VIHA (3), IH (3)</p> <p>SOR: C</p>

Level of Health Status: Getting Better from Periods of Episodic Decline	Level of Care: Care Providers
Theme	Recommendations
	<p>GB-CP-6 – Health care providers will support individuals with dementia in periods of decline or transition with appropriate care plans.</p> <p><i>Explanation:</i></p> <p>This includes personal and social information to enable staff to make the psychosocial environment as calm, respectful, and personalized as possible – to communicate effectively in a way that enhances abilities and minimizes stress. This information is provided to all personnel who come in contact with the patient, including food service and cleaning staff.</p> <p>It also means involving community staff and primary care providers who have been working with the person with dementia and family in care planning to provide continuity of care and to give a perspective on the person’s usual level of functioning, and developing discharge plans that are appropriate and prepared well before the person with dementia is discharged back into the community or to a long-term care facility.</p> <p>Sources (LOE): TDC (3), CI PG (3), VIHA (3), IH (3), NH (3)</p> <p>SOR: C</p>
	<p>GB-CP-7 – Health care providers will be knowledgeable about community services, to be able to link and refer effectively to other services in the process of care, during episodic decline.</p> <p><i>Explanation:</i></p> <p>Some of these services include:</p> <ul style="list-style-type: none"> • The Alzheimer Society of BC (ASBC) • Consultation of a dementia specialist (geriatrician, neurologist, psychiatrist) when diagnosis or management is problematic • Referral to Home and Community Care Services for long-term case management, home support, respite care, adult day care, and transitions to alternate living situations • Referral to Community Mental Health and Addictions Services for significant and complex mental health conditions affecting the health and care of the patient and caregiver • Counselling and support for caregivers • Flexible residential care options, including extended home support hours, overnight respite care, short-term residential care, enhanced day programs, and day hospital • Affordable options for transportation <p>Sources (LOE): CI PG (3), FH (3), VIHA (3), IH (3)</p> <p>SOR: C</p>
	<p>GB-CP-8 – Care providers will ensure that assessments of cognitive and functional ability and behaviour are ongoing and <i>not</i> finalized until the patient (or resident) has recovered from relocation stress (e.g., hospitalization or admission to residential care). This timeframe may be from days to weeks.</p> <p>Sources (LOE): NH (3)</p> <p>SOR: C</p>



Getting Better from Periods of Episodic Decline – Support Systems

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Getting Better from Periods of Episodic Decline Goals

1. To promote optimal health for people living with dementia as they experience periods of decline in health
2. To promote optimal support for caregivers of those living with dementia during times when those they care for experience episodic decline in health
3. To ensure that intervention, active planning, and supportive action are there for the person with dementia and caregiver for successful transitions in care



Themes for Support System Actions When Getting Better from Periods of Episodic Decline

- Supporting access to education
- Respect and support for the caregiver (during periods of episodic decline)
- Dementia-sensitive acute care
- Providing comprehensive and coordinated care
- System planning

Level of Health Status: Getting Better from Periods of Episodic Decline	Level of Care: Support Systems
Theme	Recommendations
<i>Supporting access to education</i>	<p>GB-SS-1 – Agencies and organizations will support their staff in all settings to provide interdisciplinary, comprehensive dementia care through access to comprehensive information, training and education on prevention, early recognition and management of episodes of decline, and the impact of the dementia and episodic decline on persons with dementia and their caregivers.</p> <p>Explanation: Every person’s experience with dementia is different. Health care providers need to be guided by their knowledge of specific dementias to better evaluate the person with dementia and the caregiver experiences. Ongoing continuing education and clinical consultation resources are required to achieve this.</p> <p>Sources (LOE): TDC (3), FH (3), CI PG (3), VIHA (3), IH (3), ASBC (3)</p> <p>SOR: C</p>
<i>Respect and support for the caregiver (during periods of episodic decline)</i>	<p>GB-SS-2 – Agencies and organizations responsible for planning and delivering dementia-specific programs and services will develop services that value and support the caregiver in caring for and supporting the person with dementia during periods of episodic decline.</p> <p>Explanation: Organizations and agencies should ensure that:</p> <ul style="list-style-type: none"> • Meaningful information and resources are available • Services are accessible and timely • Services are relevant to and supportive of all the phases of dementia (i.e., no gaps across the dementia spectrum), recognizing the individualized nature of the condition for each person • Services and information are flexible and adaptive to the needs of both the person with dementia and the caregiver, as every experience with dementia is different • Services and information are culturally sensitive and relevant <p>Examples of the range and types of services that are considered supportive to the caregiver and the person with dementia are (regardless of geographic locations):</p> <ul style="list-style-type: none"> • Support for staying at home as long as feasible • Knowledgeable clinicians and specialized dementia resources • Planning for life course – transitions and decisions • Enhanced services for crisis and transitions <p>Sources (LOE): TDC (3), BCMA BB (3), CI PG (3), FH (3), IH (3), VCH (3)</p> <p>SOR: C</p>

Level of Health Status: Getting Better from Periods of Episodic Decline	Level of Care: Support Systems
Theme	Recommendations
<i>Dementia-sensitive acute care</i>	<p data-bbox="393 346 1464 499">GB-SS-3 – Agencies and organizations responsible for the provision of acute care services will ensure that the acute care environment (i.e., culture, setting, processes, and practice) is sensitive and appropriate for people with dementia and their caregivers. Individuals with dementia and their caregivers expect that acute care environments will be adapted and accommodated to the needs of the person with dementia.</p> <p data-bbox="393 516 537 543">Explanation:</p> <p data-bbox="393 560 1464 617">The following list includes evidence-based approaches to ensuring a sensitive and appropriate acute care environment:</p> <ul data-bbox="393 634 1464 1549" style="list-style-type: none"> <li data-bbox="393 634 743 661">• Acute geriatric programs/beds <li data-bbox="393 678 1464 735">• Minimization of physical hazards, including provision of appropriate mobility aids, good lighting and nightlights, and reduction of obstructions underfoot <li data-bbox="393 751 1464 877">• Design and furnishings that promote independence, such as chairs designed for independent transfer; visual cues for way finding, continence management and orientation (clocks, calendars, etc.), minimizing visibility of unsafe areas, making provision for the safety of people who may get lost (wandering alert system) <li data-bbox="393 894 1464 982">• A calm milieu conducive to the patient’s best functioning by reducing extraneous visual and auditory “clutter” (e.g., unnecessary noise, furniture and equipment lying about) and intrusion without warning into the person’s space <li data-bbox="393 999 1414 1056">• Helping visitors to support and stimulate patients, e.g., by providing privacy and comfortable seating <li data-bbox="393 1073 1317 1100">• Employing principles of elder-friendly design when redecorating or upgrading units <li data-bbox="393 1117 1464 1270">• Staffing of emergency services with clinicians who are knowledgeable about dementia, who have a high suspicion for dementia, and who will have the ability and resources to appropriately respond to the acute emergent needs of the person with dementia; alternatively, appropriate services to address the acute emergent needs of persons with dementia and their caregivers (e.g., acute behavioural problems). <li data-bbox="393 1287 1464 1344">• Clinical practice that is holistic (i.e., clinicians assess the whole person – not just the cause for the acute care episode) and based on a shared care model <li data-bbox="393 1360 1442 1417">• Development of appropriate interdisciplinary discharge plans prior to discharging a person with dementia back into the community or to a long-term care facility <li data-bbox="393 1434 1016 1461">• Training in dementia care for staff in acute care settings <li data-bbox="393 1478 1425 1535">• Availability of interdisciplinary discharge/transition teams to support the transition from acute care to other settings <p data-bbox="393 1560 1122 1587">Sources (LOE): TDC (3), IH (3), FH (3), BCMA BB (3), VIHA (3)</p> <p data-bbox="393 1604 480 1631">SOR: C</p>

Level of Health Status: Getting Better from Periods of Episodic Decline	Level of Care: Support Systems
Theme	Recommendations
<i>Providing comprehensive and coordinated care</i>	<p>GB-SS-4 – Agencies and organizations will support increased and improved communication and linkages between specialists, primary care physicians and staff, community care services, long-term care facilities, assisted living, mental health services, acute care, and family caregivers, specific to periods of episodic decline and transition. This includes support for the use of electronic health records and the inclusion of general practitioners/primary care providers in care planning and follow-up.</p> <p>Explanation:</p> <p>Acute care staff will communicate with general practitioners and community care providers to understand baseline functioning of the patient and the existing care plan. Community and primary care providers will maintain continuity of care planning and support to the person with dementia and caregiver during episodes of acute/emergent care.</p> <p>Sources (LOE): TDC (3), IH (3), VIHA (3)</p> <p>SOR: C</p>
<i>System planning</i>	<p>GB-SS-5 – Agencies and organizations will have services and programs developed specifically to meet the transition needs and risks of people in early, mid, and late stages of dementia, during periods of episodic decline.</p> <p>Explanation:</p> <p>Services and programs will follow guidelines that:</p> <ul style="list-style-type: none"> • Integrate the principles and goals of excellent dementia care • Use a chronic disease management approach • Are based on Canadian Consensus Guidelines • Are informed by people affected by dementia • Ensure linkages with community support and partnerships, particularly the Alzheimer Society and its volunteers • Include rehabilitation support • Are culturally relevant • Recognize the need to monitor people with dementia who live alone, and develop programs to manage and support this group of people to minimize the risk of relying on emergency care when crises occur <p>Dementia care pathways will be used, and as gaps in services are identified, choices and options will be created for persons with dementia and caregivers (e.g., transportation). Assessment models, care plans, referral, timelines, and care protocols and decision tools will be adapted to ensure timely and appropriate interactions.</p> <p>Sources (LOE): TDC (3), BCMA BB (3), FH (3), IH (3), VCH (3), VIHA (3), NH (3), ASBC (3)</p> <p>SOR: C</p>

