

The Dementia Policy Lens Toolkit

a framework to facilitate policy, guidelines and programs that support excellence in dementia care

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THE DEMENTIA POLICY LENS (DPL) TOOLKIT

The Dementia Policy Lens Toolkit is a framework to facilitate policy, guidelines and programs that support excellence in dementia care. Use of the DPL toolkit will ensure that policy/guidelines/programs being developed or reviewed, are assessed for (1) their likely effect on people with dementia and those who care for them, and (2) exceptions and/or changes required to accommodate this very vulnerable population

There are two main (and related) reasons (discussed in Appendix 2) why identification and implementation of optimal dementia care is imperative

- **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; and,
- **The Numbers Rationale** - the demographic imperative facing BC and the rising economic burden associated with increasing numbers of dementia cases.

This Dementia Policy Lens (DPL) toolkit (1) reflects the values and perspectives of those affected by dementia and of their families, (2) supports (and provides information about), the principles of excellence in dementia care, (3) includes a Dementia Policy Lens for analyzing planned and current policies, guidelines and /or programs to ensure they support excellence in dementia care/ have no unintended negative effects on the well being of people with dementia and their caregivers (4) supports the Dementia Service Framework (5) is a guide to reflective practice.

Who Should Use the Dementia Policy Lens Toolkit?

The Dementia Policy Lens Toolkit can be used by policy makers and analysts, program managers, evaluators, clinicians/service providers, seniors' organizations and advocates, researchers and educators.

Why Use the Dementia Policy Lens?

The Dementia Policy Lens can be applied to evaluate policies, guidelines and programs that directly or indirectly affect people with dementia and their families/caregivers.

- To guide the development of new, and the review of existing, policies, guidelines and/or programs.
- To monitor the impact of changes to policies/guidelines/ programs on those affected by dementia
- To identify gaps in current policies and programs
- To complement quality assurance programs, accreditation processes and program reviews.
- To guide the response to an issue or need (e.g., advocacy, policy critique)

Benefits of Using the Dementia Policy Lens

- Promotes and facilitates reflective practice
- Raises awareness about the challenges that people with dementia and their families in general, may face.
- Promotes analysis and discussion of policy and program changes on current and future people with dementia, and their families.
- Increases likelihood of policies/guidelines/programs being appropriate to needs of people with dementia and their families/caregivers by ensuring that their values and priorities are considered.
- Facilitates translation of knowledge about dementia by applying the Dementia Policy Lens to provincial and HA Dementia Strategies, organizational mandates and practices, staff orientation and education, health care professional training, etc.

Organization of the Dementia Policy Lens Toolkit

There are three sections in this Toolkit. First, the Dementia Policy Lens (p. 4), for policy makers/analysts responsible for high level policy at the regional and provincial level, is presented. Second, the Dementia Policy Lens Worksheet (p. 6), for clinicians, operational managers and others assessing guidelines and programs, expands the Dementia Policy Lens questions to guide deeper analysis. Third, on p. 13, appendices provide information about (1) the development of the Dementia Policy Lens Toolkit and its' evaluation, (2) dementia, values, the gaps in the system of care and the rationale for making improvements (3) resources to support the Dementia Policy Lens Toolkit..

DEMENTIA POLICY LENS (DPL)

****The Dementia Policy Lens is intended for high level policy development/analysis or as a quick scan of guidelines and/or programs. See the DPL Worksheet (next section) for explanations of questions and to deepen analysis for each section****

Describe the Policy/Guideline/Program

Review the purpose and objective of the policy to which the DPL is being applied.

Apply the Lens: Respond to each question with Yes, No, Not Sure or Not Applicable (N/A)

