

# BUILDING BRIDGES

A CALL FOR  
A COORDINATED  
DEMENTIA STRATEGY  
IN BRITISH COLUMBIA

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*April 2004*

BRITISH  
COLUMBIA  
MEDICAL  
ASSOCIATION



**“If you don’t build it – they will come anyway.”**

... common saying

This document was produced by the British Columbia Medical Association's Council on Health Promotion. In 2003/04, the Council undertook a project called "Seniors Living Well" to raise awareness around seniors' health issues among various audiences in the province. To this end a project group was formed to develop this paper.

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## **Executive Summary**

This document is about improving how we care for people with dementia in British Columbia. Dementia is a complex, degenerative condition that erodes an individual's cognitive abilities. It is a vicious disease that over time steals people's memories, talents and even their identities. The most well known form of dementia is Alzheimer's disease, but there are many other forms. People suffering from dementia require a considerable level of care and support from their families, and the health care system.

Dementia is a "sleeping giant" that our healthcare system is simply not prepared for. The challenges in the years ahead regarding dementia are considerable. Today there are at least 45,000 people in British Columbia living with dementia. By 2011, it is estimated there will be 55,000 people with dementia in BC – an increase of 22% in just 7 years.<sup>1</sup> Historically, 8% of all Canadians over age 65, and 34.5% of people over age 85, have some kind of dementia. Seniors, particularly those over age 85 are the fastest growing segment of BC's population.

The effort and resources that patients and their families need to care for people with dementia are enormous. Yet today, British Columbia is one of the few remaining provinces in Canada without a coordinated dementia strategy. Provinces such as Ontario, Alberta and Manitoba, as well as other countries such as New Zealand and Australia are considerably further ahead.

**Therefore, the British Columbia Medical Association is calling on the provincial government to develop and implement a coordinated dementia strategy.**

This document identifies six major challenges that must be addressed if we are to improve how we care for these people. To address these challenges, the BCMA is making 23 recommendations in the following six areas:

- 1) Make caring for dementia a priority
- 2) Include dementia in chronic disease management
- 3) Support the provision of comprehensive care
- 4) Match residential and community services with needs
- 5) Improve the coordination of services
- 6) Provide coverage for dementia medications

The BCMA believes that a critical first step in this process is to include dementia in chronic disease management. BC has embarked on several initiatives related to improving the management of chronic diseases, and it is imperative that dementia be included in these efforts.

The Ministry of Health Services should establish a dementia task force in order to bring the key stakeholders to the table. Given that dementia will have significant human resource and financial impact over the next decade, it must have a higher priority than it does now.

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<sup>1</sup> Canadian study of health and aging: study methods and prevalence of dementia. Canadian Medical Association Journal (CMAJ) – 1994, March 15; 150(6): 899-913

We must ensure that the proper incentives and support structures regarding dementia care are in place for primary care physicians. This is part of the larger challenge of BC's growing shortage of family physicians. These support structures must also extend to other health care providers, agencies and especially the families of those suffering from dementia. In this light, the BCMA sees a greater role for agencies such as the Alzheimer Society of British Columbia.

BC also needs to do a better job of collecting, analyzing and sharing information on dementia. This will assist in delivering more efficient care, but will also assist in dementia research. As we move forward, the province and health authorities must look at where seniors, particularly those with dementia are choosing to live.

Lastly, BC needs to catch up to the rest of Canada in terms of providing coverage for medications for dementia. It is recognized that guidelines and protocols must be in place to ensure appropriate use of these medications. However, it is unacceptable that BC, unlike other provinces, has chosen to cover medications for other chronic conditions, but not for dementia.

The BCMA is committed to a constructive dialogue on dementia, and will be actively engaging government, other health care providers and key agencies in developing this strategy. There is a considerable amount of hard work being done to care for British Columbians with dementia, and it is now time to bring these pieces together.

## **List of Recommendations**

### **1) Make caring for dementia a priority.**

- That the provincial government establish a task force on dementia with a 12 month mandate to review, design and begin implementation of a dementia strategy in BC.
- That the task force establish an expert advisory group of practising physicians and other healthcare providers, Health Authorities, Ministry of Health, researchers and advocacy groups such as the Alzheimer's Society of British Columbia.
- That each Health Authority should include their responsibilities within the dementia strategy in their work plans and performance agreements.
- That an evaluation process for the dementia strategy be incorporated at the outset and that the results of this evaluation be made available to the public.

### **2) Include dementia in chronic disease management.**

- That dementia be included in the current BC Chronic Disease Management Care Program, starting with the development of a provincial registry for dementia.
- That the Ministry of Health Services develops and distributes clinical guidelines for the diagnosis and management of dementia. The BCMA will support this endeavor through the Guidelines and Protocol advisory committee.
- That appropriate preventive activities (attention to diet, exercise, alcohol consumption, and drug abuse) for dementia continue to be promoted and advocated to the public.

### **3) Support the provision of comprehensive care.**

- That government and physicians work together to ensure that patients with dementia are able to access a family physician and appropriate specialty care.
- That a community group, such as the Alzheimer Society of British Columbia, be funded to participate in the provision of coordinated care through education, information and support services for the patients and their families at the health authority level.
- That the BCMA will produce a patient pamphlet on dementia for distribution to physician offices.
- That dementia is reviewed as a prospect for inclusion under the BCMA/Ministry of Health Full Service Family Practice Incentive Program.
- That undergraduate and post-graduate medical and nursing education programs in the province reflect the importance of dementing illnesses in our society.



#### **4) Match residential and community services with needs.**

- That the Ministry of Health review disability adjusted standards for the provision of community and residential services for people with dementia.
- That the assisted living model be adapted appropriately to meet the needs of people with dementia on key issues such as medication management, nutrition, safety and supervision.
- That Health Authorities work to implement and/or expand a range of respite services, including emergency support, planned short-term respite programs, and day programs.
- That the Ministry of Health in conjunction with Health Authorities conduct an evaluation of existing and planned long-term care resources and assisted living based on the projected distribution of seniors by RHA, and this review be made public.
- That the Ministry of Health continues to improve the prioritization mechanisms to ensure equitable access to long-term care facilities.

#### **5) Improve the coordination of services.**

- That government and Health Authorities work to provide incentives to improve linkages between family physicians and long-term case managers and other care providers and coordinators.
- That a clinical information summary (paper or electronic) for patients with dementia be developed that is accessible to health care professionals involved in care of individuals across the system of care and over time.
- That the Ministry of Health and Health Authorities work with practicing physicians, long-term care facilities and other agencies 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.

#### **6) Provide coverage for dementia medications.**

- That Pharmacare expand coverage to include dementia medications.
- That maintenance or a slowing in the rate of decline of cognition or function be accepted as a standard of efficacy in the pharmacological treatment of dementia in BC.
- That BC physicians (through guidelines and protocols) are provided with ongoing information on dementia pharmacotherapy and effective drug utilization.

## **1.0 Introduction**

Dementia is a progressive condition that gradually erodes a person's mental abilities. This condition develops insidiously and steals what is often most precious to us – our memories, talents, identities and our ability to communicate. There are many types and stages of dementia. In some cases the progression of dementia can be slowed, but never cured. Alzheimer's disease is the most well known form of dementia, making up over 60%-70%<sup>2</sup> of all dementia sufferers.

Those living with dementia are some of the most vulnerable people in our society, and their numbers are increasing dramatically. Dementia represents a "sleeping giant" within BC's health care system. We are already experiencing problems caring for the number of dementia patients we have today. In no way are we prepared for the numbers of patients with dementia our province will need to care for, even by 2010.

The challenges facing us are considerable. Today people over age 85 are the fastest growing segment of BC's population. Unfortunately, one-third of this age group also suffers from some form of dementia. People suffering from dementia require tremendous amounts of care and resources – both from family and friends as well as from health professionals and our health care system.

Several health care systems around the world and in Canada have, or are in the process of introducing a coordinated strategy for dementia - British Columbia is not. Fortunately, there are many areas where there are resources and hard work being done for people with dementia in BC. However, a more aggressive and better-coordinated approach is required.

Therefore, the British Columbia Medical Association (BCMA) is calling on the provincial government to work with care providers, patients, their families, and associated organizations to develop and implement a coordinated dementia strategy for British Columbia. The objective of this strategy should be to connect, enhance and improve on the good work already being done in British Columbia so we are adequately prepared to care for those suffering from this terrible illness.

This document outlines the major challenges and recommendations for taking the first steps to achieving that strategy. These are only first steps, and are intended to set the stage for the debate and work that must be done to manage this chronic disease.

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<sup>2</sup> <sup>2</sup> World Health Organization, 2003, <http://www.who.int/inf-fs/en/fact265.html>

## 1.1 What is dementia?

Dementia is a clinical syndrome resulting in a decline in all areas of mental ability over time. Dementia impacts the parts of the brain involved with learning, memory, decision-making, and language cognitive abilities. Dementia also causes changes in personality, mood, and behavior.<sup>3</sup>

There are several stages of dementia, ranging from mild to severe. To confirm and characterize possible cases of dementia, physicians perform physical examinations, conduct laboratory tests and diagnostic imaging investigations to exclude other conditions that may cause or exacerbate cognitive loss. Recognition of dementia in its early stages is difficult, but increasingly important for those inflicted with the disease, their families, and the health care system.

## 1.2 Who gets dementia, and is there more than one kind?

Dementia is a disease. While dementia is more prevalent in older persons, it is not a normal part of aging. After reaching 65 years of age, the chance of developing dementia increases significantly as people age. For example, approximately 8% of people over 65 have some form of dementia, but once people reach 85 years of age the rate increases to 34.5%.<sup>4</sup> The two risk factors that appear to be associated with an increased chance of developing dementia are a person's age and a family history of dementia.

There are many types of dementia, but the diseases listed below make up the majority of dementia cases. In some instances, people can have more than one of these conditions.

**Alzheimer's Disease** is the most common form of dementia. Alzheimer's disease is a degenerative brain syndrome characterized by a progressive decline in memory, thinking, comprehension, calculation, language, learning capacity and judgment. Between 60% and 70% of all people with dementia have Alzheimer's disease.<sup>5</sup> It may occur alone or in combination with other types of dementia, particularly vascular dementia.