Level of Health Status: Getting Better from Periods of Episodic Decline	Level of Care: Support Systems
Theme	Recommendations
	<p>GB-SS-6 – Organizations and agencies will provide continuous services and support for clients and caregivers during periods of episodic decline (e.g., home care support and respite care). They should ensure that organizational structures, policies and procedures, and guidelines for best practice dementia and geriatric care are in place to support comprehensive integrated care. They should ensure that service delivery approaches, including staffing levels and time allotted, meet the diverse and extensive client needs during periods of transition.</p> <p><i>Explanation:</i> Having in place mechanisms for ongoing evaluation of dementia care and identification of opportunities for continuous improvement (i.e., establishing indicators and following up) will help to resolve system issues that prevent comprehensive and coordinated care.</p> <p>Sources (LOE): BCMA BB (3), TDC (3), VIHA (3), IH (3), ASBC (3)</p> <p>SOR: C</p>



Getting Better from Periods of Episodic Decline – Health Care Environment

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Getting Better from Periods of Episodic Decline Goals

1. To promote optimal health for people living with dementia as they experience periods of decline in health
2. To promote optimal support for caregivers of those living with dementia during times when those they care for experience episodic decline in health
3. To ensure that intervention, active planning, and supportive action are there for the person with dementia and caregiver for successful transitions in care



Themes for Care Provider Actions When Getting Better from Periods of Episodic Decline

- Planning for improvements in dementia care
- Improving knowledge about dementia

Level of Health Status: Getting Better from Periods of Episodic Decline	Level of Care: Health Care Environment
Theme	Recommendations
<i>Planning for improvements in dementia care</i>	<p>GB-HCE-1 – Policy makers will ensure that persons with dementia in British Columbia (including those who are experiencing periodic episodes of decline) receive equitable access to services that address their needs for:</p> <ul style="list-style-type: none"> • Appropriate assessment of needs to ensure person/environment fit • Support in their own homes and access to adequate, affordable, and appropriate housing across the continuum of support as needed • Health-related transportation services • Effective transitions (e.g., flow of information, caregiver counselling and support) <p>Sources (LOE): IH (3) SOR: C</p>
<i>Improving knowledge about dementia</i>	<p>GB-HCE-2 – Institutions with a role in the education and continuing education of health care providers will ensure that all health care provider undergraduate, postgraduate, and continuing education programs in the province address the importance of preventing premature institutionalization during a reversible illness and the environmental interventions necessary during an episodic illness (e.g., the danger of dehydration, safety measures, and increased presence of familiar caregiver).</p> <p>Sources (LOE): GMHEI (3) SOR: C</p>

Note: Some Health Care Environment recommendations in the Staying Healthy, Living with Dementia, and End of Life sections are also applicable to this section.



Coping with End of Life – Individual

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Coping with End of Life Goals

1. To ensure that people with dementia move to the end of their life with dignity
2. To ensure that caregivers of people with dementia are supported through and after the end-of-life stage of the dementia journey



Themes for Individual Actions When Coping with End of Life

- Activated partners in care
- Applying planned life and care decisions
- Self-advocacy

Level of Health Status: Coping with End of Life		Level of Care: Individual
Theme	Recommendations	
<i>Activated partners in care</i>	<p>EOL-I-1 – Families and caregivers will advocate for the appropriate care and treatment for the person with dementia. This will include decisions about where the person with dementia will receive the best care at the end of life and that the location is aligned with the person’s expressed values and beliefs. This is particularly important when the person with dementia can no longer communicate verbally.</p> <p>Explanation:</p> <p>Family and caregivers for people at the end-of-life stage of dementia will notice changes in cognition, behaviour, mood, or function and report these to their physician or a specialist team (e.g., mental health) for further investigation and follow-up as required.</p> <p>Individuals at the end-of-life stage of dementia can expect to have their dependent physical care needs routinely met (e.g., toileting, oral care, skin care, nutrition, pain, etc.).</p> <p>Individuals at the end-of-life stage of dementia can expect to have their psychosocial needs met.</p> <p>Sources (LOE): ASBC (3), NH (3), IH (3), CARMHA (1, 2, 3)</p> <p>SOR: C</p>	
	<p>EOL-I-2 – Family members and caregivers will consider requesting additional physical, mental, emotional, and spiritual support as the person with dementia nears the end of life and after their death.</p> <p>Explanation:</p> <p>Family members and caregivers will take responsibility for staying as healthy as possible and for reaching out for help as required. They are also responsible for requesting information on programs developed specifically to meet the end-of-life needs of persons with dementia and their families and caregivers.</p> <p>Sources (LOE): TDC (3), VCH (3), IH (3), FH (3), CARMHA (1, 2)</p> <p>SOR: C</p>	
	<p>EOL-I-3 – Families and caregivers will seek a referral to agencies (e.g., the Alzheimer Society of BC) for information, self-advocacy strategies, support, and education regarding end-of-life decisions and care for the person with dementia.</p> <p>Sources (LOE): ASBC (3)</p> <p>SOR: C</p>	
<i>Applying advance life and care decisions</i>	<p>EOL-I-4 – Families and caregivers of people with dementia will ensure that a person’s values, beliefs, concerns, and wishes have been discussed (and are in writing) and are being used to guide decision making when the individual is no longer able to speak for himself or herself.</p> <p>Explanation:</p> <p>The families and caregivers of people with dementia can expect to receive the correct information and support in order to make substitute decisions for health care as appropriate, and are responsible for asking for clarification if inconsistent information is provided.</p> <p>Sources (LOE): TDC (3), ASBC (3), IH (3), NH (3), VCH (3), VIHA (3)</p> <p>SOR: C</p>	

Level of Health Status: Coping with End of Life		Level of Care: Individual
Theme	Recommendations	
	<p>EOL-I-5 – Families and caregivers will seek information about all the risks and benefits of any medical intervention being considered for the person with dementia at the end of life.</p> <p>Sources (LOE): CARMHA (2)</p> <p>SOR: B</p>	
<i>Self-advocacy</i>	<p>EOL-I-6 – Families and caregivers will consider participation in research to provide the voice and experience of the person with dementia to research on end-of-life care for persons with dementia.</p> <p>Sources (LOE): FH (3)</p> <p>SOR: C</p>	



Coping with End of Life – Care Providers

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Coping with End of Life Goals

1. To ensure that people with dementia move to the end of their life with dignity
2. To ensure that caregivers of people with dementia are supported through and after the end-of-life stage of the dementia journey



Themes for Care Provider Actions When Coping with End of Life

- Providing appropriate care and interventions
- Families and caregivers as partners
- Personal professional development

Level of Health Status: Coping with End of Life	Level of Care: Care Provider
Theme	Recommendations
<i>Providing appropriate care and interventions</i>	<p>EOL-CP-1 – Care providers will have a good understanding of end-of-life care needs for people with dementia and will guide and counsel families and caregivers in that care.</p> <p>Explanation:</p> <p>Health care providers should engage families and caregivers in care planning by:</p> <ul style="list-style-type: none"> • Reviewing expectations for quality of life and intensity of care and support on the part of persons with dementia and their families • Discussing with persons with dementia and their families the initiation or revision of advance care planning, building upon what has already been done • Providing information about, and initiating preventive action on, the disease course in advanced stage/end of life such as: <ul style="list-style-type: none"> – Likelihood of recurrent and inter-current infections – Co-morbidities such as depression, pain • Clarifying specific care decisions pertaining to various treatments/medical practices related to end-of-life treatment and care, such as: <ul style="list-style-type: none"> – Antibiotic therapy – Enteral tube feeding – Oral care as a means of preventing inter-current infections – CPR – Artificial hydration – Transfer to hospital <p>Sources (LOE): ASBC (3), CI PG (3), CARMHA (1, 3)</p> <p>SOR: C</p>
	<p>EOL-CP-2 – Health care providers in palliative care programs will quickly assess for and treat all symptoms associated with end of life, including pain, nausea, and fatigue.</p> <p>Explanation:</p> <p>Pain is common in the Living with Dementia and the Getting Better stages as well as the Coping with End of Life stage, but the individual may be asymptomatic or unable to identify the pain to the care provider because of the dementia. Providers need to maintain a high index of suspicion with agitation or other behavioural changes. Assessment is challenging and requires a combination of patient report, caregiver report, and direct observations.</p> <p>Sources (LOE): ASBC (3), NH (3), CI PG (3), CARMHA (1, 2, 3)</p> <p>SOR: C</p>

Level of Health Status: Coping with End of Life	Level of Care: Care Provider
Theme	Recommendations
<i>Families and caregivers as partners</i>	<p>EOL-CP-3 – Care providers will recognize, respect, and provide adequate support to families and caregivers and include them as active partners of the team.</p> <p>Explanation:</p> <p>Families and caregivers should expect that in partnership with care providers, there will be ongoing monitoring to ensure that health status changes are noticed and responded to, with a focus on a therapeutic environment, creative strategies, and focusing on outcomes at the person level. The family should be satisfied with the assessment and strategy to address process.</p> <p>Sources (LOE): VCH (3), TDC (3), ASBC (3), NH (3), VIHA (3)</p> <p>SOR: C</p>
	<p>EOL-CP-4 – Care providers will give families and caregivers the correct information and support needed to make substitute decisions for the person with dementia at the end of his or her life.</p> <p>Explanation:</p> <p>Care providers will provide family and caregivers with information relevant to end-of-life care for the person with dementia that includes care options (including nutrition), interventions, pharmacological management, non-pharmacological interventions, caregiver support, and the involvement of other services. The information will be provided in a manner that aids the substitute decision maker in making decisions that are consistent with the values, beliefs, and planned life and care decisions of the person with dementia.</p> <p>Sources (LOE): TDC (3), ASBC (3)</p> <p>SOR: C</p>
<i>Personal professional development</i>	<p>EOL-CP-5 – Physicians and other health care providers will increase their knowledge of advance care planning, including skills in implementing decisions previously made by persons with dementia and their families and caregivers; information about interventions commonly required during the end-of-life stage of dementia; and the provision of accurate information and appropriate support when decision making related to end-of-life care, including substitute decisions, is required.</p> <p>Sources (LOE): CARMHA (3)</p> <p>SOR: C</p>
	<p>EOL-CP-6 – Physicians and other health care providers who care for individuals with dementia will possess the required skills and knowledge to conduct end-of-life discussions with individuals and their significant others.</p> <p>Explanation:</p> <p>This would include a skill set to:</p> <ul style="list-style-type: none"> • Be able to convey difficult news • Possess interpersonal skills to facilitate engaging and listening to patients, their families, and other health care providers • Encourage shared decision making around planning and choosing appropriate interventions • Knowledge of best practice palliative care interventions for dementia • Explaining the anticipatory course of dementia at end of life <p>Sources (LOE): CARMHA (3)</p> <p>SOR: C</p>