Process	<p>1. Are those affected by the policy/guideline/program involved? <u>Rationale:</u> Policies/guidelines/programs must promote the full engagement of people with dementia and their families. Involvement of people with dementia and their caregivers in the development and review of the policy/guideline/program will increase the likelihood that the policy/guideline/program will meet their needs.</p> <p>2. Are collaboration and partnership evident? <u>Rationale:</u> The process of developing, implementing and evaluating policies/guidelines/programs must emphasize collaboration and partnership amongst the full range of stakeholders and the people affected.</p>
Policy/ Program Content	<p>3. Is diversity recognized and addressed? <u>Rationale:</u> Policies/guidelines/programs must recognize diversity amongst people with dementia and their families and be flexible enough to respond to the changing needs of diverse groups. This requires that the diverse needs, circumstances, and aspirations of marginalized/vulnerable sub-groups (e.g., younger adults with dementia; minority ethno-cultural populations), are identified and addressed. Diversity should not negatively affect a person's eligibility for and accessibility to services and support.</p> <p>4. Is accessibility facilitated? <u>Rationale:</u> Policies/guidelines/ programs must enable participation and/or accommodate the unique needs of people with dementia and their families by considering accessibility broadly (e.g., cost, health literacy, eligibility criteria, stigma). There should be equal access to programs and applicability of policy/guidelines throughout region/province.</p> <p>5. Does the policy/guideline/program reflect/support person centered care? <u>Rationale:</u> Person centred care is a cornerstone of optimal dementia care and should underpin policies/guidelines/programs which requires having knowledge of individuals and the capacity to accommodate individuality.</p> <p>The dementia journey is punctuated by periods of episodic declines, during which responsive, flexible and continuous services and support is required for the person with dementia and for families. Organizational structures, policies and procedures, and guidelines for best practice dementia and geriatric care need to be in place to support comprehensive integrated care. Service delivery approaches, (including staffing levels and time allotted) are needed meet the diverse and extensive needs of people with dementia and their families during periods of transition.</p> <p>6. Does the policy/guideline/program consider values important to those affected by dementia? <u>Rationale:</u> Policies/guidelines/programs must be based on respect for the person with dementia, their needs, their values, and their choices , and guided by values important to them,</p> <ul style="list-style-type: none"> • Respect and Dignity • Self Determination and Independence

<ul style="list-style-type: none"> • Social Inclusiveness/ Relationships/ Participation • Fairness and Equity • Security • Protection and Risk Management <p>7. Does the policy/guideline/program facilitate/support a relationship based approach by:</p> <ul style="list-style-type: none"> • Providing support to family/caregivers? • Ensuring care providers are competent? • Supporting care providers? <p><u>Rationale:</u> Policies/guidelines/programs must be underpinned by a relationship based approach that recognizes the relationship between personal, social and service-provider systems, and the connections between individuals involved in dementia care - the person with dementia, the informal helping system (family and friends), and the formal helping system (health care professionals, paid care providers). Dementia care is affected by the dynamics and interactions among these individuals/systems. The needs and experiences of the person living with dementia, their families/caregivers and care providers are unique and deserving of respect and support</p> <p>8. Does the policy/guideline/program facilitate/support a dementia friendly care environment?</p> <p><u>Rationale:</u> Policies/guidelines/programs that contribute to/support a physical and social/care environment that is dementia friendly, reduce stressors and facilitate optimal functioning</p> <p>9. Does the policy/guideline/program support a comprehensive and integrated care system?</p> <p><u>Rationale:</u> Policies/guidelines/programs must be designed as part of/to support a system with the capacity and ability to address the clinical and support needs of people with dementia and their families/ caregivers</p> <p>10. Does the policy/guideline/program reflect value and principle based system planning?</p> <p><u>Rationale:</u> Policies/guidelines/programs that reflect a values- and principles-based approach in planning and service provision facilitate/support excellence in dementia care.</p> <p>11. Is accountability addressed?</p> <ul style="list-style-type: none"> • Is accountability factored into the policy/guideline/program? • Are resources and capacity aligned with responsibility? • Does the policy/guideline/program reflect compliance with the applicable standards and legal frameworks?
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Assess and amend policy/guideline/program, if necessary, before proceeding.

Note strengths of the policy/guideline/program

Identify individual areas that require improvement and how potential negative effects could be addressed or off-set. Note who needs to be involved to address this process, and what information needs to be gathered. Set target dates.

Repeat application of DPL overview, or apply full DPL (next section), until policy/program is acceptable.

DEMENTIA POLICY LENS (DPL) WORKSHEET

The Dementia Policy Lens (DPL) worksheet can guide reflective practice. It can be used by clinicians and operational managers to develop or evaluate guidelines and programs to ensure they promote excellence in dementia care. It also augments the DPL questions (p. 2), which it mirrors, providing explanations for each and facilitating deeper policy analysis. For both application some questions may be not applicable (N/A)

Preparation

Describe the Guideline/Program

Review the purpose and objective of the policy/guideline/program to which the DPL is being applied.