**Vascular Dementia (VaD)** is the result of a single or multiple stroke or changes in the small blood vessels of the brain. Strokes can be large or small, and can have a cumulative effect (each stroke adding further loss of function).<sup>6</sup> The result is a gradual or sudden loss of brain cells resulting in dementia.

**Lewy Body Dementia** is a form of progressive dementia identified by abnormal structures in brain cells called "Lewy bodies." These are distributed in various areas

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<sup>3</sup>: Canadian Medical Association Medical Encyclopedia, 1992, Web MD 2003, [http://my.webmd.com/content/article/45/1626\\_50835.htm](http://my.webmd.com/content/article/45/1626_50835.htm)

<sup>4</sup> Canadian study of health and aging: study methods and prevalence of dementia. Canadian Medical Association Journal (CMAJ) – 1994, March 15; 150(6): 899-913

<sup>5</sup> World Health Organization, 2003, <http://www.who.int/inf-fs/en/fact265.html>

<sup>6</sup> CMA Medical Encyclopedia, 1992, p. 336-337

of the brain. Lewy Body Dementia often demonstrates features of both Alzheimer's or Parkinson's Disease.<sup>5</sup>

**Fronto-Temporal Dementia (Formerly Pick's Disease)** is a progressive disease that affects certain areas of the brain (i.e., temporal and frontal lobes). Symptoms of this disorder may include loss of intellectual abilities, but changes in behavior and personality are often seen early in the disease. Affected individuals may exhibit apathy and a general lack of concern about their surroundings.<sup>7</sup>

#### **Other Types of Dementia:**

**Huntington's Disease** is a genetic disorder in which certain nerves in the brain gradually degenerate over time. People with Huntington's disease develop jerky, involuntary movements and have progressive mental impairment. Symptoms do not usually appear until 35-50 years of age.<sup>8</sup>

**Creutzfeldt-Jakob Disease (CJD)** is an extremely rare degenerative brain disorder. As the disease progresses, individuals may develop confusion, depression, behavioral changes, impaired vision, and/or impaired coordination. As the disease progresses, people develop dementia, muscle weakness and loss of muscle mass.<sup>9</sup>

**Other causes of Dementia:** Dementia can also be caused by other factors. Examples include HIV/AIDS, excessive alcohol use, and brain injury.

**Mixed combinations of Dementia:** People can also suffer from a combination of dementias. For example, a person with Alzheimer's disease could also develop vascular dementia as a result of a stroke.

A related condition is called mild cognitive impairment (MCI), but it should not be confused with dementia. MCI is a more serious form of cognitive impairment with memory loss, but does not mean a person has dementia. There are several criteria that differentiate MCI from general memory loss or dementia:<sup>10</sup>

- An individual's report of his or her own memory problems, preferably confirmed by another person
- Measurable, age-associated memory impairment detected with standard memory assessment tests
- Normal general thinking and reasoning skills
- Ability to perform normal daily activities

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<sup>5</sup> Alzheimer Society of Canada, 2003, <http://www.alzheimer.ca/english/disease/dementias-lewy.htm>

<sup>7</sup> WebMD, 2003 - <http://my.webmd.com/content/healthwise/78/19505>

<sup>8</sup> CMA Medical Encyclopedia, 1992

<sup>9</sup> Adapted from WebMD - <http://my.webmd.com/content/healthwise/89/22274>

<sup>10</sup> R. C. Petersen, PhD, MD; J. C. Stevens, MD; M. Ganguli, MD, MPH; E. G. Tangalos, MD; J. L. Cummings, MD; and S. T. DeKosky, MD. "Practice parameter: Early Detection of dementia: Mild cognitive impairment (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology." *Neurology* 2001; 56: 1133-1142. <http://aan.com/professionals/practice/pdfs/gl0070.pdf>

### 1.3 Stages of dementia

Dementia is a progressive degenerative disease. While some forms are treatable, the condition of the majority of people suffering from dementia tends to deteriorate over time. Therefore, people tend to move through “stages” of the disease. There are no universally agreed upon categories of dementia. However, common sets of categories based on tests for mental competency are mild, moderate and severe dementia.<sup>11</sup>

**Mild:** some thinking impairment and memory loss. The person is still able to function somewhat independently.

**Moderate:** increasing memory loss, thinking and concentration. Independent function is occasionally or consistently compromised, requiring general observation.

**Severe:** significant inability to think coherently, considerable loss of memory, language skills, and living skills. The person cannot be left unsupervised.<sup>12</sup>

A person with dementia will typically move through all three stages over the course of their illness. As dementia progresses, there can be significant changes to the person’s personality and mood. Over time families often see the person they know “disappear” - even to the extent that a person with severe dementia may no longer recognize their own spouse and/or children. People with dementia may also encounter depression, increased irritability and more severe behavioral episodes.

A prevalence rates study completed in 1997 (Graham et. al), found that in a random sample of 1,000 Canadians over age 65, a total of 80 people would have some form of dementia. Of those 80:

- 23 would have mild dementia
- 31 would suffer from moderate dementia, and
- 26 would have severe dementia.<sup>13</sup>

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<sup>11</sup> Based on data obtained from the CSHA, categories were determined using the mini-mental state examination (<http://www.minimental.com/>), Scores range from 25-30 for normal, 21-24 for mild, 14-20 for moderate, and less than 13 in severe AD.

<sup>12</sup> For the precise diagnostic categories, please see the **Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV) - Dementia of the Alzheimer's Type:** <http://www.behavenet.com/capsules/disorders/alzheimersTR.htm>

<sup>13</sup> Graham et. al., Lancet, 1997, p. 1794 – identified the prevalence of dementia in people over 65 as 2.3 per 100 for mild, 3.1 for moderate and 2.6 for severe.

## **2.0 Looking ahead – dementia and BC’s baby-boomers**

For the past decade politicians and policy analysts alike have talked about the impact that baby-boomers (those born between 1946 and 1965) will have on our society as they enter their senior years. A key date is the year 2011, which is when the first baby-boomer turns 65. Given that dementia tends to affect seniors, it is important to understand just how many people our health care system and society will need to care for. This chapter provides a glimpse into what our society and health care system will soon encounter.

“With an aging population there will likely be an increase in the number of people who require joint replacement or suffer from Alzheimer’s disease and other types of dementia.”

Royal Commission on Health Care, 2002

Today’s seniors are far healthier than seniors of a generation ago. Advances in medical care combined with people’s increased focus on healthy choices are not only lengthening life expectancy, but keeping them healthier as well. The focus of this paper is not on treating seniors as a burden, but rather to ensure that the structures are in place to keep them healthy and independent for as long as possible. However, even with these improvements, the demographic pressures will be considerable. Unfortunately, the chance of developing dementia increases with age. So while people are living longer, they are also more likely to develop dementia.

## **2.1 BC’s aging population – the wave of the future**

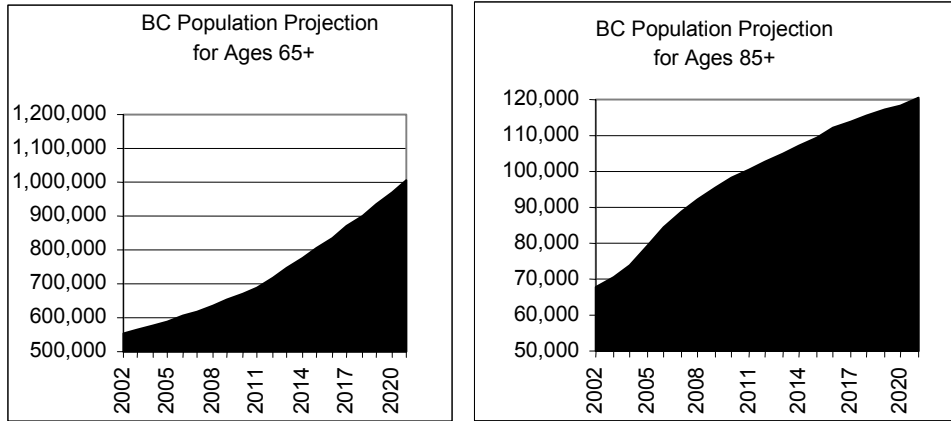
### **2.1.1 Seniors’ population projections**

Today, phrases such as the “gray-wave” and the “seniors tsunami” are used by media and politicians to describe the demographic changes that are occurring in our society. To put these phrases in context, consider the following<sup>14</sup>:

- In 2002 there were over 550,000 British Columbians over age 65. Of these, about 67,500 were over the age of 85.
- By 2011 there will be almost 690,000 people in BC over age 65 – an increase of almost 140,000. This is a 25% increase from 2002. This rate of increase is twice BC’s projected growth rate for the population as a whole.
- By 2011 there will be more than 100,000 seniors over age 85 – a 49% increase in less than 10 years. This is the fastest growing segment of BC’s population.
- By 2021 it is projected there will be more than one million seniors in BC, of these more than 120,000 will be over 85. This means the number of people over age 65 and over 85 in BC will have almost doubled in less than 20 years.
- By 2021 almost 1 in 5 people in BC will be over age 65.

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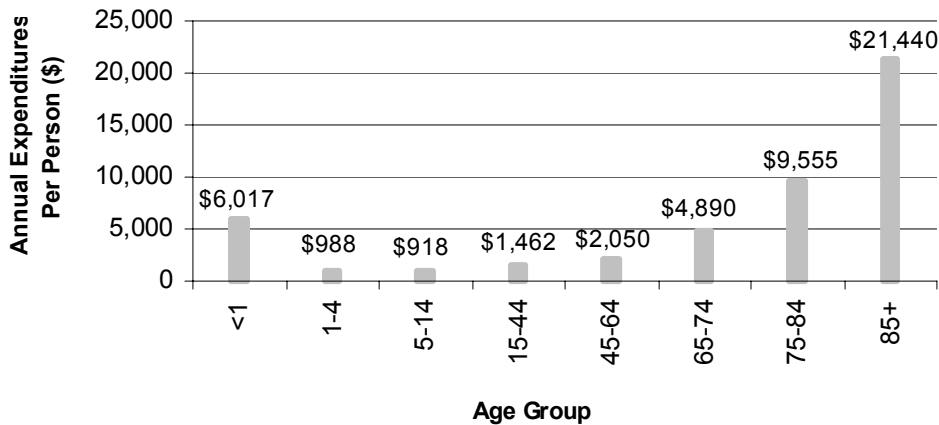
<sup>14</sup> Source for all population data in these bullets is from BC STATS, Forecast 02/05



Source: BC STATS, Forecast 02/05

A fact that many governments around the world are struggling with is that older persons tend to use more health care services. Older people with dementia use even more services. Once people reach age 65, their use of services begins to climb rapidly, as the following chart demonstrates. For example, in 2001 the BC provincial government spent an average of \$1,462 per year on health services for someone between 15 and 44 years of age. In contrast, government spent \$4,890 for health services for people between the ages of 65 to 74 years of age. **After age 85 this figure rose to \$21,440 per person per year.** Note that these figures only include government expenditures (services covered by the public system), and do not include private expenditures made by the individuals. Given that people over 85 are the fastest growing group in BC, the pressures in the years ahead are formidable.