Level of Health Status: Coping with End of Life		Level of Care: Care Provider
Theme	Recommendations	
	<p>EOL-CP-7 – Health care providers will access additional training specific to end-of-life care for people with dementia.</p> <p><i>Explanation:</i></p> <p>People with dementia and their caregivers should expect physicians and other interdisciplinary health care providers to be aware of and educated in medical guidelines to provide end-of-life care that is supportive.</p> <p>Sources (LOE): TDC (3), IH (3), VIHA (3), CARMHA (2)</p> <p>SOR: C</p>	



Coping with End of Life – Support Systems

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Coping with End of Life Goals

1. To ensure that people with dementia move to the end of their life with dignity
2. To ensure that caregivers of people with dementia are supported through and after the end-of-life stage of the dementia journey



Themes for Support System Actions When Coping with End of Life

- Respecting and valuing families and caregivers
- Supporting professional development and education
- Progressive practice framework
- Planning and organizing services
- Appropriate built environment

Level of Health Status: Coping with End of Life	Level of Care: Support Systems
Theme	Recommendations
<i>Respecting and valuing families and caregivers</i>	<p>EOL-SS-1 – Agencies and organizations will initiate system changes to ensure that the end-of-life care and support needs of individuals with dementia and their families and caregivers are met.</p> <p>Explanation:</p> <p>Agencies and organizations responsible for services will recognize the value of families and caregivers in end-of-life care for the person with dementia.</p> <p>Agencies and organizations should provide comprehensive end-of-life care planning that is actively inclusive of family caregivers and individualized in approach.</p> <p>Sources (LOE): CARMHA (2), TDC (3), NH (3)</p> <p>SOR: C</p>
<i>Supporting professional development and education</i>	<p>EOL-SS-2 – Agencies and organizations will provide all their staff with current information and education regarding end-of-life care for dementia.</p> <p>Explanation:</p> <p>Service providers working in palliative care programs provided through the health authority and community organizations should receive regular high-quality continuing education on the palliative needs of persons with dementia and their families/caregivers.</p> <p>Sources (LOE): TDC (3), ASBC (3), VIHA (3), IH (3), CARMHA (2)</p> <p>SOR: C</p>
<i>Progressive practice framework</i>	<p>EOL-SS-3 – Agencies and organizations responsible for services will follow evidence-informed guidelines for end-of-life dementia care.</p> <p>Explanation:</p> <p>Principles and goals of excellent dementia care should be integrated into all palliative care programs provided throughout the health authority and community organizations. Care providers should understand and work from these principles.</p> <p>Multidisciplinary guidelines, collaboratively developed, can have a positive impact on end-of-life dementia care.</p> <p>Sources (LOE): TDC (3), ASBC (3), CARMHA (2)</p> <p>SOR: C</p> <hr/> <p>EOL-SS-4 – Agencies and organizations will support care providers in addressing ethical issues, and when ethical conflicts arise, provide access to ethics experts for consultation.</p> <p>Explanation:</p> <p>There are always difficult day-to-day decisions to be faced when caring for a person with dementia – from knowing how to deal with wandering to end-of-life decisions. Many of these decisions are underpinned by value judgments about right and wrong and reflect a particular view of dementia. These ethical decisions need to be considered in the context of relationships, treatment, safety and quality of life, culture, and ethnicity. Care providers require practical guidance and advice, drawing on the experiences of family caregivers as well as on existing research, acknowledging the importance of empathy and different perspectives in order to reach the best decision for end-of-life care for persons with dementia.</p> <p>Sources (LOE): ASBC (3)</p> <p>SOR: C</p>

Level of Health Status: Coping with End of Life	Level of Care: Support Systems
Theme	Recommendations
<i>Planning and organizing services</i>	<p>EOL-SS-5 – Agencies and organizations will have programs developed specifically to meet the end-of-life needs of people with dementia.</p> <p>Explanation:</p> <p>Staffing levels and time allotted will meet diverse and extensive end-of-life needs of persons with dementia. Staff will be able to meet the end-of-life needs of culturally diverse individuals.</p> <p>The eligibility criteria for palliative care programs will be inclusive of dementia.</p> <p>There will be access to an interdisciplinary team and palliative specialists as required.</p> <p>Agencies and organizations will establish the tools, protocols, practice guidelines, decision support, and accountability mechanisms needed for effective palliative dementia care. This includes policies and other support mechanisms that ensure that any previously stated wishes of the person with dementia are routinely recognized, valued, and included in end-of-life care planning.</p> <p>Sources (LOE): CARMHA (2, 3), TDC (3), ASBC (3), FH (3), IH (3), NH (3), VIHA (3)</p> <p>SOR: C</p>
<i>Appropriate built environment</i>	<p>EOL-SS-6 – Agencies and organizations will deliver end-of-life care in health care environments that are designed to be sensitive and supportive to the palliative needs of persons with dementia and their families.</p> <p>Explanation:</p> <p>All residential care facilities should be designed in full for dementia care, making due allowance for appropriate subenvironments for individuals needing complex care who are cognitively intact. Whenever new buildings are constructed, appropriate space should be made available for end-of-life dementia care.</p> <p>The families and caregivers of people with dementia can expect appropriate end-of-life care, provided in an environment designed to provide optimal care.</p> <p>Sources (LOE): ASBC (3), VIHA (3)</p> <p>SOR: C</p>



Coping with End of Life – Health Care Environment

	Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Individual				
Care Providers				
Support Systems				
Health Care Environment				

Coping with End of Life Goals

1. To ensure that people with dementia move to the end of their life with dignity
2. To ensure that caregivers of people with dementia are supported through and after the end-of-life stage of the dementia journey



Themes for Health Care Environment Actions When Coping with End of Life

- Planning for improvements in dementia care
- Creating dementia-sensitive policy
- Improving knowledge about dementia end-of-life care
- Supporting a dementia research agenda

Level of Health Status: Coping with End of Life	Level of Care: Health Care Environment
Theme	Recommendations
<i>Planning for improvements in dementia care</i>	<p>EOL-HCE-1 – Policy makers will develop policies that ensure that the built environment supports the needs of people with dementia at the end of life.</p> <p><i>Explanation:</i></p> <p>Appropriate care environments and facilities that support end-of-life dementia care should be available.</p> <p>Long-term care facilities should be provided with adequate resources, including staff training, to avoid inappropriate transfers to hospital and to provide excellent palliative care.</p> <p>Sources (LOE): TDC (3), VIHA (3), ASBC (3), CARMHA (1, 2)</p> <p>SOR: C</p>
<i>Creating dementia-sensitive policy</i>	<p>EOL-HCE-2 – Policy makers will apply a dementia policy lens to end-of-life policies, to avoid inadvertent negative impacts on individuals with dementia.</p> <p><i>Explanation:</i></p> <p>End-of-life health care and other policies that affect this population are examined to ensure that all are free of ageism and stigma and are based upon principles of person-centred care.</p> <p>Sources (LOE): TDC (3), ASBC (3)</p> <p>SOR: C</p>
	<p>EOL-HCE-3 – Policy makers will ensure equitable access to appropriate services and supports in the home for those who plan to die there, at equivalent cost to individuals who are institutionalized (e.g., for incontinence and similar care products; home support; respite; palliative care consultation/team).</p> <p>Sources (LOE): CARMHA (3)</p> <p>SOR: C</p>
	<p>EOL-HCE-4 – Policy makers will establish province-wide end of life criteria that enable the designation of people with dementia as “palliative” within a timeframe that provides equitable access to the appropriate end of life services and supports.</p> <p><i>Explanation:</i></p> <p>Identifying and estimating end of life for a person with dementia is difficult and often inaccurate. Policy should allow flexibility in the palliative program to accommodate the clinical course of dementia.</p> <p>Sources (LOE): CARMHA (4)</p> <p>SOR: C</p>
	<p>EOL-HCE-5 – Government will ensure that employment policies support the involvement of family at the end of life, such that family members are able to take compassionate leave from work.</p> <p>Sources (LOE): CARMHA (2, 3), TDC (3), ASBC (3), FH (3), IH (3), NH (3), VIHA (3)</p> <p>SOR: C</p>
	<p>EOL-HCE-6 – Government will ensure that appropriate policy and education are developed to: (1) identify best practice in end-of-life decision making, and (2) support the health care provider and the family in making decisions that respect the advance care plans of persons with dementia.</p> <p>Sources (LOE): CARMHA (3)</p> <p>SOR: C</p>