Apply the DPL

Answer yes, no, not sure or not applicable (N/A) to each question, using column on the left .

Process Factors

1. Are those affected by the policy/guideline/program involved?

Rationale: Involvement of people with dementia and their caregivers in the development/review of the policy/guideline/program will increase the likelihood that the policy/program will meet their needs.

	Are mechanisms in place for people with dementia, their caregivers or advocates to be consulted and actively involved in the design, implementation, and evaluation of policies/guidelines/programs that affect them?
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2. Are collaboration and partnership evident?

Rationale: The process of developing, implementing and evaluating policies, guidelines and programs must emphasize collaboration and partnership amongst the full range of stakeholders and the people affected.

	Has the policy been developed in collaboration with stakeholders (government and non-government, voluntary, private) who will be affected?
	Are linkages defined amongst stakeholders (e.g., caregivers, care providers, programs, health authorities), along the continuum of care, across settings and between sectors?
	Are the communication channels, roles, responsibilities and performance expectations in place for stakeholder/partners in care?

Assessing Policy/Guideline/Program Content

3. Is diversity recognized and addressed?

Rationale: Policies, guidelines and programs must recognize diversity amongst people with dementia and their families. This requires that the diverse needs, circumstances, and aspirations of marginalized/vulnerable sub-groups are identified and addressed. Diversity should not negatively affect a person's eligibility for and accessibility to services and support. Programs must be flexible enough to respond to the changing needs of all people with dementia and their caregivers, and be equally accessible throughout the province.

Think about the people with dementia and their families who will be affected by the policy/program---consider whether there are special needs related to, for example, their ethno-cultural membership, age (e.g., younger adults with dementia), low income, employed, other diagnoses (e.g., chronic illness, mental illness, developmental challenges), or sexual orientation. List these groups in the table below.

Think about these groups as you answer the DPL questions about the policy/program being developed/reviewed.

- Consider whether the people with dementia and their families affected by the policy/guideline/program are likely to experience inequities or negative impacts resulting from the factors you have identified, above.

Does this policy/program avoid negative effects for people with dementia and/or their caregivers who are:	

Does this policy/program take into account potential negative effects resulting from:	
	Family status (single, childless)
	Isolation (social or geographic)
	Geographic location
	Living situation (homeless, alone, complex care, hospital)

Notes _____

4. Is accessibility facilitated?

Rationale: Policies/ guidelines/programs must enable participation and/or accommodate the unique needs of people with dementia and their families by considering accessibility broadly.

	Is pertinent and appropriate information (e.g., eligibility, access) readily available? (Taking into account literacy, health literacy, vision/hearing impairments, language, culture, sexual orientation, etc)?
	Are sufficient resources likely to be available in a timely manner? (e.g., are there wait lists; night care?)
	Is transportation readily available?

Is accommodation made for unique needs associated with	
	Staffing (e.g., consistency)
	Low income
	Communication (language, literacy, disability, e.g. hearing)
	Cultural "norms"/ practices
	Stereotyping (e.g. challenging behaviours)
	Other (specify)

Notes _____

5. Does the policy/guideline/program reflect/support person centered care?

Rationale: People living with dementia and their caregivers will have different capacities 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 the individual and their caregiver over time, and respectful of individuality, are required.

- Consider whether people with dementia and/or their families affected by the policy/program are impacted by challenges such as: decline in behaviours, health and/or functional status, on- going losses/change; bereavement; changes in support network (including changing/inconsistent staff); relocation to congregate settings, transfer between care environments.

	Does the policy/program support people with dementia and their caregivers through transitions?
	Are 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, available when needed?
	Are there processes to ensure transfer of information between care providers and settings?
	Is access to enhanced resources/ services during periods of crisis and transition?