**Total British Columbia Government  
Annual Expenditure On Health Per Person - 2001**



Source: National Health Expenditure Trends, 1975 to 2003,  
Canadian Institute for Health Information, 2004

### 2.1.2 Where BC’s seniors live

Knowing where BC’s seniors live is critical to the planning of services today and for the future, as this has implications for funding and resources. The Fraser Health Authority has the highest number of seniors in BC (30.5% of all BC seniors) at 175,668, while the Northern Health Authority has the lowest number at 25,268 (4.4% of BC’s seniors).

Health Authority	Total Population (est. July 2004)	# of Seniors 65+	% of Provincial 65+ Population	65+ as % of Regional Population
Fraser	1,470,919	175,668	30.5%	11.9%
Interior	694,543	119,523	20.8%	17.2%
Northern	304,357	25,268	4.4%	8.3%
Vancouver Coastal	1,054,509	134,922	23.4%	12.8%
Vancouver Island	<u>700,729</u>	<u>120,612</u>	<u>20.9%</u>	<u>17.2%</u>
Total / Average	4,225,057	575,993	100.0%	13.6%

Source: BC Stats, PEOPLE Run 28 (Population data)

Another element to consider is what proportion of an RHA’s population consists of seniors. Vancouver Island and the Interior Health Authorities have the highest proportion of seniors in their populations (17.2% each). On the other end of the scale, only 8.3% of the Northern Health Authority’s population is over 65.

Assuming current trends continue, seniors will live in higher proportions in certain areas of the province, most notably in the Interior and Vancouver Island health authority. However, in terms of absolute numbers, the Fraser Health Authority will continue to have the largest number of seniors of any health authority in the province. Predictably, all of these health authorities will need enhanced dementia related services.

## 2.2 Dementia in BC – the numbers today and tomorrow

**A conservative estimate is that there are over 45,000 people in British Columbia living with dementia today.**<sup>15</sup> As outlined earlier, BC is experiencing a rapid increase in the number of seniors in our society. Unfortunately this also means that BC will experience a surge in the number of people suffering from dementia.

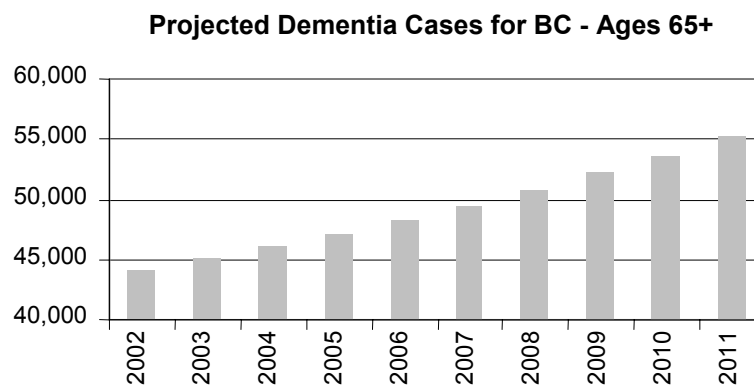
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<sup>15</sup> Based on BC STATS, Forecast 02/05 estimating 564,248 people in 2003 in BC over age 65 and assuming 8% have some form of dementia based on dementia rates in Canada from The Canadian Study of Health and Aging - CSHA, 2003, [http://www.csha.ca/r\\_design.asp](http://www.csha.ca/r_design.asp) and Lancet 2000 Nov 11; 356(9242): 1627-31.



So what does all this mean for the future?

If current trends continue, by 2011 there will be over 55,000 people in BC with dementia – an increase of over 10,000 people (22%) in less than 8 years.<sup>1</sup>



Source: BC STATS, Forecast 02/05 – Dementia rates based on 8% of people over 65.

### **2.3 The costs of dementia – human and financial**

The rapid increase in the number of people with dementia will have a broad impact on families and the health care system. Above it was identified that there will be 10,000 additional people with dementia in BC by 2011. However, the number of people affected is much wider as the families of those with dementia will also be significantly impacted. Therefore in any discussion of costs, it is important to note there are several layers of costs resulting from dementia, including:

- costs to the family in terms of direct costs (for care not covered by the public health care system), time (i.e. absence from work) and health declines, including stress;
- costs to the health care system for medical and long-term care and medications and costs to the health system for health decline of caregiver;
- costs to the economy in terms of sick leave, lost productivity and lower tax revenues.

In 1994, a study by Ostbey and Crosse estimated the total annual net cost of dementia in Canada was \$3.9 billion.<sup>16</sup> Recently, the Alzheimer Society of Canada updated this figure,

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<sup>16</sup> T. Ostbye and E. Crosse, “Net Economic costs of dementia in Canada”, CMAJ, 1994, Vol 151 (10) 1457-1464.

estimating the total cost of dementia in Canada in 2003 to be \$5.5 billion a year on persons with Alzheimer disease and related dementias.<sup>17</sup>

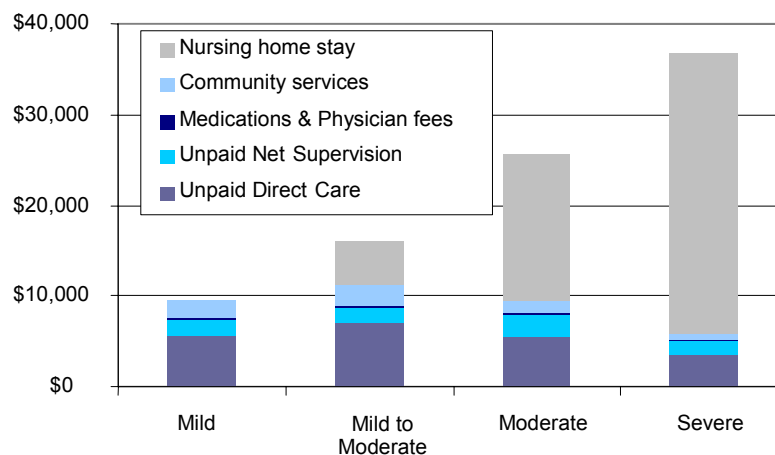
In 1998, Hux et al.<sup>18</sup> conducted a study to cost out the societal and financial burden of Alzheimer's disease. This study estimated not only the costs for things like long-term care and community services, but also included estimates for unpaid direct care provided by families. **However, hospital related costs for dementia were not included in the study as they were unavailable.** What they found was that the annual cost of dementia increases dramatically as the severity of the disease progresses. Mild Alzheimer's cost an estimated \$9,451 per year, but this increases to \$36,794 for people with severe Alzheimer's. The primary reason is as severity increases, so does reliance on nursing homes. For people with severe Alzheimer's, nursing home costs made up 84% of the total cost of care. The table on the following page from their study highlights the changes in services as the disease progressed. These figures are expressed in 1996 dollars, meaning these cost estimates will be higher today.

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<sup>17</sup> Alzheimer Society of Canada, 2003, <http://www.alzheimer.ca/english/media/facts2003.htm>

<sup>18</sup> Hux et. al., "Relation between severity of Alzheimer's disease and costs of caring", CMAJ, 1998, Sept 8, (159): 457-65

**Annual Cost of Alzheimer's Disease  
Per Patient By Severity**



Category	Definition	Mild	Mild to Moderate	Moderate	Severe
Unpaid Direct Care	personal care (meals, bathing, toileting) provided by a friend or family member	\$5,655	\$7,047	\$5,379	\$3,506
Unpaid Net Supervision	unpaid time a friend or family member spends monitoring the person as they cannot be left alone	\$1,597	\$1,603	\$2,525	\$1,452
Medications & Physician fees	visits to doctors and the cost of medications	\$226	\$230	\$260	\$310
Community services	support services such as home making services, meal delivery,	\$1,973	\$2,315	\$1,227	\$568
Nursing home stay	time spent in a long-term care facility	\$0	\$4,859	\$16,332	\$30,958
	<b>Total</b>	<b>\$9,451</b>	<b>\$16,054</b>	<b>\$25,723</b>	<b>\$36,794</b>

Source: Hux et. al., "Relation between severity of Alzheimer's disease and costs of caring", CMAJ, 1998, Sept 8, (159): 457-65

In the vast majority of cases, dementia is incurable. Symptoms can be alleviated and the progress of the disease can be slowed, but not stopped, by available therapies. This means that eventually, the majority of people with dementia will go through each of these stages and incur the costs outlined above.

### **2.3.1 The cost of dementia in the future – a possible scenario**

Unfortunately, the availability of precise costing data on dementia is extremely limited. Indeed, a key recommendation in this paper outlines the need for better information on costs of treatment and care for people with dementia. Based on what data is available, consider the following scenario based on BC's population projections. Note that this does not include hospital or emergency room costs.

- It is estimated there are over 45,000 people in British Columbia living with dementia today.<sup>19</sup>
- There will be at least 55,000 people with dementia in BC by 2011.<sup>20</sup>
- Using the rates outlined earlier<sup>21</sup>, out of the 55,000 people with dementia in 2011 we can estimate that:
  - 15,812 will have mild dementia
  - 21,313 will have moderate dementia
  - 17,875 will have severe dementia

Based on these estimates, the potential total public and private costs for caring for dementia in BC for 2011 could be at least **\$1.25 billion**<sup>2</sup> even before hospital costs are included.

**This is \$22, 727 per person with dementia, per year.**

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<sup>19</sup> Based on BC STATS, Forecast 02/05 estimating 564,248 people in 2003 in BC over age 65 and assuming 8% have some form of dementia based on dementia rates in CSHA.