Level of Health Status: Coping with End of Life	Level of Care: Health Care Environment
Theme	Recommendations
<i>Improving knowledge about dementia end-of-life care</i>	<p>EOL-HCE-7 – Institutions with a role in the education and continuing education of health care providers will ensure that all health care professionals receive dementia education, including end-of-life dementia care, in their primary course work as well as through continuing education programs.</p> <p>Sources (LOE): FH (3), ASBC (3), CARMHA (2)</p> <p>SOR: C</p> <hr/> <p>EOL-HCE-8 – Institutions with a role in education (including public education) and continuing education will ensure that providing high-quality, evidence-based continuing education on end-of-life issues and dementia care for families, caregivers, and health care service providers is a provincial priority and is provided in a consistent and coordinated manner province-wide.</p> <p>Explanation:</p> <p>Access to education on end-of-life dementia care should be available throughout the province for individuals with dementia, caregivers of people with dementia, and care providers of people with dementia, including those working in acute care settings, assisted-living environments, long-term care settings, and the community; primary care physicians; the general public; and the community to decrease fear and ageist values and attitudes.</p> <p>Sources (LOE): TDC (3), ASBC (3), CARMHA (2)</p> <p>SOR: C</p>
<i>Supporting a dementia research agenda</i>	<p>EOL-HCE-9 – Policy makers, working with other stakeholders, will facilitate knowledge transfer between researchers and practitioners about the end-of-life needs of people living with dementia and their caregivers (for example, through dementia research conferences and meetings).</p> <p>Examples of research gaps:</p> <p>Known gaps in the research on dementia end-of-life care include:</p> <ul style="list-style-type: none"> • How to make an accurate prognosis about when individuals with dementia will die • Whether or not hospice care is a “better” place than nursing homes for individuals with dementia who have palliative care needs • Prevention and management of contractures • Development of nutritional guidelines for end of life • How can families be involved in decision making? • How should information about end of life and treatment (e.g., antibiotics, CPR) be communicated to families? • When should treatment be ended? • Are advance care plans effective (for the person with dementia, for the care providers)? • Reliable appropriate pain assessment when the individual cannot communicate verbally • What is best practice in palliative care for those with dementia? • Need to understand what we do or do not do that supports caregivers • Would providing appropriate support during the end-of-life stage and following bereavement have positive impacts on caregivers’ health and mortality?

Level of Health Status: Coping with End of Life	Level of Care: Health Care Environment
Theme	Recommendations
	<ul style="list-style-type: none"> • Lack of research into role of spirituality at end of life for those with dementia and their caregivers • What kind of policy changes would facilitate access to palliative care in the home or to hospice care? <p>Sources (LOE): TDC (3), CARMHA (3)</p> <p>SOR: C</p>
	<p>EOL-HCE-10 – Policy makers will ensure that publicly funded biomedical and psychosocial dementia research of relevance to end-of-life issues is conducted.</p> <p><i>Explanation:</i></p> <p>Policy makers should also ensure that the resulting research informs policy direction, program development, and strategic planning.</p> <p>This recommendation is also directed to the province in its role of establishing policy and processes for the collection of tissue for pathology research purposes, in order to enhance the province’s knowledge about how dementia affects BC citizens.</p> <p>Sources (LOE): ASBC (3)</p> <p>SOR: C</p>
	<p>EOL-HCE-11 – Policy makers will ensure that a comprehensive study of the costs of dementia end-of-life care is funded and implemented.</p> <p><i>Explanation:</i></p> <p>The study should include an examination of individual, system, and societal costs of end-of-life care for persons with dementia. The study should also include the impact on caregivers and anticipated drug costs. Appropriate stakeholders should be consulted.</p> <p>Sources (LOE): TDC (3)</p> <p>SOR: C</p>

Note: Some Health Care Environment recommendations in the Staying Healthy, Living with Dementia, and Getting Better sections are also applicable to this section



Document Reference Library

7. Document Reference Library

- Better Health in Old Age. Resource Document from Professor Ian Philp, National Director for Older People's Health, to Secretary of State for Health, March 2001, Department of Health.
<http://www.dh.gov.uk/assetRoot/04/09/32/16/04093216.pdf>
- Building Bridges: A Call for a Coordinated Dementia Strategy in British Columbia. British Columbia Medical Association (BCMA), April 2004.
http://www.bcma.org/public/patient_advocacy/building%20bridges.pdf
- Clinical Practice Guidelines. Northern Health Authority, October 2005.
- Clinical Standards: Older People in Acute Care. National Health Service Scotland, October 2002.
<http://www.nhshealthquality.org/nhsqis/files/Older%20People%20in%20Acute%20Care.pdf>
- Consultation Paper for the National Framework for Action on Dementia. Australian Health Ministers' Conference, 2005.
- Dementia Framework for South Australia 2004-2009. Government of South Australia, Department for Families and Communities.
- Framework for Dementia Care. Fraser Health Authority, September 2006.
- Framework for Integrated Support and Management of Older People in the NSW Health Care System, 2004-2006. New South Wales, Department of Health.
http://www.health.nsw.gov.au/pubs/2004/pdf/fw_older.pdf
- Guidelines for Elderly Mental Health Care Planning for Best Practices for Health Authorities. British Columbia Ministry of Health Services, February 2002.
http://www.healthservices.gov.bc.ca/mhd/pdf/elderly_mh_care.pdf
- Interior Health Authority Chronic Obstructive Pulmonary Disease Service Framework.
http://www.qrp.pops.net/iha_wg/wg.htm
- Interior Health Authority Dementia Website.
<http://www.interiorhealth.ca/Health+Services/Senior+Care/Dementia/>
- Penny MacCourt, *End of Life in Dementia Care: Research Evidence to Support the Provincial Dementia Service Framework (CARMHA)*. 2007.
<http://www.carmha.ca/publications/index.cfm?fuseaction=publications.showOnePublication&contentID=4>
- National Framework for Action on Dementia 2006-2010. Australia Department of Health and Ageing.
<http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-dementia-nfad-0610.htm>

- Recognition, Diagnosis and Management of Cognitive Impairment in the Elderly. Guidelines and Protocols Advisory Committee (Physician Guidelines).
- Service Framework for Dementia Care. Vancouver Island Health Authority, 2006.
- M.H. Ebell, J. Siwek, B.D. Weiss, S.H. Woolf, J. Susman, B. Ewigman, M. Bowman, “Strength of Recommendation Taxonomy (SORT): A Patient-Centred Approach to Grading Evidence in the Medical Literature,” *Journal of Family Practice* 53 (February 2004): 111.
http://www.jfponline.com/pdf%2F5302%2F5302JFP_AppliedEvidence1.pdf
- Transforming Dementia Care in BC. Alzheimer Society BC (TDC), April 2005.
- Vancouver Coastal Health Authority Dementia Website.
<http://www.vch.ca/dementia/index.htm>

Appendices

Appendix A: Your Stories

The following stories are taken from the Vancouver Coastal Health website.

Is It Dementia? – Your Story

Looking back, I think I probably knew that something was wrong. The signs were there ... the memory lapses, the confusion, the angry outbursts. I guess there's knowing, and then there's knowing ...

For a while, I had been feeling sort of fuzzy in my head. I was having trouble remembering things. Some days I was okay, but other days I would dial a phone number and forget who I was phoning. Or I'd be taking notes at a meeting and would lose track of the discussion.

I thought of many things to blame it on, such as menopause and stress.

Normally I'm a very organized person. I have been working in the same office for the past 22 years, and I'm the one who keeps track of all the details, the "go to" person who knows where to find everything. That's why my co-workers noticed when I started making mistakes – misplacing files, or forgetting to write appointments on the calendar. A colleague sat me down one day, "Clara, are you okay? You're always so organized; it's not like you to be forgetful. Is something going on with you? Is there anything I can do to help?"

I assured my co-worker that I was fine, and that I just hadn't been sleeping well lately. In fact, I was starting to get really worried. My aunt had dementia, and I found myself wondering if it ran in families. I wondered if I might lose my job if my boss saw that I was having trouble doing my work. Since I live alone, who would look after me if I became very ill? It was all very frightening. Part of me felt that as long as I didn't admit that anything was happening, the problem would go away.

Then, about a month ago, I forgot my best friend's name! It just disappeared into a black hole in my brain where I couldn't get at it. That was a sign I couldn't ignore.

My co-worker had never given up on me, and now she encouraged me to phone my doctor and talk to her about what has been happening. She kept checking to see if I had made the call, so I finally picked up the phone. After listening to my story, my doctor said that there could be a number of possible explanations. But she agreed that what I've been noticing might be early signs of dementia, and the sooner that I find out, the more chance I'll have to do something pro-active about it. I made an appointment for tests this week, and in the meantime I'm writing down all the symptoms that I and others have noticed.

There, I've taken the first step. What surprises me is the huge sense of relief I feel, even though I don't yet know what the tests will show. There has been a big black cloud hanging over me, always in the back of my mind. A secret I couldn't reveal to anyone. Now it feels good to be finally dealing with this situation, taking control, and reaching out for help. I'm going to find out what's wrong, and take it from there.

I think fear of the unknown is worse than anything else.

Living with Dementia – Your Story

At first, I refused to accept I had dementia. I was furious! Why me? I'm too young – only 67! Those doctors didn't know what they are talking about!

I had a million excuses for what was going on. I badly wanted to believe in a different explanation for my symptoms. I was angry, then confused, then scared ... it was a very difficult period for me and my family. I became quite depressed. Life seemed so hopeless, so unfair!

It took a long time, and I still get angry sometimes, but gradually I've begun to accept that my life is going to be different from now on. So now what? What happens next?

I know there's no cure for dementia; it's a progressive disease. But as much as I can, I need to manage the changes that are taking place. I've started reading about dementia to understand what I'm dealing with. My daughter brought me some material from the Alzheimer Society. At first, it seemed overwhelming and I couldn't take it in – too much new information at once. So I read a little bit at a time. I soon started to learn about some of the positive things I can do to slow the progress of my dementia, to maintain my independence for as long as possible.