Notes

6. Does the policy/guideline/program consider values important to those affected by dementia?

Rationale: Person centred care is based on an understanding of what people with dementia and their caregivers' value, and policy/guidelines/programs must be based on respect for the person with dementia, their needs, their values, and their choices, and guided by them:

	Respect and Dignity	<ul style="list-style-type: none"> • Is the policy/program flexible enough to respond to the uniqueness of each individual? • Are privacy and confidentiality ensured? • Are people with dementia and their families portrayed positively?
	Self Determination and Independence	<ul style="list-style-type: none"> • Does the policy/program <ul style="list-style-type: none"> • Provide opportunities to make choices? • Reflect knowledge of what is important to the person? • Promote coping skills/strengths? • Promote and support options and informed choices for people with dementia and their caregivers at each phase of the disease/transition point? (Consider whether a full continuum of options is available)?
	Social Inclusiveness/ Relationships/ Participation	<ul style="list-style-type: none"> • Are any barriers (e.g. financial, technological, institutional, attitudinal, etc.) to the participation of people with dementia and their families removed? • Is access to the social/support networks of family and friends facilitated? • Is access to the community (e.g., cultural/geographic) of the person with dementia and their family facilitated? • Is spirituality supported? • Is a sense of mattering facilitated?
	Fairness and Equity	<ul style="list-style-type: none"> • Are the procedures and criteria inherent in the policy/guideline/program fair and reasonable? • Does it consider individual versus collective needs?
	Security	<ul style="list-style-type: none"> • Does the policy/program <ul style="list-style-type: none"> • Provide the security of being able to plan for future (appropriate housing and services, death). • Provide a sense of safety? • Facilitate a sense of belonging? • Reduce the risks of crime, disease or injury? • Facilitate physical security? • Facilitate economic security?
	Protection and Risk Management	<ul style="list-style-type: none"> • Does the policy/program <ul style="list-style-type: none"> • Facilitate appropriate interventions to protect people with dementia when warranted? • Provide for the timely and effective management and communication of risks to people with dementia, their families and between care providers? • Provide for the reduction of risks to the health, security and well-being of people with dementia and their families? • Ensure that the least intrusive measure is taken? (given the risks) • Ensure the preferences of people with dementia are taken into account as much as possible?

		<ul style="list-style-type: none"> • Respect and protect the legal rights of people with dementia and their families? • Are legal tools in place (and promoted) for people with dementia and their families to plan for future health, personal, and financial care in advance, with a well understood, accessible and person-centered default process for those unable to plan in advance?
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Notes _____

7. Does the policy/guideline/program facilitate/support a relationship based approach to care?

Rationale: A relationship based approach recognizes that the relationship between personal, social and service-provider systems is a principle that must guide all policies and programs. It is understood that care is affected by the dynamics and interactions among these systems and the individuals within them

➤ Support is provided to Family/Caregivers

	Do policies/guidelines/programs support the caregiver as a client with his or her own right to access care and services?
	Are families/caregivers provided with consistent information about dementia (e.g., phases, transitions, future life and care planning)?
	Are families/caregiver provided with education and training in dementia care?
	Are families/caregivers provided with information about available resources and their access facilitated to these?
	Are home support services available for tasks needed by people with dementia and their caregivers, such as cooking, cleaning and shopping?
	Are affordable and accessible options for instrumental activities of daily living such as shopping, banking, laundry and housecleaning, available?
	Are additional hours of home support for night care, challenging behaviours, transitions, and for people with end stage dementia, available?
	Is counselling and emotional support available for caregivers?
	Are ambulatory and inpatient options for assessment and treatment, and accessible community geriatric services available when/where required?
	Are families/caregivers consulted about care/part of the team?
	Are family/caregiver needs taken into account when planning/providing care for people with dementia (e.g., age, health, capacity to provide care, competing responsibilities)?

Notes _____

➤ Care providers are competent

	Are all those who have contact with people with dementia expected/enabled to have a general knowledge of dementia?
	Are all direct care staff expected/supported to have skills and knowledge necessary to care for people with dementia and their families?
	Is comprehensive, coordinated and ongoing education available for all staff in dementia care?
	Does the policy/program/practice provide the organization and its workforce; its practitioners and service providers, with an understanding of diversity?
	Are processes in place to ensure that care is based on current best practices in dementia care/CPGs pertinent to each phase of the dementia journey?

	Do recruitment, orientation, staff development and staff appraisals incorporate need for skills and knowledge in dementia care?
	Are health care professionals knowledgeable about tools that are available to support the person with dementia and their families in future care and life planning (e.g., enduring powers of attorney and representation agreements)?
	Are systems in place to monitor the knowledge transfer into practice?