<sup>20</sup> Based on BC STATS, Forecast 02/05 estimating 689,569 people in BC in 2011 over age 65 and assuming 8% have some form of dementia based on dementia rates in Canada from CSHA.

<sup>21</sup> Graham et. al., Lancet, 1997, p. 1794 – identified the prevalence of dementia in people over 65 as 2.3 per 100 for mild, 3.1 for moderate and 2.6 for severe.

### **3.0 Dementia in BC – the Challenges**

As a person moves through the various stages of dementia, they, their families, and caregivers draw on a range of health services. Adding to the complexity is the fact that our current health care system is facing considerable structural, fiscal and human resource challenges as governments across Canada struggle with health reform. It is within this context that this chapter will outline the main challenges for dementia care in BC – recognizing that many issues correlate and interact with other challenges in the health care system. This chapter also includes information obtained from a survey of BC general practitioners across British Columbia in September 2003 on dementia.

“As our population ages the need for preventative health programs, as well as acute and other health services, will increase. Seniors will make up 21 per cent of BC’s population by 2027.”<sup>3</sup>

British Columbia Ministry of Health Services

### **3.1 Challenges in dementia care**

#### **1) Making dementia a government priority**

The most immediate challenge regarding dementia is its status in terms of BC’s current health priorities. Given our aging population and the implications for the health care system, dementia should be a higher priority issue for the BC government, as it has been in other provinces such as Ontario, Manitoba and Alberta. Currently this is not the case. Consider the following words of warning from Australia:

“Dementia should be a national priority. It is set to become the number one cause of disability burden in Australia by 2016.”

Alzheimer’s Australia, March 2003

As one example, consider the BC Ministry of Health’s document *The Picture of Health – How we are modernizing British Columbia’s health care system*. This document is intended to set out the vision for BC’s health care system for the future. While the document does focus on the needs of seniors and long-term care, no discussion of dementia or Alzheimer’s Disease occurred in the 58-page document.

Recently there have been indications from the BC Ministry of Health that they are considering increasing their focus on dementia and its implications on the health care system. This is a welcome sign.

## **2) The difficulty of providing complex care by physicians**

One of the most demanding aspects of providing primary care for someone with dementia is time. Across the course of care for dementia, the demands on primary care physicians are higher than for a patient without dementia. The diagnosis and disclosure of dementia to patients and their families may require multiple visits. There are often hours of follow-up required on an ongoing basis to manage and coordinate care for the patient. Physicians are also often left to assist families with their ethical decision-making and grief counseling. To complicate matters, physicians are often also managing other chronic conditions for the patient, such as diabetes or high blood pressure.

A challenge for dementia care is that BC is experiencing an increasing shortage of physicians providing full service family practice. Although the full-spectrum GP as first point of contact is a fundamental strength of BC's primary care delivery system, this type of practice is diminishing. There are two basic causes of this shift in care. First, there is a growing public demand for episodic care of low-severity health problems. Second, there are few incentives for physicians to shoulder the greater responsibilities of comprehensive practice.<sup>22</sup> This is a significant problem across primary care, and is not limited to dementia.

This trend appears to be increasing, particularly among newer medical graduates. Almost 33% of Canada's GPs less than 30 years of age work in walk-in clinics, while only 18% of their counterparts aged 40-54 do so.<sup>23</sup> This trend compounds the existing problem that BC already does not train enough doctors.

The result is that at the exact time BC will need more full service primary care physicians, we are heading into a greater shortage of them. Fortunately, there are steps being taken to begin to address this problem. Recently, in September of 2003 the BCMA in conjunction with the Ministry of Health introduced the Full Service Family Practice Incentive Program. This program provides funding to physicians who support maternity and chronic disease management. The General Practices Services Committee (a joint committee of the BC Ministry of Health Services, the BC Medical Association and the Society of General Practitioners of BC) is taking the lead on this project.<sup>24</sup> This is an example of how a collaborative approach taken by government and physicians can result in a positive and proactive solution. This document proposes that dementia be included within these discussions.

“As we age, we are more likely to be impacted by chronic diseases. When that happens, people need a range of options to assist them...B.C.'s current health care system is well designed to support acute and episodic care, but changes are needed to better support the complex task of managing chronic diseases such as cancer, diabetes, pulmonary diseases, congestive heart failure and depression. Partnerships that span the entire health care system have emerged to support the nearly 1 million British Columbians who are today living with chronic diseases.”

Health Services Minister, the Honourable Colin Hansen, BC Legislature, March 2, 2004

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<sup>22</sup> BC Medical Association, excerpt from “ENSURING EXCELLENCE: RENEWING BC'S PRIMARY CARE SYSTEM, A Discussion Paper by BC's Physicians”, September 2002, [www.bcma.org](http://www.bcma.org)

<sup>23</sup> College of Family Physicians, 2002, “Updated data release of the 200 ‘National Family Physician Workforce Survey’ – The Janus Project”, [www.cfpc.ca](http://www.cfpc.ca)

<sup>24</sup> More information available at <http://www.healthservices.gov.bc.ca/cdm/practitioners/fullservice.html>

### **3) Need for accessible community geriatric services for dementia patients**

A common criticism of our health care system is that it was originally designed for episodic care, but today is not adequately geared towards the chronic care needs of our aging population. Dementia is a prime example of this, as it is a “marathon of care” – not a sprint. The disease is a long process that requires ongoing care and dedication from family, caregivers and the health care system.

A common theme of health reform today is the notion of empowering individuals to take more control and initiative in the course of their care. A key difference for dementia sufferers is that they lose the very tools they need in order to remain independent. “Self-managing” their disease after a certain point is simply not an option. The result is much of the responsibility shifts to family members and care providers.

For dementia, a significant demand is the time required to care and watch over those suffering from the disease as it progresses. While in many cases they may not require advanced nursing care, they simply cannot be left unattended for any length of time. This time can be paid publicly, privately or provided by friends and families – but it is a necessary and unavoidable component of care, and the demand for these services is going to increase. The following table identifies examples of services utilized during the stages of dementia:

<b>Stage of Dementia</b>	<b>Examples of Service Required</b>
<b>Mild</b>	<ul style="list-style-type: none"><li>• Home support may be required for assistance in preparing meals and general housekeeping</li></ul>
<b>Moderate</b>	<ul style="list-style-type: none"><li>• Assistance required for greatest level of daily activities: bathing, medication management and mobility</li><li>• Respite for caregivers is also an important consideration at this stage</li><li>• Supervision is increasingly important</li></ul>
<b>Severe</b>	<ul style="list-style-type: none"><li>• Assistance required for virtually all personal care (meals, toileting, dressing)</li><li>• Most individuals require placement in a long-term care facility where they can be under constant supervision</li><li>• The care required is typically too great for a family member to manage at home</li></ul>

Unfortunately, at the present time we do not have the infrastructure or human resources in place to meet even today’s needs. There are long waiting lists for public long-term care facilities, limits on the number of hours available for home and nursing care, and limited ability for Health Authorities to help families work through the system.

This aspect of dementia care is invariably tied to the larger debate regarding what services are covered and are not covered under our public health care system. Patients and families will require increasing community support if patients are to continue to remain in their

communities – it is unavoidable. However, it is also unlikely that our health care system will be able to completely cover the entire range of services required by BC’s long-term care population today, let alone in the future. Therefore, this is a discussion that British Columbians will be required to hold as the need for community support services for our aging population increases over the next two decades.

#### **4) The need to improve coordination of services**

People can suffer from dementia for years – even decades. Throughout that period they will interact with multiple health care providers, agencies and facilities. To patients and their families this can sometimes be an intimidating and bewildering process. Health care providers and other groups also face challenges in coordinating the care and information exchange that occurs over the course of the patient’s care. Essentially both patients and health care providers are on a long journey without a detailed road map.<sup>25</sup> This can result in some cases in duplication of efforts, people seeking inappropriate levels of care (e.g. emergency department) when they either do not know about, or do not have access to the appropriate resource. Simply put, all sectors of the system need to improve how services and information for dementia patients are coordinated.

The following two diagrams illustrate a “before and after” model. The first chart shows how people are dealing with the system today, including various problems. An important area for patients and their families is at the primary care level – particularly during early to mid-stages of dementia. This is where they will often receive care and information from a variety of sources. Key challenges include:

- The need for improved communication between health care providers and facilities (e.g. availability and efficiency of accessing information).
- A shortage of residential/long-term care beds (patients who should be in a long-term care facility aren’t – and require increased services in other areas as a result).
- A lack of continuous support for families for home care support and respite care.
- Use of emergency departments as a “place of last resort” for acute behavioral and other dementia related problems
- Poor data collection and sharing for example, dementia is a major unrecorded cause of ALC days and deaths. Alternative Level of Care – Days spent in a hospital bed when a lower level care bed (i.e. long-term care) is more appropriate.
- The considerable amount of time physicians and other care providers spend attempting to access, secure and follow up on aspects of care.

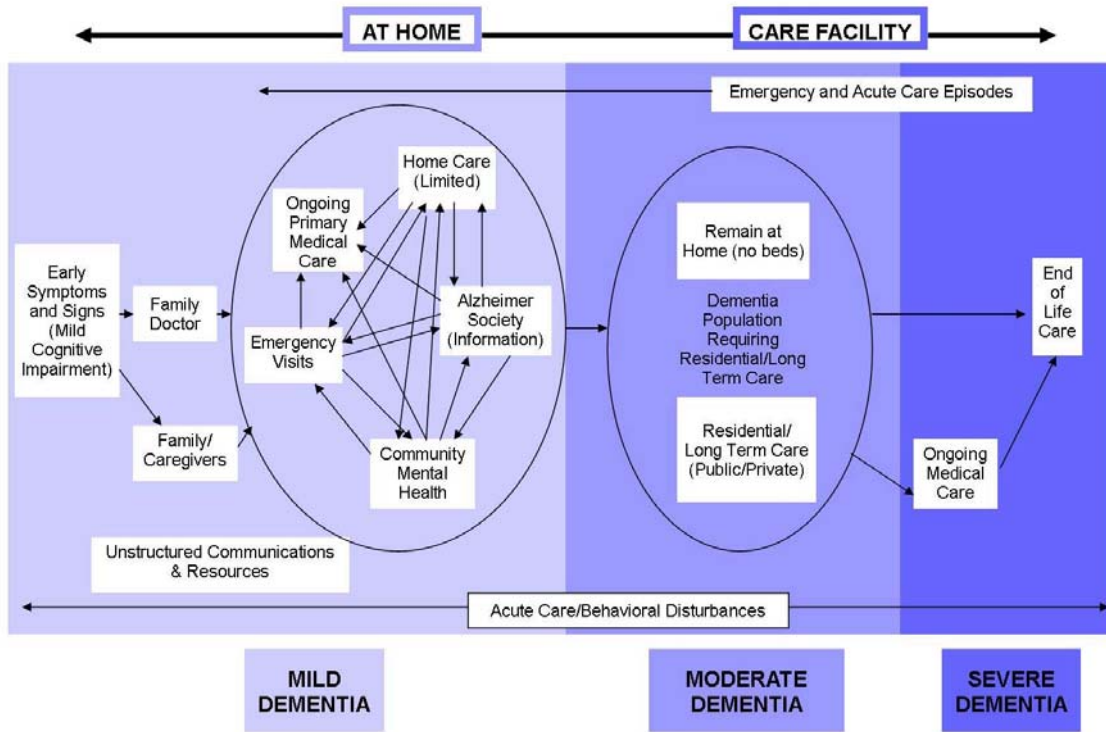
The second diagram represents what dementia care in British Columbia could look like if a coordinated dementia strategy were implemented successfully.