My focus now is on staying as healthy as I can. With the new medication I'm on, I'm not as tired. I'm eating better. I've cut back on work and stress, and I am spending more time with my grandchildren. They tell me that I need to exercise my brain, so the kids are teaching me new card games. Sometimes they even let me win.

I have a new doctor, now, and I have more confidence in her. She takes the time to explain things clearly, and to answer my questions. We're working together to figure out which medications and treatment options work best for me. I often arrive at my appointments with a list of questions about things I've read or that people have told me. And I've learned about the helpline at the Alzheimer Society, which has helped me with many of my concerns. I'm learning to take control of this disease, and to seek out the help I need.

So far I've been to one dementia support group meeting, and I'll definitely go back. I was surprised at the mix of people in my group – truck drivers, university professors, moms, office workers and musicians. One woman talked about how she felt so alone with this disease – how friends seemed uncomfortable around her, like she was no longer the same person. “It's like you're losing your self, the person you used to be.” I found myself nodding in agreement with a lot that was said. At first I wasn't sure about the idea of a support group, but I think I will find it helpful. Time well spent.

I worry about what will happen to my family, but at least I can do something about that. My daughter has begun to help my wife with the day-to-day household finances,

something that used to be my job. I've started to put my financial and legal affairs in order – that way I can rest easy that it's all looked after. Things like arranging for someone to take over my business, transferring family assets out of my name, signing a representation agreement giving family members the legal authority to make decisions for me when I'm no longer able. There's a lot to think about, but with help from my accountant and lawyer, we're taking it step by step.

I've been wondering how much longer I'll be able to drive safely. I've heard of people needing to pull over because they couldn't remember where they were going. How will I know when it's time for me to stop driving? Hopefully that won't be for some time yet.

One good side-effect of all this future planning is that we've started talking about other difficult topics, like what happens if my wife can no longer care for me at home, or even what kind of funeral arrangements I might want ... I find it very hard to think about these things, but it's not going to get any better if we put it off. Dealing with it all now brings me some peace of mind.

Some days are good; other days less so. There are certainly bumps in the road. I try not to get too frustrated when I start to say something and forget what I was saying. What really irritates me, though, is when I can't find things. I'm trying to give myself more time to remember, so I don't feel rushed. And I'm working on other strategies – like keeping my keys and wallet in a special place. I've stuck notes all over the house to remind me to lock the door when I leave, or take out the garbage on Tuesdays. I get lots of practical tips like this from my support group.

What is hardest for me is not knowing the future. How long do I have? How fast will I deteriorate? If I'm sounding depressed, Sonja gives me the dog's leash and suggests that we take a walk. I always feel a bit better after getting outside in the fresh air.

My family and some of our friends provide tremendous support. Sonja was even saying the other day that this illness seems to have brought us closer together. I think she's right. We're facing this together, and helping each other cope. I know it hasn't been easy for her – she's had to work at being patient with me, trying to understand what I'm going through. She's also had to let go of some of her plans and dreams for our retirement years. It's certainly not easy for me, either, although I'm coping much better now than I did a few months ago.

Overall, I know I'm doing all that I can at this time to help both of us manage this change. Just the same, I sure wish things were different.

Care at Home – Your Story

Every day is a marathon. So much to do, so many demands on my time. Caring for my mother with Alzheimer's ... my father ... my husband and children ... on top of full-time work. At times I feel completely overwhelmed, and I wonder how much longer I can keep it all up.

When my parents moved in, our family life was turned upside down. They could no longer live safely in their own home. Several times my mother wandered off and got lost, and my father was frantic. Twice she forgot to turn off the iron. She wasn't remembering to eat. So it was necessary for my parents to move in with us. This isn't the first time my mother has been diagnosed with dementia. Ten years ago she had a stroke and ended up in hospital, and her speech was very confused. The doctors figured she had dementia, and made arrangements to transfer her to psychiatric care. This sounded wrong to me. I didn't think my mother had shown any signs of dementia up until that point, so I questioned the doctor's diagnosis, demanding a review of her symptoms. Sure enough, it turned out she had aphasia – the stroke had affected her ability to communicate. I've since learned that it's not uncommon for symptoms that might have some other cause to be blamed on dementia, especially with older folks. It took a while, but eventually my mother's speech improved.

Now, ten years later, she really does have dementia. There wasn't much discussion about my parents moving in with us – I'm the only daughter in a fairly traditional Chinese family, so it's expected that I would care for them. My father ... well, he isn't yet at the point where he can acknowledge my mother's condition. He seems ashamed of her. There's still a stigma around mental illness and dementia in our community, especially among the older generation. It's not talked about. Instead of admitting that my mother's mind is deteriorating, my father just gets impatient and angry with her. He complains that he now has to do all the cooking. This isn't what elderly Asian men are accustomed to doing.

I hope I can find a way to talk to him so he'll listen. I know this isn't easy for him – he's losing somebody important to him. It's scary for me, too. It would help us both if we could talk about it.

When I'm home, my mother follows me around the house like a puppy. She's anxious and fidgety, and is always wringing her hands. I know she needs reassurance and understanding, but I'm tired after a day of work and it's a challenge for me to be patient. If I snap at her she looks hurt, and I feel guilty.

Caring for my parents in our home has been hard on my own family. I never seem to have uninterrupted time to spend with my children. My young son has been quite angry lately, and his sister feels uncomfortable about bringing home her friends. I'm thinking I'll take the children out to a special lunch next week so we can talk. I can

reassure them and answer any questions they have. They are old enough to understand what's happening to their grandparents. I could ask the kids for suggestions on how we can make this work better.

Looking back, I realize that I should have insisted that my parents make decisions about their future when they were still capable of having this conversation. But I was busy with my babies ... anyway, it never happened. Now that they can no longer cope on their own, and have reached this crisis point, it's fallen onto my shoulders. Since my parents put off seeking medical attention, I'm just now starting to figure out where to go, what questions to ask, and what treatment or resources are available. It seems so complicated! At first I didn't have a clue where to reach out to for help.

A turning point for me was when I met the case manager assigned to my mother. That poor woman listened to me pour out my story, and let me cry for a while. She assured me that I was doing an amazing job under difficult circumstances. Apparently I could have sought out support long before this, but it's not uncommon for families not to seek help until they are in crisis.

The case manager was adamant that I needed to find time to care for myself. I have to create some balance in my life, and I shouldn't feel guilty about taking time out. As she said, if the primary caregiver gets sick and goes down, she takes everybody else down with her. She helped me understand my mother's behaviour, and the progression of the disease. We discussed some medications and treatments I should discuss with my mother's doctor. And then we started working on a plan to help me cope. There will be a care team helping my mother, and I'll be part of that team.

I learned about an adult day centre that might be appropriate for my mother a couple of days a week. I'll persuade her to at least try it. Some of the staff and the participants speak Mandarin, which should make her feel more comfortable. That will also give my father a break – maybe he can get together with some of his friends for coffee like he used to.

If we can get some home care support on the other days, especially to take my mother for a walk or give her a bath, I won't be under as much pressure when I get home from work. The case manager will also look into some respite care for me, so I can spend time with my family or get away for a break.

We talked about the future, and what additional support I might need to keep my mother in my home as long as possible. I left the case manager's office feeling stronger and more optimistic than I had in weeks. I noticed that the trees are in bloom! When I got home, I made tea and sat down with my mother to look at old family photos for half an hour. My kids came by and were curious about some of the pictures, and my father told us stories I had never heard from before I was born. I think I'll be bringing out those photos again.

My husband came home from work, and announced he was going to pick up Chinese take-out food for dinner – no cooking required! Everybody cheered, and my mother's face lit up with an enormous smile.

I'm going to take this one day at a time.

Making Decisions about Care – Your Story

My sister is on the phone, calling from the reserve. I've never heard her sound so exhausted and depressed. She apparently had a fight today to get my mother to take her medication. Mom knocked the pills out of her hand, sending them flying all over the floor. And there was an earlier scene when my mother kicked at the door, shouting that she was being held prisoner. My sister had installed a special doorknob cover to stop Mom from going outside and wandering off again, because two days ago it took hours to find her in the pouring rain.

"I'm not sure how much longer I can do this," said Sis. "I really want to do what's best for Mom, but I'm going crazy trying to cope."

I've also been finding it much more difficult, lately, to manage my mother's care. Even though my sister and I take turns looking after her, I'm wondering if it's more than we can handle. My mother's behaviour is now more erratic, her care is becoming more complex, and she really needs someone watching her constantly.

When my mother was diagnosed with dementia five years ago, my sister asked if I would help with her care. That was a hard decision for me, as my mother and I never really got along. She's got strong opinions, so there were lots of arguments when I was at home. I left the reserve and moved to the city years ago. I like my independent life here, and I wasn't sure I wanted much contact with my mother.

But my sister needed my help, so I said yes. She still lives on the reserve, where there isn't a lot of outside medical support for someone living with dementia. There's one doctor, but my sister hasn't found him to be particularly helpful. Here in the city there's easier access to doctors, pharmacists and other specialists.

One problem I'm finding, though, is that with my mother's Indian status, it's a nightmare to find out what services she can access, both here and on the reserve. I'm trying to figure out where I can go to find out what's available for First Nations people with dementia.

In addition to her dementia, mother has diabetes, so that adds complications. She's no longer capable of keeping to her diet, so we always need to be watching what she eats, have her blood sugar levels monitored and give her insulin injections. I've rushed her into the emergency ward a couple of times when she went into a diabetic coma.

Just down the road from my apartment there's a drugstore, and the pharmacist there has helped me a lot. I told her how stressed out I was getting looking after Mom, and she asked what extra support I was getting. She suggested that the information on home and community care on Vancouver Coastal Health's website would be a good

place to start finding out what help was available. She also talked about adult day centres for seniors and Aqua-fit classes at the recreation centre.