Notes _____

➤ **Care providers are supported**

	Does the work environment support providers in their clinical practice?
	Is there consistent access to adequate supervisory assistance and support?
	Is time available for communication (between care providers, across settings)?
	Is support necessary to translate research and evidence into practice available?
	Is there access to specialized consultation (e.g., psychogeriatric, behaviour management)?
	Is there access to resources to assist in resolving ethical issues?
	Is emotional support to assist with coping (e.g. death, responsive behaviours), available?
	Are the diverse needs and circumstances of service providers recognized?

Notes _____

8. Does the policy/guideline/program facilitate/support a dementia friendly care environment?

	Does the physical environment reflect best practices in dementia- friendly environments
	Does the physical environment compensate for mobility issues, sensory changes, etc)
	Is the care environment (i.e., culture, setting, processes and practice) sensitive and accommodating for people with dementia and their families?

Notes _____

9. Does the policy/guideline/program support a comprehensive and integrated care system?

Rationale: The system must be designed with the capacity and ability to address the clinical and support needs of people with dementia and their families/ caregivers through all phases and transitions of dementia.

	Is there sufficient service delivery capacity to support people with dementia and their families/caregivers, through:
	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
	Resources to implement non-pharmacological/psychosocial approaches to prevent/manage challenging behaviours
	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 (i.e. counselling, support, recreational)
	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.

	Clinically appropriate staffing levels, mix and time allotted to meet diverse and extensive client needs, to communicate with each other, and to support care planning and multidisciplinary care, throughout the care system?
	Processes that ensure continuity in care and consistent client assignment, as appropriate to client need, throughout the care system?

Notes _____

10. Does the policy/guideline/program reflect value and principle based system planning?

	Are knowledge about dementia, and the values and principles of excellence in dementia care reflected in:
	Service frameworks
	Mission statement, Philosophy
	Program planning, strategic development, resource allocation
	Staffing (numbers, allocation, recruitment),
	Accountability processes (e.g., Quality assurance)
	All service sectors policies/programs/guidelines (e.g., home and community, residential and acute care)?
	Research

Notes _____

11. Is accountability addressed?

	Is the policy/guideline/program based on current evidence and/or best practices?
	Can the policy/program be evaluated for process and outcome?
	Are resources and capacity aligned with responsibility?
	Are performance expectations of partners in care clearly defined and monitored for results
	Are the rights and duties of all parties in applicable legal framework reflected in the policy?
	Is there compliance with applicable standards and legal frameworks?

Notes: _____

Interpreting the Results

1. Summate the columns- How are we doing? Where can we improve?

YES>NO? You are well on your way to a positive policy/guideline/program. But look for some ways it could be improved. Go back and determine if there are any changes that will yet increase the number of “Yes” responses.

NO>YES? Your policy/guideline/program should be re-examined for content and overall intent. Many needs, wants, and concerns of people with dementia and their caregivers may not be met. A good source of input is from those affected by dementia.

NOT SURE> Either YES or NO You need to gather more information before proceeding with your policy/guideline/program. This will ensure it more comprehensive and holistic.

NOT APPLIC> Either YES or NO Go back and critically examine your policy. Are there really this many categories that do not apply to your policy /guideline/program? Or does much of the policy/guideline/ program not apply to the needs, wants, and concerns of those for whom it is intended?

2. Review your notes and your discussions. Note strengths of the policy/guideline/program

3. Identify areas that require improvement and ways that potential negative effects could be addressed or off-set. Note who needs to be involved to address this process, and what information needs to be gathered. Set target dates.

Issues Identified	Actions/Information Needed	Who needs to be involved	Target date

4. Make a Recommendation

Answer yes or no to whether the policy should be *accepted*, or *accepted as revised*, whether there is a *need for more information*, or if *revision is required*.

Accepted		
Accepted as revised		
Need more information to decide from whom, where		
Needs revision		

5. Revise the policy, and re-apply the lens, starting at the beginning. Repeat until the (revised) policy is recommended for acceptance.

APPENDIX 1

How the Dementia Policy Lens Toolkit Was Developed (Method)

Processes

The conceptual framework for the DPL draws on the principles of the Dementia Service Framework, the BC Guidelines for Best Practices in Elderly Mental Health Planning, the National Framework on Aging, Population Health, and others derived from a scan of the literature.