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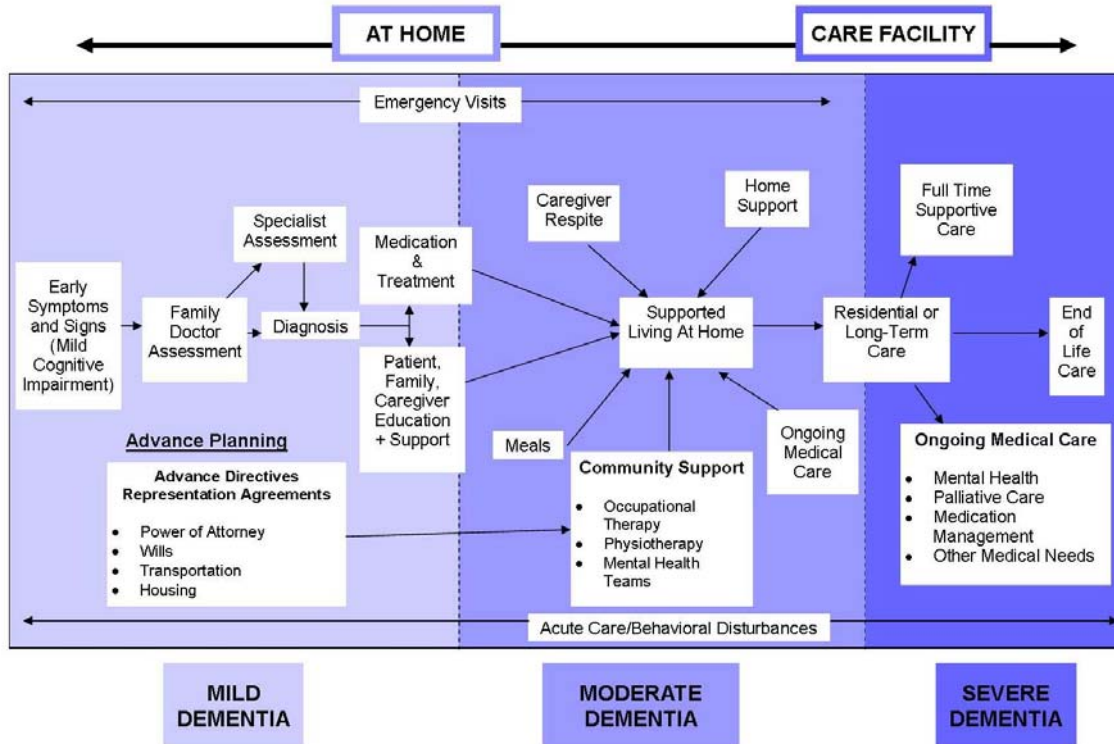
<sup>25</sup> Today in BC there are select avenues through which a patient or caregiver is able to find information or assistance on dementia – the best known being the **Alzheimer Society of British Columbia** (<http://www.alzheimerbc.org/>). This is a not-for-profit organization dedicated to providing information and support to people suffering from Alzheimer’s as well as their families.



**Before a Dementia Strategy:**



**After the Dementia Strategy:**



The “after” model incorporates improvements such as:

- An expanded role for the Alzheimer Society of BC at the regional and community level
- Improved advance planning by patients and their families (e.g. representative agreements)
- Better-coordinated and shared information among care providers (e.g. diagnosis, care management and pharmacotherapy guidelines, utilization reporting, improved access to information)
- Improved access to home and community support for patients and their families to support their living at home longer
- Greater access to residential and long-term care beds as needed
- Improved everyday functioning, including mental functioning
- Better management of acute/behavioral disturbances
- Improved self-management involving the patient and the caregivers
- Better access to information and services coordination support for patients and their families

#### **5) Lack of dementia drug coverage**

For most people suffering from dementia, there is presently no cure. That being said, certain drugs have been shown to definitively slow the progression of the disease. These drugs are from a group known as cholinesterase inhibitors. The three best known are **donepezil**, **rivastigimine** and **galantamine** (brand names Aricept, Exelon and Reminyl). The benefit of these drugs, particularly for people in early stages of the disease, is an improvement in mental functioning. These drugs have also shown that they can maintain a person’s cognitive ability – essentially “holding the line” for a limited period on their degradation of cognitive ability. While these drugs may not be effective for every person with dementia, over time these drugs have the potential to delay the need for admission to nursing home and other forms of care support for some people.

“Overall, the results of this meta-analysis indicated that ChEIt therapy in AD (Alzheimer’s Disease) is efficacious compared with placebo therapy. In addition, few patients need to be treated to achieve global improvement in 1 more patient and even fewer to achieve stabilization.”<sup>4</sup>

Unlike many other chronic conditions in BC (e.g. high blood pressure), dementia does not have its key medications covered under pharmacare. In this regard BC is out of step in terms of coverage compared with many other provinces in Canada. The following table outlines coverage for these drugs across Canada:

Covered*	Not Covered
Ontario	British Columbia
Alberta	PEI
Nova Scotia	
Saskatchewan	
Manitoba	
Quebec	
New Brunswick	
Newfoundland	

\*As of January 1, 2004

Rising drug costs are a major concern for many provincial governments – BC included. However, these drugs have the potential to reduce current and future costs by delaying the need for home support and long-term care. More importantly, they can improve the lives of people with dementia and their families.

It is encouraging that Pharmacare has expressed some interest in examining these medications. The BCMA recognizes that proper guidelines must be in place to ensure these drugs are used in the most effective manner. However, the development of any such guidelines must include and meet the approval of practicing physicians who will use these drugs in the care of their patients.

## 6) Uneven distribution of residential care

Residential care is an important part of dementia care – particularly as the disease progresses. Over time patients with dementia require increasing levels of supervision and may require additional security measures to prevent wandering.

A key element to planning for dementia services in the future is knowing where BC seniors are choosing to live compared with where the infrastructure is to care for them. A snapshot of existing residential care beds and population figures reveals that some health authorities appear to have a lower ratio of beds than other authorities when you consider the number of seniors in their authority. The age group used for this comparison in this section are those over age 75, as people are more likely to require residential care at this point.

There are over 278,000 people in BC today over the age 75, and they represent 6.6% of BC's total population.<sup>26</sup> The highest number of seniors (age 75 and older) live in the Fraser (84,788) and Vancouver Coastal (65,956) Health Authority. However, the highest

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<sup>26</sup> BC Stats, people run 28

proportion of those over 75 live in the Vancouver Island and Interior health authority where they make up 8.8% and 8.1% of the authorities' total population respectively. The fewest number of seniors over age 75, both as an absolute number and proportion of total population live in the Northern Health Authority.

In March of 2004 British Columbia had a total of 25,076 residential care beds.<sup>27</sup> This equals 90 beds per 1,000 seniors over age 75. The largest number of beds is in the Fraser (7,555) and Vancouver Coastal (7,026) Health Authority. In contrast, Vancouver Island and Interior healthy authorities have the highest proportion of seniors over age 75, but have the lowest number of residential care beds per 1,000 populations (80.2 and 79.5 beds per 1,000 respectively).

Health Authority	Total Population (est. July 2004)	Number of Seniors Age 75+	% of total Provincial Population Age 75+	Seniors Age 75+ as % of Regional Population	Number of residential care beds*	Beds per 1,000 population Age 75+
Fraser	1,470,919	84,788	30.4%	5.8%	7,555	89.1
Interior	694,543	56,513	20.3%	8.1%	4,490	79.5
Northern	304,357	9,570	3.4%	3.1%	1,050	109.7
Vancouver Coastal	1,054,509	65,956	23.7%	6.3%	7,026	106.5
Vancouver Island	700,729	61,768	22.2%	8.8%	4,955	80.2
<b>TOTAL</b>	<b>4,225,057</b>	<b>278,595</b>	<b>100.0%</b>	<b>6.6%</b>	<b>25,076</b>	<b>90.0</b>

Source: BC Stats, PEOPLE Run 28 (Population data), Ministry of Health Services, March 2004 (Bed Counts)

\* Breakdown: Assisted living 106, Family care home 64, Group home 207, Residential care facility 24, 663, TCU 36, does not include group homes or family care homes.

In no way is this table meant to suggest certain health authorities have an excess supply of residential care beds, as there are shortages in all health authorities and the demand for these beds is expected to increase dramatically.<sup>28</sup> These figures do not adjust for morbidity in the health authorities.

A newer concept in community and long-term care is the term “assisted living”<sup>29</sup>. This concept promotes a varied level of assistance based on need. It correctly outlines that we should allow seniors to live as independently as possible for as long as possible as long as their safety and quality of life are ensured. However, the very nature of dementia limits the application of the assisted living model. As dementia progresses, the person’s ability to live independently decreases, and their need for supportive care services increases – sometimes rapidly. For this reason, the assisted living concept needs to be adapted appropriately to meet the needs of people with dementia .

<sup>27</sup> Defined as “calculated residential care beds” meaning beds that are open and able to accept residents.