Our shared care arrangement gives both my sister and me a break now and then, but Mom gets confused and unsettled every time she has to move from one place to the other. She's reverted back to her childhood language, and the reserve is the only place there are other people who still speak this language. Not that she gets a lot of visitors when she's there, anyhow. Partly it's because she's pretty confused much of the time. Also, people in the village don't know much about dealing with people with dementia. My sister feels very isolated in the community, as well as protective of Mom.

One good thing that has come out of all this – my sister and I are now much closer. We talk all the time on the phone. We compare notes, and share strategies that have worked for us to deal with my mother's difficult behaviour. It sure helps to have someone who understands and lets you rant when you need to. Even so, caring for someone with dementia is tough.

Last time my mother moved back here, I was shocked to see how much she has deteriorated. She used to love going to the park to listen to music, or wandering through the mall, but this time she was withdrawn and apathetic. I noticed the difference because I hadn't seen her for a few months. We have now started keeping track of her behaviour, so we have a better record.

My sister has always hoped to keep my mother at home until the end. She hasn't allowed herself to think about residential care options. But the way things are going, I wonder how we are going to be able to continue to manage this. How can I work and look after my mother if she needs round-the-clock supervision? At the same time, I worry about what kind of placement we would be able to find for her, especially as she is no longer speaking in English. Will there be a place that's respectful of her culture? I wonder where I can find out more about that.

It's hard to think clearly when you're feeling stressed out. I really don't know what's the best thing to do. But after listening to my sister on the phone today, I know the time has come to make some decisions.

Remaining at Home – Your Story

There are difficult, challenging days with my mother-in-law that leave us physically and emotionally drained. But there are also magical times, moments of joy and shared love, and those I wouldn't miss for the world.

I know that not everyone is able to make the decision that we made, nor would they want to. My wife and I certainly chewed over the options and grappled with our decision to care for my mother-in-law at home. Could we properly look after an elderly woman with advanced dementia?

We looked into the support that was available to us. We considered whether our own physical and emotional health was up to the challenge. Were we making this decision for the right reasons, not just out of a sense of guilt or obligation? We consulted with our grown children.

In the end, we decided that, yes, we really wanted to keep Mary's mother at home with us. We hope she'll be here until the end of her life.

We sponsored Frances to immigrate to Canada twelve years ago, and she has lived with us ever since. Seven years ago we learned she had dementia. By now it is well advanced, and we certainly thought about residential care options. But both Mary and I come from close families, and she's always has a special bond with her mother. We're retired and have the time, the resources, and the ability to care for her at home. We feel honoured that we can do this for Frances – it's a way of giving back. It's our wish that she will live out her life surrounded by family, and with as much dignity and respect as is possible.

Don't get me wrong – it's a struggle. Frances needs feeding and bathing, and she's often up at night. She's had periods where she has been abusive and angry, and she has accused us of all sorts of things. Although we know this is part of the disease, it is still not easy to deal with. Having Frances with us constantly puts strain on our marriage and affects our social life. We have to build in regular "time outs" to give ourselves a break. I escape to the golf course. We would never have considered becoming her primary caregivers if we didn't know that we would have lots of back-up. Working together with our case manager, we have put into place a care team and a network of supporters.

We were able to tap into some funding programs to modify our house to make it suitable and safe for Frances. We now have an outdoors garden area that's secure so she can go outside but she can't wander away. Inside we've installed lots of safety items such as covers on the stove knobs so she can't turn them on, monitors throughout the house, and equipment to make day-to-day chores easier for a frail, elderly woman.

We have regular home support, as well as respite care. We also pay someone to come in twice a week to do art with Frances, and our house is decorated with colourful paintings. Mary's grown daughters also come and stay over from time to time to allow us to get away. As Frances's condition progresses, we will need further nursing assistance. Eventually we may seek out palliative and hospice care. We're fortunate that it's available to us here – I know that people in rural areas don't have as much access to these services.

We have created a circle of care and love around Frances, and the rhythm of our days revolves around her needs. We enjoy her pleasure over little things – her rock collection, the antics of the cat, afternoon tea, and reconnecting with old Broadway musicals that remind her of her youth. She has her favourite walks, and she loves nature programs on TV.

We had a family gathering here last weekend to celebrate Frances's 88th birthday, and she was showered with attention. She was delighted with the cake and the candles, and the loudest voice was hers, singing, "Happy Birthday to Me!"

Will she still be singing next year?

Moving to Residential Care – Your Story

Brenda: Tuesdays are my day to drive down to visit my parents here at the residential care home. I usually stay all day and spend the night with my son and his family in town before heading back up the coast.

I wish I lived closer and it wasn't such a major effort to get here, but the staff at the care facility include me as part of the extended "team" in my parents' care. They try to schedule any case meetings for Tuesdays, and we're also in touch by phone a lot. They know that I want to take an active role in the decisions that affect my parents' care. I think it's important that I stay on top of things.

I've been able to place both my father and mother in the same facility. Father is up on the dementia floor. At this point I'm not even sure he knows who I am any more. I'm some woman who badgers him to come out for walks. Oh – and according to him, I'm stealing his money.

My mother has a bed on the main floor. At 84, her brain is still sharp and she's very aware of the world around her, but her body is deteriorating. With her arthritis, she can no longer walk. Plus she has a heart condition and emphysema. But I wheel her up to have lunch with Dad, and I can tell he likes that.

Tuesdays are the day I schedule their doctor and dentist appointments, buy prescriptions or new reading glasses, borrow talking books from the library, and do all the other chores that always seem to need doing, even with both of them in care. It's more than the staff can take on.

Darius: Brenda is doing a wonderful job for her parents, and we staff are grateful for the help. I know it's not easy for her to get down here every week. She's also had to deal with some difficult behaviour from her father. I remember when he started accusing her of imprisoning him and trying to kill him ... well, it's not uncommon to see those personality changes, but it must be tough on a daughter who has cared for him faithfully all these years.

Brenda: Actually, that behaviour bothered my son more than me. Jules gets in to visit his grandfather about every two weeks, and he hated listening to Dad's constant criticism and accusations. Jules used to try to defend me, but of course Dad is not rational, so there's no point in arguing. Then my father's speech deteriorated to the point where he became almost incoherent. Since then, Jules has found his visits easier!

Somehow, I've always been able to see my old Dad, my real Dad, underneath the cloak of dementia. It helps me to treat him with respect and dignity. He was a

wonderful man, and I try to remember him like that. Still, sometimes you'll see me walking along the pathway outside, taking a lot of deep breaths.

Last time Jules visited he brought his young daughters with him, but apparently that didn't go well. Tonight I'll make a point of talking to the kids to help them understand why their Great Gramps, who used to be their biggest fan, wouldn't respond to their efforts to talk to him about their new kitten. They need to be reassured that it's not their fault, and it's not his fault either. We'll brainstorm some other ideas they can try next time.

Darius: We see a lot of difficult family emotions and dynamics here. Adult children feel torn up to see their parents decline, and grieve what they've lost. Perhaps they feel guilty that they aren't spending more time visiting, or they resent the time they do spend. Sometimes they regret not having paid enough attention to their parents in the past, and now it's too late. It's hard not to be affected by what your parents say and how they treat you, even if rationally you know that they are in the grip of the disease. It brings up a stew of childhood issues. Sometimes those emotions spill over into our family councils, where we meet to discuss their parents' care needs.

We try to explain the physiological reasons for the behaviour, and that seems to help. Sometimes spouses and adult children choose to become part of our caregiver support group, where they can let out their emotions in a safe place with others who understand. Even as staff, we sometimes become overwhelmed caring for people with this difficult disease, and we need support mechanisms ourselves.

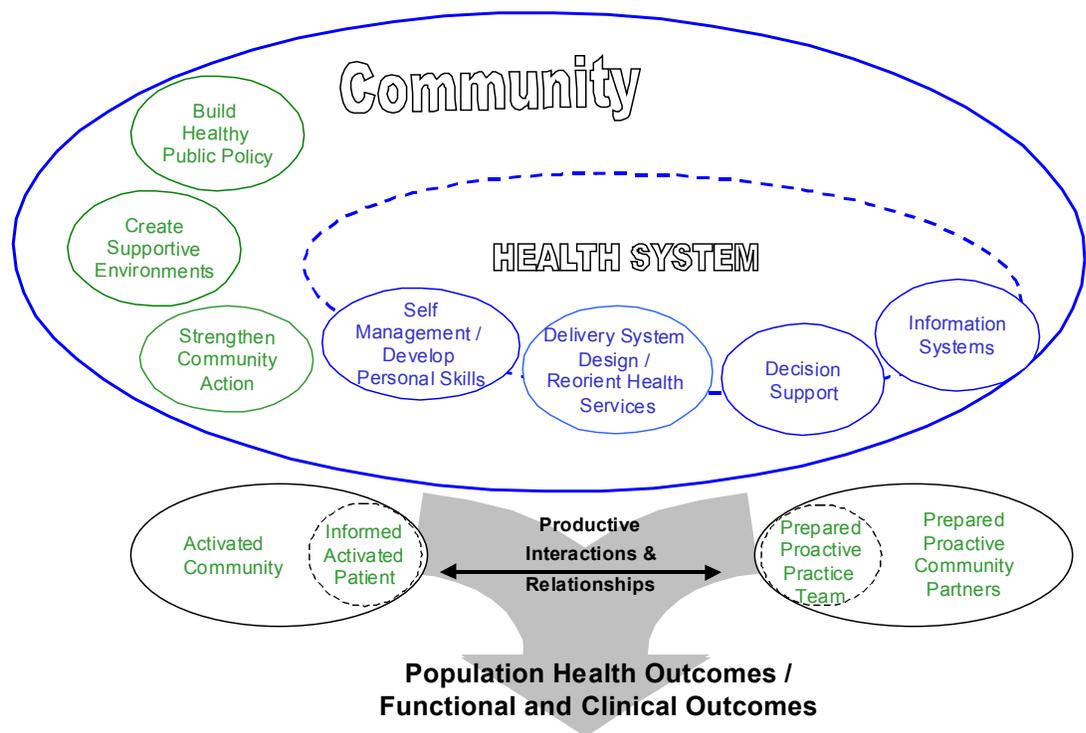
Brenda: One thing I am so grateful for is the talking and the planning we did before my Dad's health deteriorated. Dad was adamant that he and Mom shouldn't be a burden, and that I shouldn't feel badly about putting them in a home. Knowing that has made this process so much easier for me. He and Mom hoped to stay together, whatever happened, and so I feel like I've been able to do what he most wanted by having them in the same facility. That brings me some peace of mind. I've heard horror stories from other caregivers who are now dealing with legal and financial matters that should have been sorted out long ago. Thanks, Dad, for your foresight and love!