A scan of the literature was undertaken that focussed on (1) values and perspectives expressed by people with dementia (2) caregivers descriptions of what factors they feel contribute to excellent dementia care for their loved one, and to excellent support for themselves (3) pertinent theoretical frameworks and care models (e.g., person-centred care, dementia friendly care, dementia friendly policy, etc.) .

Ethical approvals were obtained from the University of Victoria and from each Health Authority (HA) to carry out the research.

Recruitment

People with dementia and family caregivers were recruited through the ASBC and HAs, (in compliance with ethical parameters). Information was gathered from caregivers attending ASBC public policy workshops, *Regional Advocacy Training Workshop*, in several regions. Key informants (e.g., care providers, educators, policy analysts) were identified through the ASBC, HAs, and the BC Psychogeriatric Association.

Participants

Thirty five people with MCI or early stage dementia were interviewed, a few in focus groups. Sixty caregivers participated in the research and were interviewed in focus groups, or through their participation in ASBC public policy workshops. Fifteen key informants were interviewed in focus groups and individually.

Data Collection

Information was collected in 2008 through semi-structured interviews and focus groups with (1) people with mild cognitive impairment (MCI) or early stage dementia, (2) care givers, (3) key informants in policy, practice, education and program planning sectors, (4) ASBC *Regional Advocacy Training Workshops*

Those who have MCI or dementia were asked for their perspectives on what constitutes excellent care, their hopes for their future and what they value in services and service providers.

Family caregivers were asked for their perspectives regarding quality care for their loved one, and support for themselves. Information was gathered from caregivers at ASBC public policy workshops about their views on how dementia care and services are currently organized and provided.

Key informants were asked to contribute their views on the components of programs, services and policies that are imperative in supporting people with dementia inconsistent with the DSF principles.

Evaluation of the DPL

The DPL was applied to a policy, program or service by each HA partner and the ASBC. They then completed an accompanying evaluation form, followed by a discussion with the researcher, about the utility of the DPL toolkit. Overall feedback was positive but a need for two mirrored versions of the DPL, to address the different needs of policy makers and clinicians, was identified. The DPL was refined and the DPL toolkit created to address the need to “package” the DPL for specific target groups (e.g. policy makers, HA managers , clinicians).

Dissemination

The finalized DPL toolkit was distributed at the 2nd Alzheimer BC Learning Forum. It was also disseminated to ASBC, the MoH Home and Community Care , to each HA , and to other key organizations and government departments concerned with the care of older adults with dementia.

APPENDIX 2

Dementia, Values, Gaps In The System Of Care And The Rationale For Making Improvements¹

1. What is dementia ?

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 behavior, 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 behavior;
- Impaired judgment and reasoning; and,
- 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.

There are different forms of dementia and the most common forms 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); and
- Disturbance in executive functions such as planning, organizing, sequencing, and abstracting.

Vascular Dementia:

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

Dementia with Lewy Bodies:

This disease often has features of both Alzheimer'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:

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:

Dementia caused when damage to brain cells occurs from excessive consumption of alcohol.

¹ This appendix is taken from the Dementia Service Framework

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 or 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. These three stages are described below.

Mild:

The person who has mild dementia is still able to function somewhat independently; however, memory loss and thinking impairment is 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 behavior 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 caregiver(s) 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.

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

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.

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. Gaps in the System of Dementia Care

An analysis of current gaps in the system of dementia care within 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; and,
7. There is a gap in the formal integration, collaboration and communication across care settings, between health care providers, and across health authorities.

As a result of these gaps, inadequate, inappropriate and poor care and support is received by people living with dementia and their caregivers creating a cycle of poor health outcomes, crisis intervention, and high utilization of inappropriate services. The cumulative impact of these shortfalls on people with dementia, their families and caregivers, and on the system itself is profound.

For the person with dementia...

- Depression and functional changes go unrecognized and unmanaged;
- 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; and,
- 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;
- Deterioration in their mental and physical health, for example, depression;
- Cross-generational effects as people struggle to balance the needs of their parents with the needs of their children; and,
- Decreases in on-the-job productivity due to absenteeism and lack of focus.

For the health care system...

- Lack of focus on proactive management of care;
- Sub-optimal emergency and hospital responses;
- Inappropriate use of pharmacological interventions; and,
- Delays in recognition, diagnosis, and treatment, meaning that individuals enter the system at more of a crisis point.