<sup>28</sup> In 2001 the BCMA estimated that BC would require at least 10,000 additional long term care beds by 2015 in the document “Turning the Tide – Saving Medicare for Canadians” www.bcma.org

<sup>29</sup> **Assisted Living:** Provides housing, most meals, housekeeping, social activities, a limited range of medical care and assistance with activities of daily living. Source: The Picture of Health: How We are Modernizing British Columbia’s health care system; British Columbia Ministry of Health Planning; December 2002; page 37

## **3.2 A survey of dementia in family practice**

### **3.2.1 Survey objectives**

In September 2003 the BCMA conducted a random survey of 1,000 family physicians on the issue of dementia. The survey was intended to provide an initial snapshot of a series of issues surrounding dementia in primary care today. The survey sought to obtain data on the following:

- Opinions of practicing physicians on the key challenges facing dementia care
- Estimates of the number of patients with dementia in family practices
- Dementia related medical training and continuing medical education courses
- Current resources for treating and managing dementia
- Issues in the diagnosis, disclosure and treatment of patients with dementia

### **3.2.2 Methodology**

The BCMA randomly surveyed 1,000 primary care physicians from around BC. A total of 312 surveys were returned, yielding a response rate of 31.9%.<sup>30</sup> The results are considered accurate +/- 5% 19 times out of 20.<sup>31</sup> All results in the following section have been rounded to the nearest full percent.

### **3.2.3 Practice characteristics**

Several questions were asked to establish the practice characteristics of physicians who responded to the survey. Questions included the size of their community, the number of patients in their practice, the style of their practice and the percentage of seniors in their practice.

47% of respondents indicated they live and work in large urban areas with populations of 75,000 or more such as Vancouver, Victoria, Kelowna, Kamloops and Nanaimo. Another 24% indicated they worked in an urban setting with a population between 25,000 and 75,000 such as Penticton and Vernon. The remaining 29% described themselves as working in a rural community with a population of less than 25,000.<sup>32</sup> 80% of the respondents received their medical school training in Canada, yet only half of those individuals were educated and trained in British Columbia.

54% of respondents work in a group practice, with a further 17% working in solo practice. Another 10% indicated they currently work in a walk-in clinic, with the remaining

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<sup>30</sup> Note: Sample size was revised to 977 as 23 surveys were sent to invalid addresses or physicians who had recently retired.

<sup>31</sup> The margin of error for this survey is +/- 5% at the 95% confidence level.

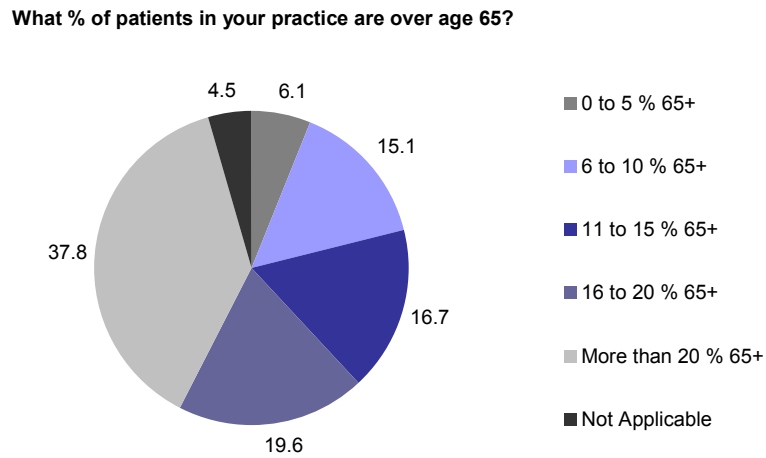
<sup>32</sup> <http://www.bcstats.gov.bc.ca/data/pop/pop/mun/Mun9603s.htm>

(BC Cities of 75,000+ are Vancouver, Surrey, Burnaby, Richmond, Abbotsford, Coquitlam, Saanich, Kelowna, Delta, Langley, North Van District, Kamloops, Victoria, Prince George and Nanaimo)

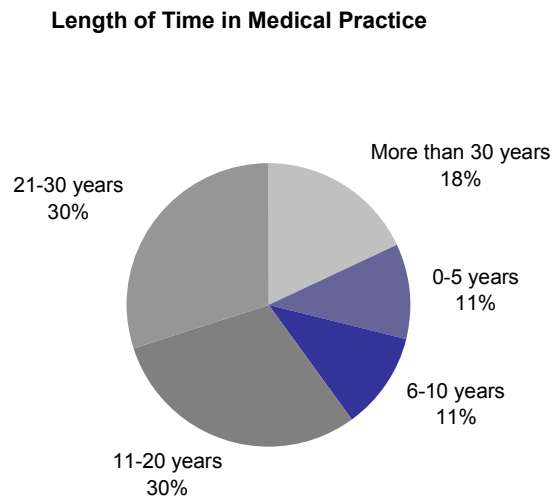
(BC Cities of 25,000-75,000 are: Maple Ridge, Chilliwack, New Westminister, PoCo, North Van City, West Van, Vernon, Mission, Penticton, Campbell River, North Cowichan and Port Moody)

respondents working in hospitals or other settings. When asked about the number of patients in their practice, almost 70% of physicians surveyed have over 1,000 patients in their practices, and nearly 20% of those maintain over 2,000 patients. Over 40% of respondents said they are no longer accepting new patients.

**When asked about the number of seniors in their practice, 37.8% of physicians indicated that over 20% of their patients are over the age of 65.**

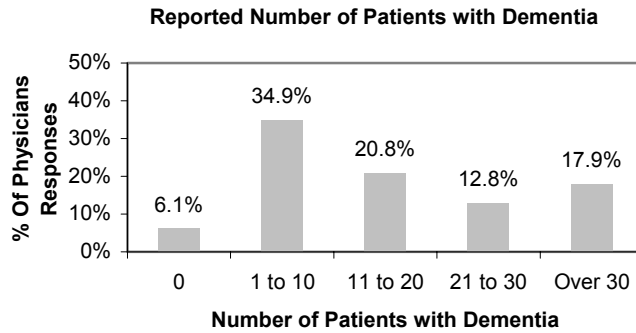


The survey also asked physicians about the number of years they have been in practice. Results show that 48% of family physicians have been in practice for more than 20 years.

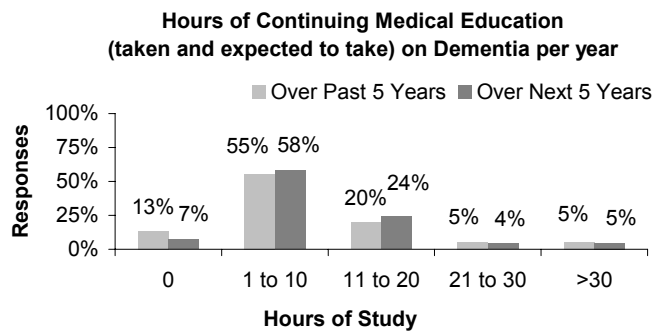


### 3.2.4 Dementia within medical practices

94% of physicians who responded have at least one patient with dementia in their practice. Over 52% of physicians reported having more than 10 patients with dementia. 10% of physicians also indicated they diagnose more than 10 new cases of dementia each year.



The results also indicate that physicians recognize the increasing need to understand and learn about dementia. About 66% of respondents feel that given the role that dementia plays in their practices today, that the instruction and training they received on dementia during medical school was inadequate. Over 86% of the physicians surveyed have already actively sought to increase their knowledge on dementia by taking continuing medical education (CME) courses on dementia. The majority of these physicians received between 1 and 10 hours of CME on dementia.



Looking to the future, an even greater number of physicians plan to complete post-graduate education on dementia - 93% of physicians indicated they plan to take additional dementia training over the next 5 years. One in every four respondents plans to complete between 11 and 20 hours of instruction time. These figures speak for BC family physicians' recognition of the growing role dementia will play in their practices in the future.

### **3.2.5 Disclosure of dementia**

Unlike many diseases, physicians may not be able to disclose their diagnosis to their patient. Depending on the stage of the illness, patients may have difficulty accepting or understanding their illness. As a result, family members or other caregivers will always be involved in the diagnosis and disclosure process. Just over half of the physicians surveyed reported they disclose a diagnosis of dementia to the patient 75-100% of the time. 80% of physicians also reported they provide the diagnosis of dementia to a family member. What this reflects is that the physician may be communicating the diagnosis to either the patient, the family member or both. Major factors that influence the disclosure of the diagnosis are certainty of diagnosis, cognitive status of the patient, the wishes of patients and family members, and the insight and emotional status of the patient.

A common complaint among physicians who work with dementia in BC is the lack of clinical guidelines to assist physicians in reaching a diagnosis for dementia and finding the appropriate manner and methodology for disclosing the diagnosis to the patient and/or caregiver. The survey asked physicians to rank how various aspects of their training typically helps them base their decision when making a dementia diagnosis. The overwhelming response was “clinical experience” (78%) with “continuing medical education” as the second highest response (64%).

The time spent in diagnosing dementia revealed interesting results. About two-thirds of the respondents spend more than 10 minutes with a patient while disclosing a dementia diagnosis. However, of those physicians, most will spend somewhere between 11-15 minutes with their patient. On average, physicians spend more time in disclosing a dementia diagnosis to caregivers or family members than they do to the patient. This accounts for the fact that family members and caregivers would need to be provided with instruction for how to care for the patient. In the first year after a diagnosis, most physicians see their dementia patients between 6 and 10 times.

### **3.2.6 Support services and resource needs**

The services physicians used or requested most frequently for their patients with dementia included home support (84%), nursing home care (80%) and home care (79%). However in terms of knowledge of support services, only 54% of physicians felt they were confident in their knowledge of local support services. Physicians clearly expressed a need for better and more up to date information on resources.

Physicians were asked an open-ended question on how and where they felt any additional resources should be allocated to assist in dementia care. **Over 90% of those who provided a response commented on the need for additional respite care, home care, daycare programs, access to specialists, Pharmacare coverage for drugs, and family support and education.** Caregiver support appeared to be a reoccurring theme among respondents. One comment submitted encompassed the sentiments expressed by many physicians:



“Very poor back-up! Family members are often left on their own. Medications for treatment are expensive and not covered – this is a major stumbling block. Long-term care, terminal care and support for the dementia patient is non-existent.”