Sometimes I worry about what life has in store for me as I get older. I know that there's no reason I will end up like my father. Genes are a factor, but they don't determine whether someone will get dementia. Just the same, I watch myself for signs. I guess that's to be expected.

I do pay attention to the new research that says you can lessen your likelihood of getting dementia, or at least delay the onset, by keeping yourself healthy and keeping your brain active. I eat good food and enjoy Tai Chi and playing bridge. I adore my grandchildren and spend as much time as I can with them. I grow roses, and I take time to smell them.

Appendix B: Expanded Chronic Care Model

The Expanded Chronic Care Model is an adaptation of the Chronic Care Model, originally developed by Dr. Ed Wagner in cooperation with the Robert Wood Johnson Foundation (Improving Chronic Illness Care).



Components of the Expanded Chronic Care Model

The Expanded Chronic Care Model suggests that by working on both the prevention and treatment ends of the continuum from a broad perspective, health care and other teams represent the best potential for improved health outcomes in the long term. The Expanded CCM recognizes the intrinsic role that social determinants of health play in influencing individual, community, and population health. This action-driven model will broaden the focus of practice to work towards health outcomes for individuals, communities, and populations.

- Decision Support** – The clinical care provided must be consistent with evidence-based best practices. In BC a number of chronic care guidelines have been developed through the joint BCMA/Ministry of Health Services, BC Guidelines and Protocols Advisory Committee. Evidence-based care for health promotion and disease prevention is also documented. Specialist expertise is integrated into primary care. Provider education modalities proven to change behaviour are utilized. Patients are informed of guidelines pertinent to their care.

- **Patient Registers/Clinical Information Systems** – In order to provide good chronic care, the team must know who the chronic care patients are, and whether they have received the medical services that are critical to managing their disease. A mechanism for physician reminders, patient recall, and follow-up is also needed.
- **Patient Self-Management/Expert Patient** – Patients must be knowledgeable about health promotion, prevention, and their chronic disease and have the skills and confidence to take responsibility for the management of healthy lifestyles, risks, and their chronic disease. The interdisciplinary team supports self-management. Effective behaviour change interventions and ongoing support with peers or professionals are provided.
- **Delivery System Design** – Infrastructure and clinical processes must be redesigned to accommodate planned visits, patient follow-up, and proactive care. The roles and responsibilities of team members must be maximized to achieve effective and efficient access and flow through the system.
- **Build Healthy Public Policy** – Policies designed to improve population health must be developed and implemented. This approach combines diverse but complementary approaches, including legislation, fiscal measures, taxation, and organizational change – the aim is to make the healthier choice the easier choice.
- **Health System** – A health system that recognizes the importance of improved chronic disease prevention and care and supports the redesign effort is critical for the achievement of improved health outcomes. The development of public policy that supports chronic disease prevention and management, the allocation of needed resources for chronic disease care, and the implementation of physician incentive programs that reward improved outcomes are necessary to sustain health system redesign.
- **Create Supportive Environments** – Creating supportive environments entails working to generate living and employment conditions that are safe, stimulating, satisfying, and enjoyable. This approach includes strategies to foster conditions for optimal levels of health in social and community environments, such as the provision of safe, accessible, and good-quality housing, etc.
- **Strengthen Community Action** – Working with community groups to set priorities and achieve goals that enhance the health of the community encourages effective public participation, where health promotion aims to support people in finding their own ways of managing the health of their community.

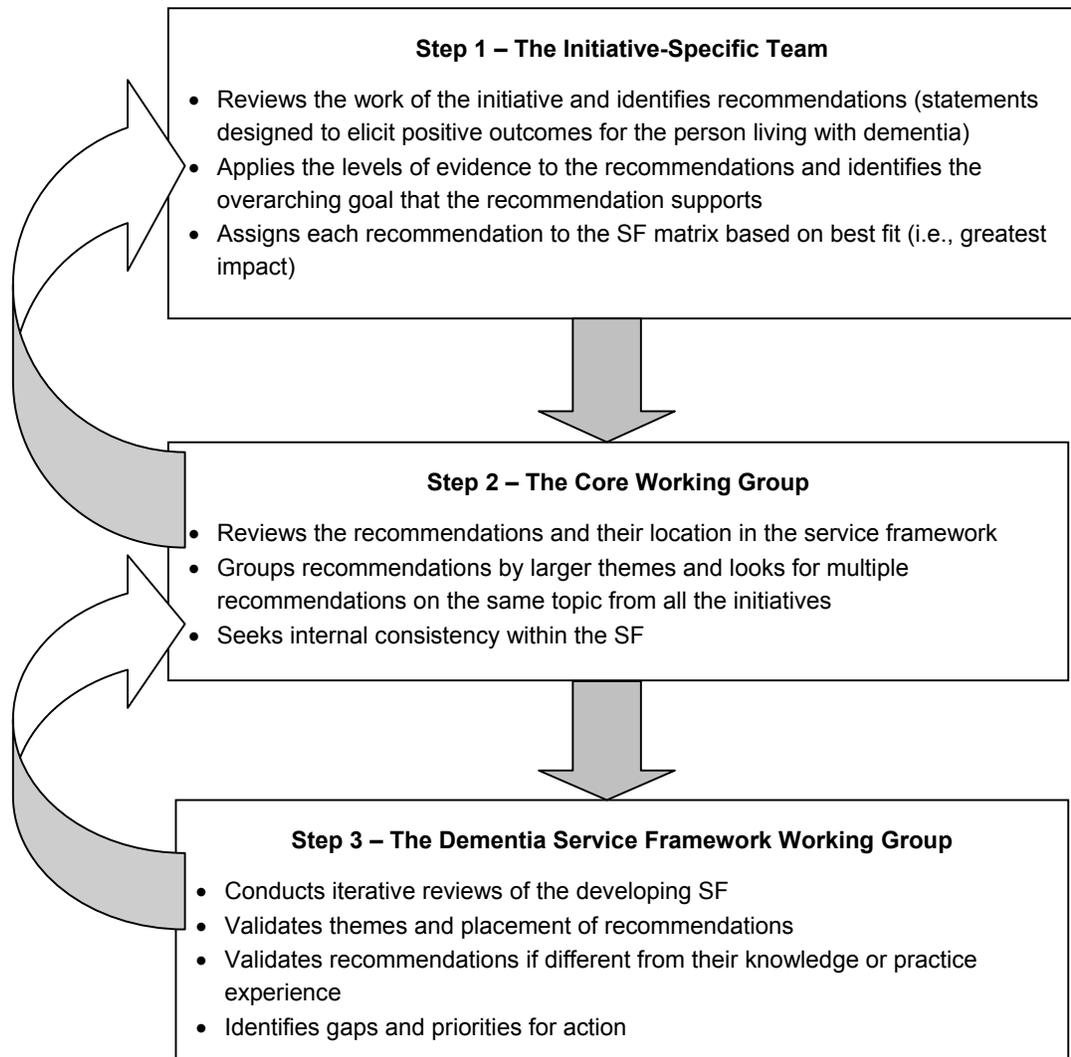
Appendix C: Translation of Initiative-Specific Recommendations into Service Framework Recommendations

For each of the initiatives from which recommendations have been drawn for the Dementia Service Framework, a process was established to:

- Identify the members of the initiative-specific team (IST) that would participate in the process
- Identify relevant recommendations from each initiative
- Assign the recommendations to the developing service framework
- Review iteratively the recommendations in each box of the matrix for “best fit,” to synthesize the recommendations into themes, to consolidate similar recommendations, and to focus the language and intent of the recommendations

The process is depicted in [Figure 2](#).