For the community.....

- Withdrawal of people with dementia and their families/caregivers from important community roles;
- Dependence on residential care rather than expanding other housing options;

- Strain placed on community agencies and volunteers trying to respond to the needs of people with dementia and their families/caregivers; and,
- Lack of dementia-sensitive policies, programming and infrastructure.

4. The need to improve dementia care

There are two main (and related) reasons why identification and implementation of optimal care is

- **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; and,
- **The Numbers Rationale** - the demographic imperative facing BC and the rising economic burden associated with increasing numbers of dementia cases.

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:

- Healthcare workers to receive additional training specific to caring for people with dementia;
- Improved continuity of care through permanent client assignment and increased staffing levels; and,
- An interdisciplinary, person-centered approach to care which includes the person with dementia, family, and direct care 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 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; and,
- 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 inter-sectoral and inter-disciplinary recommendations to strengthen dementia care in B.C. 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.

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.²

The Centre for Applied Research in Mental Health and Addiction (CARMHA) at Simon Fraser University has done modeling to project the number of dementia cases British Columbia may expect to see over the next 20 years.³

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 the figure below, the number of cases rises dramatically and is almost entirely due to the age 65+ group.

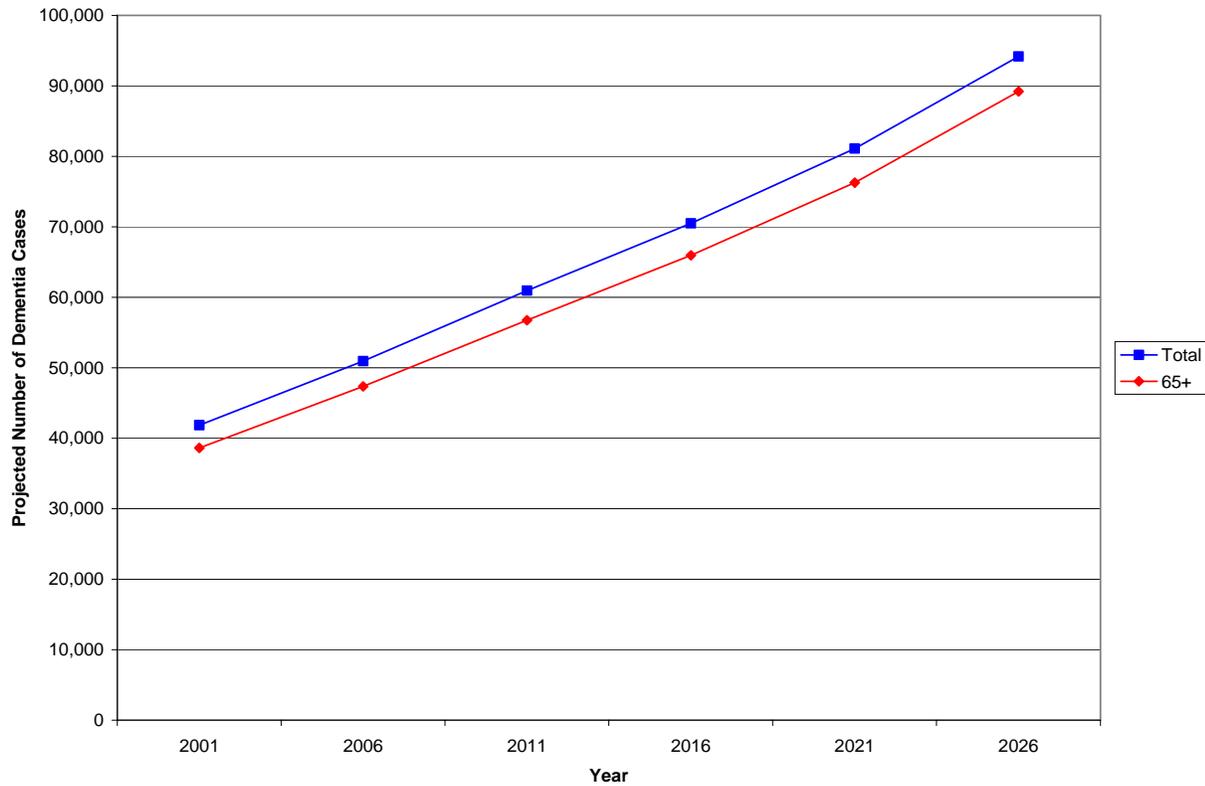
² Data from preliminary results of the national study *Rising Tide: The Impact of Dementia on Canadian Society (2009)* suggests that the number of people with dementia (and who may have dementia in the future) are higher than those presented in the Dementia Service Framework in 2007. (Retrieved March 6, 2009 from http://www.alzheimerbc.org/put_your_mind_to_it.php)