Family physicians know the burden placed on family members in caring for someone with dementia. The responses showed physicians today see a great deal of caregiver stress and burnout and feel great empathy for families as they struggle to cope with the day-to-day reality of caring for someone with dementia. One physician strongly stated:

“More long-term facilities! Families can’t cope and need more home support to provide the 24-hour care required. It is imperative that government and Health Authorities be made aware that standard community care for patients with dementia is not going to work.”

When asked about the usefulness of a comprehensive dementia information and treatment center in their health authority – over 86% of respondents felt this would be useful to assist them with dementia patients and caregivers.

#### **4.0 What are other jurisdictions doing?**

BC is not alone in facing the challenges of dementia. What makes BC different is that many other provinces and countries have implemented a specific strategy to address the challenges of dementia, while BC has not. This section provides an overview of how other systems are starting to address the challenge of rising numbers of their citizens with dementia. This is not intended as a comprehensive review, so readers are encouraged to seek additional information from the references.

Australia and New Zealand have emerged as world leaders in managing dementia. In Canada, Ontario has been among the most proactive provinces. While the health care systems themselves are quite different, the major issues and solutions that emerge surrounding dementia in the various strategies are strikingly similar. What this suggests is that there is a great deal of work that could be adapted for implementation in BC.

Eight common elements of these strategies include:

- Enhanced training for family and friends providing care
- Expanded research on dementia’s causes and treatment
- Improved data and information on cost and conditions
- Improved information for patients and their families on services
- Better relief support for family members
- Expanded resources for community and long-term care
- Expanded education and training for health professionals
- Improved availability and coordination of specialized services

## 4.1 Ontario

In 1999, the Ontario government implemented a 5-year \$68.4 million Dementia Strategy. A further \$6.3 million and \$2.3 million were added to the program in 2000 and 2003 respectively. The Ontario government partnered with the Alzheimer Society of Ontario to provide services on a number of levels. Many aspects of this strategy are up for review in Spring/Summer 2004. The strategy's ten components are:<sup>33</sup>

1. **Staff education and training** (\$1.1 million/year) - Created an annual training program for staff in long-term care, adult day care and supportive housing.
2. **Physician training** (\$500,000/year) – Provides family doctors with the opportunity to receive training to assist them in the early detection and diagnosis of Alzheimer's Disease and related dementias, optimal prescribing practices and how best to use local community services.
3. **Increase in public awareness, information and education** (\$1.8 million/year) - Hiring of one public education co-coordinator for each of the 39 chapters of the Alzheimer Society of Ontario to raise awareness of the disease, recruit volunteers, develop and facilitate caregiver support groups and coordinate training events.
4. **Planning for appropriate, safe and secure environments** (\$50,000/year) – Created annual conferences to explore safe living space for people with Alzheimer's Disease and related dementias.
5. **Respite services for family and friends** (\$7 million/year) -The province will fund the creation of new Alzheimer's day program spaces and the expansion of Alzheimer's volunteer respite programs.
6. **Research on the needs of family and friends** (\$400,000/year)- Establishes research to help determine what key community support services are needed by caregivers.
7. **Advanced Directives on care choices** – (\$650,000/year) – Consultation and development process on the creation and training on advance directives.
8. **Psychogeriatric consulting resources** (\$4.5 million/year) - New funding to employ 40 experts (with an additional 10 experts in 2001/2002) to advise staff in long-term care centres and community service agencies on how to work with people who exhibit difficult or aggressive behavior.

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<sup>33</sup> For more information on Ontario's Dementia Strategy please see <http://www.gov.on.ca/citizenship/seniors/english/alzheimer-strategy.htm> or [http://www.health.gov.on.ca/english/public/pub/ministry\\_reports/alz/summary.html](http://www.health.gov.on.ca/english/public/pub/ministry_reports/alz/summary.html)

9. **Coordinated specialized diagnosis and support** (no budget stated) - Local dementia networks are being developed throughout the province to help communities develop local support networks for diagnostic and treatment services for Alzheimer clients and their families. A booklet, [A Guide to Developing a Dementia Network](#) has been distributed.
10. **Intergenerational volunteer initiative** (\$500,000 in 2000) - Supported the recruitment, training and support of grade 11 and 12 students who volunteer to work with people suffering from dementia.

## 4.2 Alberta

In April 2000, Alberta released the document: *Healthy Aging and Continuing Care in Alberta: Strategic Directions and Future Actions* as the first step towards their dementia strategy. In that paper the Alberta government made the following pledge:<sup>34</sup>

A multi-faceted province-wide plan and authority plans will be developed to address the future needs for care and support for people with Alzheimer's disease and other dementias.

Alberta Health and Wellness, 2000

By November 2000, the Alberta government established a Task Group dedicated to developing a plan to assist the province and authority health authorities in improving care for Albertans with dementia. In July of 2002 the Task Group released its final report entitled *Alzheimer Disease & Other Dementias – Strategic Directions in Health Aging and Continuing Care in Alberta*. This report outlined six key themes:<sup>35</sup>

1. **Public awareness:** Albertans should have an increased awareness and understanding of Alzheimer disease and other dementias.
2. **Guidelines:** Guidelines should be in place for the care of clients with Alzheimer disease and dementia for all service areas. It should also cover any gaps that currently exist across the continuum of care, such as special care units and unregulated service providers.
3. **Support for informal caregivers:** Informal caregivers providing care for an Albertan with Alzheimer disease or other dementias should have access to education and support.

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<sup>34</sup> Alberta Health and Wellness, [Health Aging and Continuing Care in Alberta](http://www.health.gov.ab.ca/system/key/longterm/stratreport.pdf), April 2000. p. 8-9, <http://www.health.gov.ab.ca/system/key/longterm/stratreport.pdf>

<sup>35</sup> Alberta Health and Wellness, *Alzheimer Disease & Other Dementias – Strategic Directions in Health Aging and Continuing Care in Alberta*, p. 3, July 2002

4. **Service delivery across the continuum of care:** Community care service packages should be developed or expanded upon, in order that service areas are linked and accessible in the community. This includes a broader client assessment based on unmet needs (physical, mental and behavioral) of clients and their families, for example, respite (day and night), day programs and assisted living.
5. **Supportive environments:** The provision of small residential care-like settings, including the client's own home, should be considered as a possible service option utilizing best practice design and layouts.
6. **Education and training:** Health professionals, including physicians, non-health professionals and dementia care service providers, should have the appropriate skills and knowledge in the delivery of services.

At the same time the Alberta government approved \$3.4 million annually to cover Alzheimer's related drugs. They also provided a one-time commitment of \$625,000 towards improving Alzheimer's services. This funding was directed at improving support for informal caregivers, providing education and training for caregivers, and raising public awareness. Today, Edmonton and Calgary have each developed special care centres for persons with Alzheimer disease and other dementias.

### **Alberta Medical Association**

In January 2002, the Alberta Medical Association released two clinical guidelines to assist physicians with the diagnosis and management of dementia. They include:<sup>36</sup>

1. Guideline for Cognitive Impairment: Dementia (Symptoms to Diagnosis)
2. Guideline for Cognitive Impairment: Dementia (Diagnosis to Management)

Elements of these guideline include:

- Tools to assist in diagnosis
- Care planning for families
- Referral to the Alzheimer Society of Alberta
- Outline of available pharmacological treatment
- Contact information to all 6 regional Alzheimer Society Centres

These guidelines are available on the AMA website – [www.albertadoctors.org](http://www.albertadoctors.org)

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<sup>36</sup> Alberta Medical Association – <http://www.albertadoctors.org/>

### **4.3 Manitoba**

At the direction of the Minister of Health in early 2000, the Manitoba government embarked on an ambitious process to develop its approach to planning for dementia. In October 2002 they released their first strategy document entitled *A Strategy for Alzheimer Disease and Related Dementias in Manitoba*.<sup>37</sup>

A key element to Manitoba's approach to the strategy was a broad consultation process that brought several groups and stakeholders into the development phase. To coordinate the process, the Minister of Health created the Alzheimer Strategy Steering Group, with representatives from government, the Alzheimer Society, Health Authorities and experts on aging and dementia. This eleven person steering group was supported by fourteen working groups who, in turn, researched and interviewed health professionals and families of Alzheimer's patients in developing this strategy. The review also included 30 focus group discussions as well as a survey of 3,000 Manitobans. These interviews and surveys included the public, caregivers, health care professionals and those suffering from dementia. The final report from the steering group recommended key areas that Manitoba must address to successfully implement the strategy. They include:

- 1. Education for professionals, paraprofessionals, family, individuals, communities and the general public**
- 2. Guidelines for diagnosis**
- 3. Standards across programs and services**
- 4. Family and individual support**
- 5. Comprehensive programs and services for individuals and communities**
- 6. Case management and interdisciplinary collaboration**
- 7. Equitable access to programs and services across Manitoba**
- 8. Human and financial issues including recruitment, retention and remuneration**
- 9. Ongoing research and evaluation**

An important element of the strategy was that the recommendations focused on the specific stages that individuals and their families faced during the progression of the disease. The stages are:<sup>38</sup>

1. Pre-diagnosis to diagnosis
2. Diagnosis to direct service
3. Direct service to personal care home placement
4. Personal care home to death

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<sup>37</sup> A Strategy for Alzheimer Disease and Related Dementias in Manitoba, <http://www.gov.mb.ca/health/homecare/links.html>

<sup>38</sup> A Strategy for Alzheimer Disease and Related Dementias in Manitoba, <http://www.gov.mb.ca/health/homecare/links.html>, p. 5

## 4.4 Australia

Australia is considered a world leader in their approach to managing dementia. Over the past decade, Australia has taken a proactive approach in caring for people with dementia and support for family and friends providing care.

Australia established their dementia strategy in 1992 with the “National Action Plan for Dementia Care (NAPDC). This five year plan looked to improve aged care in seven key areas<sup>39</sup> (diagnoses and assessment, services for people with dementia, quality of service, services for families and friends of people with dementia, community awareness, research and evaluation and policy and planning). By September 2000, the Commonwealth Department of Health and Aged Care released the “Dementia Policy Framework and Commonwealth Government Initiatives”. This program provided an overview of the progress of dementia initiatives in Australia. In total, eleven different programs with a total annual budget of almost \$120 million per year was allocated<sup>40</sup>.