Figure 2. Process for translation of recommendations into the service framework (SF)



Appendix D: Summary of Potential Performance Indicators by Level of Health Status

Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
Goals			
<p>To promote an awareness of the importance of brain health for all across the life course, reducing the likelihood of disease and/or delaying its progression</p> <p>To ensure that there is early recognition of a change in an individual that leads to early detection</p>	<p>To promote and support the quality of life for people living with dementia</p> <p>To promote and support the quality of life for caregivers of people living with dementia</p>	<p>To promote optimal health for people living with dementia</p> <p>To promote optimal support for caregivers of those living with dementia during times when those they care for experience episodic decline in health</p> <p>To ensure that intervention, active planning, and supportive action are there for the person with dementia and caregiver for successful transitions in care (to promote optimal health during episodic decline in health)</p>	<p>To ensure that people with dementia move to the end of their life with dignity</p> <p>To ensure that caregivers of people with dementia are supported through and after the end-of-life stage of the dementia journey</p>
Performance Indicators at the Individual Level			
<p>Number of British Columbians seeking information on brain health – for example, through ASBC, BC Nurseline, health authorities, Internet and other sources (data source: point of contact, self-report)</p> <p>Number of British Columbians accessing programs about brain health – for example through ASBC, health authorities, other source. (data source: attendance records, self-report)</p> <p>Number of British Columbians adopting behaviours to reduce risk for chronic diseases, including dementia (data source: self-report)</p>	<p>Number of people living with dementia and their caregivers accessing programs specific to their stage of dementia (data source: attendance records, self-report)</p> <p>Number of people living with dementia and their caregivers demonstrating greater skills for self-advocacy and problem solving (data source: self-report)</p> <p>Number of people living with dementia and their caregivers utilizing strategies to enable the person with dementia to live as normally and independently as possible (data source: self-report)</p>	<p>Number of family and caregivers for people with dementia bringing forward changes in the individual's status to their physician or specialist team (data source: client charts, self-report)</p> <p>Number of families and caregivers of people with dementia applying future life and care plans (data source: self-report, client care plans or charts)</p>	<p>Number of families and caregivers advocating for the appropriate end of life care and treatment for the person with dementia (data source: self-report, client care plans or charts)</p> <p>Number of families and caregivers of people with dementia applying future life and care plans (data source: self-report, client care plans or charts)</p>

Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
<p>Number of British Columbians who bring subtle cognitive changes to the attention of their primary care provider (data source: physician billings, client charts, self-report)</p> <p>Number of British Columbians receiving an early diagnosis of dementia from their primary care provider (data source: client charts, client registry)</p> <p>Number of British Columbians disclosing their diagnosis to others (data source: self-report)</p> <p>Number of people at risk for or recently diagnosed with dementia connecting with the ASBC First Link program (data source: point of contact)</p> <p>Number of people at risk for or recently diagnosed with dementia contacting the ASBC for information, support, and education resources (data source: point of contact, self-report)</p> <p>Number of people recently diagnosed with dementia and their caregivers seeking information about dementia and dementia care (data source: self-report)</p> <p>Number of people recently diagnosed with dementia and their caregivers utilizing strategies to enable the person with dementia to live as normally and independently as possible (data source: self-report)</p> <p>Number of people recently diagnosed with dementia and their caregivers seeking information from their primary care provider about care decisions that will be required as the dementia progresses. (data source: client charts, self-report)</p>			

Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
<p>Number of people recently diagnosed with dementia and their caregivers completing future life and care plans (data source: self-report)</p>			
Performance Indicators at the Care Provider Level			
<p>Number of people with MCI or dementia diagnosed early by their primary care physician (data source: review of client charts, client registry)</p> <p>Number of people with MCI or dementia referred for confirmation of diagnosis (data source: client charts or physician billing)</p>	<p>Number of health care providers accessing training, education, and information specific to dementia (data source: self-report, attendance records at formal sessions)</p> <p>Number of health care providers demonstrating knowledge of behaviour in late stage dementia (data source: education needs assessment survey or self-report)</p> <p>Number of people with dementia and their caregivers reporting the receipt of information on dementia from their health care providers (data source: self-report)</p> <p>Assessment of the quality of education and information provided by health care providers to people with dementia and their caregivers (data source: audit)</p> <p>The number of community health workers demonstrating the required general skills and competencies (data source: self-report, needs assessment, audit of care provided)</p> <p>Number of people with dementia with future care and life plans in place (data source: self-report, point of contact with system)</p>	<p>Number of health care providers involved in supporting people with dementia through periods of episodic decline, accessing information and education on dementia (data source: self-report, attendance at formal sessions)</p> <p>Number of health care providers involved in supporting people with dementia through periods of episodic decline who demonstrate knowledge of the causes of episodic decline (data source: audit, educational needs assessment)</p> <p>Number of care plans that include goals and plans for communicating with the family (data source: chart audit)</p> <p>Number of charts with appropriate care plans in place (data source: chart audit)</p>	<p>Number of care plans that include an assessment of symptoms associated with end of life for people with dementia (data source: chart audit)</p> <p>Number of caregivers who report that they have been adequately supported and included as partners in the care team (data source: self-report, chart audit – e.g., attendance at team meetings)</p>

Staying Healthy	Living with Dementia	Getting Better from Periods of Episodic Decline	Coping with End of Life
	<p>Number of people with dementia and their caregivers reporting that they feel supported by their health care providers (data source: self report)</p> <p>Number of health care providers who demonstrate knowledge of dementia related behaviours (data source: self-report, chart audits)</p>		

Glossary

Activated partners in care	People with a health condition and their caregivers who are knowledgeable about health promotion and prevention and about their chronic disease. They have the skills and confidence to take responsibility for the management of healthy lifestyles, risks, and their chronic disease and to engage actively with the health care team.
Caregiver(s)	The individual or group of individuals who are involved in the life of individuals with dementia and who provide for their personal and care needs and support throughout the journey of the illness. Caregivers often include family, extended family, friends, and neighbours.
Co-morbidity	Refers to a situation where more than one health condition is present.
Dementia	A disturbance of the brain that affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, judgment, and executive function; usually associated with chronic or progressive diseases such as Alzheimer's disease, cerebrovascular disease, and other diseases that affect the brain.
Direct costs	The costs of treating a health condition that can be directly attributed to the health condition itself. Often these costs are understated because of limitations in data collection that may not link an interaction with the health care system to the disease.
Evidence-based¹	An examination of the underlying evidence for a particular health care practice. The evidence for the practice is examined through a comprehensive review of the literature, an evaluation of the quality of individual studies that recommend the practice, and a grading of the quality of the supporting evidence using an accepted taxonomy. All search, critical appraisal, and grading method should be described explicitly and be replicable by similarly skilled authors.

¹ M.H. Ebell et al., "Simplifying the Language of Evidence to Improve Patient Care: Strength of Recommendation Taxonomy: A Patient Centered Approach to Grading Evidence in the Medical Literature," *Journal of Family Practice* 53 (February 2004): 2.

Indirect costs	The costs that are known to be incurred by a person living with dementia and their families; however, data collection is limited or unavailable. Estimates of indirect costs are often based on self-report or extrapolation from data collected through other studies.
Levels of health care	Groupings of responsibilities for the various partners in health identified within the service framework. Four levels of care are identified: individuals, care providers, support systems, and health care environment. (See Table 4 .)
Levels of evidence²	A research concept that assesses the validity of an individual study based on an assessment of its study design using three key criteria: quality, quantity, and consistency. There are three levels of evidence used by the Strength of Recommendation Tool (SORT) taxonomy: level 1 evidence describes consistent, good-quality, client-oriented outcomes from high-quality studies (valid design with minimal bias); level 2 evidence describes limited-quality, client-oriented outcomes (due to lower-quality design that leads to more bias or inconsistent findings); and level 3 evidence describes other types of evidence that support client outcomes but may not be research-based (e.g., consensus guidelines, expert opinion [including clients’], usual practice, clinical experience).
Levels of health status	The spectrum of health and illness from the perspective of the person living with the health condition. Within the generic service framework, the four levels of health status are: staying healthy, getting better, living with the disease, and end of life. In the Dementia Service Framework, the four levels of health status are: staying healthy, living with dementia, getting better from periods of episodic decline, and coping with end of life. (See Table 5 .)
Mild cognitive impairment (MCI)	Frequently described as 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. The cognitive losses are evidenced by either self and/or informant (e.g., family, caregiver) report along with deficits on objective cognitive tasks and/or evidence of decline over time detected by neuropsychological testing. Ten to fifteen percent of people each year who are diagnosed with MCI will progress to dementia when followed over a five-year period.
Population health	An approach to health planning that aims to improve the health of an entire population. One major step in achieving this aim is reducing health inequities among population groups. Population health seeks to step beyond the focus of mainstream medicine and public health by addressing a broad range of factors that impact health on a population level, such as environment, social structure, resource distribution, etc. An important theme in population health is the importance of the social determinants of health and the relatively minor impact that medicine and health care have on improving health overall.

² Ibid.

Service frameworks	Represent a “person-centred approach to improving health outcomes across the conventional boundaries of the health system.” They present a high-level picture of optimal care that people should expect to see based upon evidence from the literature and upon best practices drawn from experts, including health professionals, care providers, and patients. Service frameworks do not attempt to prescribe how care would be provided, as this needs to be determined locally according to local priorities and capacity. Rather, service frameworks offer a menu of priority action-oriented recommendations that allow all stakeholders to define how they will contribute to improved services and better outcomes.
Stakeholder	Any group or individual who has an interest in, is impacted by, or has an ability to effect change in dementia care, services, and outcome.
Strength of recommendation³	A lettered grading scale applied to a body of evidence (typically more than one study or research domain) when making recommendations for clinical practice. The strength of recommendation takes into account: the levels of evidence of the individual studies; the types of outcomes measured; the number, consistency, and coherence of the evidence as a whole; and the relationship between benefits, harms, and costs of the recommendation as it applies to client outcomes. An A-level recommendation is based on a consistent and good-quality client-oriented body of evidence; a B-level recommendation is based on an inconsistent or limited-quality client-oriented body of evidence; and a C-level recommendation is based on a body of evidence from other sources, such as a consensus of expert opinion, opinion, disease-oriented (as opposed to client-oriented) evidence, and, in the absence of any other source, usual practice.
Transitions	People living with dementia and their caregivers often refer to the significant transitions associated with the disease. The transitions are typically key changes for the person and his or her caregiver as the disease causes deteriorations in function (cognitive and physical) that trigger significant life and care planning decisions and a decrease in quality of life. Typical transition points are the receipt of the diagnosis of dementia, the need to make decisions that are linked to a loss of independence (e.g., loss of ability to drive), changes in living environment (e.g., a need to move in with a family member), and decisions about residential and end-of-life care.

³ Ibid.