(Highlights include:

- 1 in 11 Canadians over the age of 65 has Alzheimer's disease or a related dementia.
- An estimated 500,000 Canadians have Alzheimer's disease or a related dementia
- Of the 500,000 Canadians affected by dementia, more than 71,000 of them are *under* the age of 65, and approximately 50,000 of them are *under* the age of 60.
- In just five years, as many as 50% more Canadians and their families could be facing Alzheimer's disease or another form of dementia.
- As it stands today, the number of Canadians living with Alzheimer's disease or a related dementia will more than double within a generation (25 years).
- Further results of *Rising Tide*, evaluating the social and economic impact of dementia on Canadian society, will be released later in 2009.

³ Dementia Projections for British Columbia. Centre for Applied Research in Mental Health and Addiction, SFU. September 2006.

TABLE 2: 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.**

Direct Costs

The direct health care costs are staggering as shown in CARMHA’s costing model below.⁴

TABLE 3: 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.

⁴ Dementia Projections for British Columbia. Centre for Action Research in Mental Health and Addiction, SFU. September 2006.

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

Indirect Costs

Indirect financial costs tend to be borne primarily by people with dementia and those who care for them. These include:⁵

- 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; and,
- Transfer costs such as welfare and disability payments.

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; and,
- The years of healthy life lost due to disability (YLD)—the morbidity burden.⁶

⁵ As analyzed in *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. March 2003. Alzheimer's Australia. Canberra.

⁶ Ibid

In Australia in 2002, the burden of disease attributable to dementia was estimated as 117,083 DALYs. Morbidity was the major source of 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 at risk for, or diagnosed with the condition, remain healthy for as long as possible. The service framework is the ideal vehicle for reorienting the entire system in these directions.

APPENDIX 3

List of Resources

The following projects have been funded by the Alzheimer Society of British Columbia through a provincial grant to improve dementia care in British Columbia. More information, and contacts, can be found at www.alzheimerbc.org

Dementia Journey live at www.dementiajourney.ca

The Dementia Journey website connects people with helpful resources and information about dementia. Originally created by the Vancouver Coastal Health Authority for Lower Mainland residents, an expanded site was launched on Oct. 20. The new site contains information from across the province, including an interactive map of local services. The site uses personal stories of people impacted by dementia to guide users to information for those with dementia, caregivers, families and health professionals.

Sustainable Caregiving Project at evaluation stage

The Interior Health Authority worked in four communities to run a six-month pilot project that established (or refined, if they already existed) screening and referral processes for caregivers, to enhance early detection of high caregiver burden and stress. Since each community has different caregiver supports already in place, methods and results in each community were a bit different. Evaluations of the trial run are now underway, with results expected in January.

Multi-lingual project holds Chinese Community Forum

This UBC initiative provides culturally sensitive dementia information in Cantonese, Mandarin, Hindi, and Punjabi. More than 600 people listened to eight physicians speak at the Chinese Community Forum on Oct. 11, where the dementia section of the Chinese Online Health Network (iCON) was launched. Provided entirely in Chinese, iCON(www.iconproject.org) includes information on diabetes, heart health, and now dementia.

E-Learning Project

Under development by the Northern Health Authority, this initiative will provide user-friendly dementia education through the Internet to health professionals, people with dementia, caregivers and families starting in early 2009.

First Link program

A partnership between the Vancouver Island Health Authority (VIHA) and the Alzheimer Society of B.C., *First Link* connects people who have received a diagnosis of dementia with important information and services as early as possible in the disease process. A second part of this initiative, a program for caregivers called *Coping with Transitions in Dementia Caregiving: Dimensions of Loss and Grief*, launched in October.

Dementia Education Framework (DEF)

A project of the Fraser Health Authority, this provincial Framework will provide the foundation for consistent and coordinated programming to address the educational needs of people with dementia, caregivers, family members and health-care providers. .