In August 2002, Australia’s Commonwealth Department of Health and Ageing released its comprehensive “Aged Care in Australia Strategy for 2002-2007”.<sup>41</sup> A major component of the strategy included a focus on dementia. The purpose of this strategy is “to support healthy ageing for older Australians and quality, cost effective care for frail older people and support for their carers.”<sup>42</sup>

In March of 2003 Alzheimer’s Australia, an organization similar to the BC and Canadian Alzheimer Society released a major report “The Dementia Epidemic: Economic Impact and Positive Solutions for Australia”. This document provided a detailed review of dementia, ranging from epidemiological to economic impacts – and is one of the most detailed analysis of the economic impact of dementia completed to date. The analysis and recommendations sections encompassed the complete spectrum of care issues with dementia.

Recommendations covered a total of twelve different areas:

Prioritization of dementia	General practice	Home and community support services
Research	Other medical and acute care services	Families and friends
Prevention and early intervention activities	Pharmacotherapy	Health financing
Residential care	Cross-cutting issues	Strengthening community services provided through Alzheimer’s Australia

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<sup>39</sup> Alzheimer’s Australia – “The Dementia Epidemic”, p. 76 [www.alzheimers.org.au](http://www.alzheimers.org.au)

<sup>40</sup> Some for a 4 year period (supposedly ending in 2004/2005), others on an ongoing annualized basis.

<sup>41</sup> Commonwealth Department of Health and Ageing, “The National Strategy for an Ageing Australia” August, 2002, [http://www.olderaustralians.gov.au/ageing\\_policy/index.htm](http://www.olderaustralians.gov.au/ageing_policy/index.htm)

<sup>42</sup> Commonwealth Department of Health and Ageing, “Aged Care in Australia”, August 2002, p. 3 <http://www.health.gov.au/acc/about/agedaust/agedaust.htm>

## **4.5 New Zealand**

Given the size of its population and economy, New Zealand is often compared with British Columbia. From economic reforms to health care restructuring, New Zealand has been a common source of information and study for BC's policy analysts. Compared with other OECD nations, New Zealand has a younger population – with only 13% of its population expected to be over age 65 by 2010. That being said, in 2002, there were approximately 38,000 people with dementia in New Zealand.<sup>43</sup>

In April 2002, the New Zealand government introduced a ten year strategy outlining the future direction of health and disability support services for older persons in New Zealand. While the “Health of Older People Strategy” addresses a wide range of initiatives, several major actions and objectives pertain to dementia.<sup>44</sup> First steps of this strategy include:<sup>45</sup>

1. Improving the availability of information about health and support programs.
2. Producing a service development plan for dementia by fall 2003. (completed)
3. Develop dementia specific standards for residential care by fall 2003. (completed)
4. Reduce dementia-associated depression.

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<sup>43</sup> “Dementia in New Zealand: improving quality in residential care”, A report to the Disability Issues Directorate – Ministry of Health, January 2002

<sup>44</sup> New Zealand Ministry of Health, Health of Older People in New Zealand - <http://www.moh.govt.nz/olderpeople>

<sup>45</sup> Hon. Ruth Dyson, Minister for Disability Issues “Health of Older People Strategy – Health sector action to 2010 to support positive ageing”, April 2002

## 5.0 Recommendations

A major focus of government, physicians and health policy analysts at this time is improving how our health care system treats patients with chronic conditions. The discussion of chronic disease management is inevitably included in any discussion on primary health care reform today. A major challenge within this discussion is the increasing shortage of family physicians.

A key focus of improving care for chronic diseases is on “helping patients to better manage chronic conditions themselves.” Unlike other chronic conditions, people with dementia are limited in their ability to improve self-management of their condition. Indeed, dementia attacks the very resource they need to do it – intellect. It is also increasingly challenging for their families and caregivers.

“Community care is good policy – but only if it acknowledges that the home-based care of a person with dementia can be a skilled, exhausting, costly, long-term, lonely job for the person doing the caring.”

- Alzheimer’s Australia, 2002

What is needed in BC is a coordinated strategy that combines research, health care services and support for patients, family members and other caregivers for people with dementia.

Dementia must be treated as a chronic disease. This requires ongoing evaluation and treatment from a coordinated team of health care professionals and community support workers.

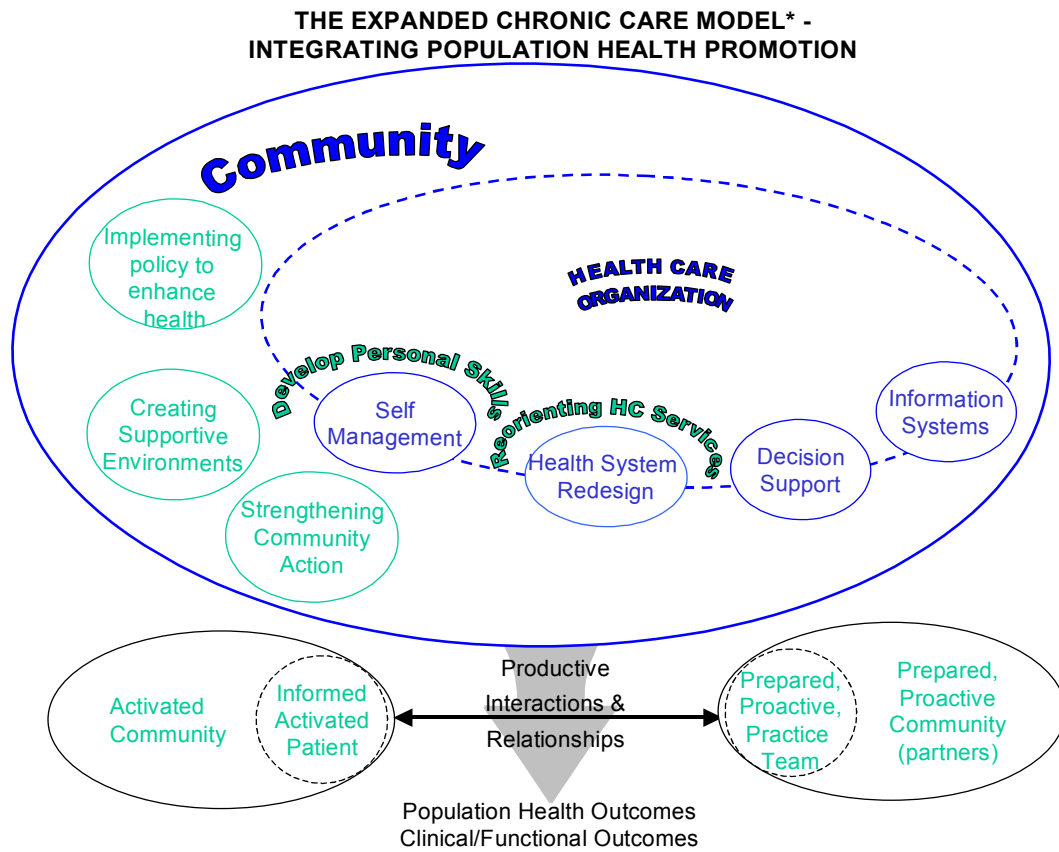
Therefore, the **Expanded Chronic Care Model** of treatment is recommended to best serve current and future British Columbians affected by dementia. This model is being used by doctors and government in British Columbia to work with other chronic conditions such as diabetes, and would be equally effective for dementia. This needs to include a review across the spectrum from pre-diagnosis through to end of life care.

The Expanded Chronic Care Model identifies essential elements of a health care system to encourage high-quality chronic disease care. These elements include:

- The community
- The health system
- Self-management support
- Delivery system design
- Decision support
- Clinical information systems



This model represents a system of complementary components of treatment, each of which play a role in evidence-based patient care. When the parts interact in concert with one another, it fosters productive interactions between informed patients who take an active part in their care, and providers with resources and expertise to provide the best patient care and treatment possible. The model results in healthier patients, more satisfied providers, and an overall cost savings. Comprehensive proposals for change, such as this model, may give rise to a temptation to pick and choose selected aspects for implementation. However, the very nature of a systemic model means each component is reliant upon the other parts for success.



Created by: Victoria Barr, Anita Dotts, Brenda Marin-Link, Darlene Ravensdale, Sylvia Robinson, Lisa Underhill (2002)

\*Adapted from the Chronic Care Model: Glasgow, R., Orleans, C., Wagner, E., Curry, S., Solberg, L. Does the Chronic Care Model Serve Also as a Template for Improving Prevention? *The Milbank Quarterly*, 79(4), 2001. Also the World Health Organization, Health and Welfare Canada, Canadian Public Health Association. Ottawa Charter of Health Promotion. WHO, Copenhagen. 1986

The challenge is how to make this model work for dementia in BC. This document has identified several key challenges in dementia care today. The following list of recommendations is aimed at improving how we care for the current and impending sufferers of dementia.

These recommendations include some of the first steps of moving towards a coordinated dementia strategy, but they do not encompass the full range of issues. This is deliberate as there are many other groups that must be included in this discussion.

### **1) Make caring for dementia a priority**

Both the Ministry of Health and Health Authorities need to give dementia a higher priority in order to prepare for the demands dementia will place on our health care system in the years ahead. The BCMA recommends that the provincial government create a Provincial Dementia Strategy Task Force. This task force should have a designated timeline (maximum of 1 year) to meet, designate the elements of the strategy for BC, and begin implementation. Once the major elements are in place, this committee should reduce its scope to a monitoring role. This task force should focus on incorporating work from other jurisdictions and adapting them into elements of BC's strategy.

#### **Recommendations**

- That the provincial government establish a task force on dementia with a 12 month mandate to review, design and begin implementation of a dementia strategy in BC.
- That the task force establish an expert advisory group of physicians and other healthcare providers and advocacy groups composed of Ministry of Health staff, researchers and the Alzheimer's Society of British Columbia.
- That each Health Authority should include their responsibilities within the dementia strategy in their health authority plans and performance agreements.
- That an evaluation process for the dementia strategy be incorporated at the outset and that the results of this evaluation be made available to the public.

### **2) Include dementia in chronic disease management**

The Ministry of Health should include dementia in its Chronic Disease Management Care Program, as part of the overall dementia strategy.<sup>46</sup> This would involve development of a provincial dementia registry, guidelines for care, clinical tools, education and information support. Development of a system of care for individuals across the spectrum of dementia would involve collaboration with practicing physicians.

#### **Recommendations**

- That dementia be included in the current BC Chronic Disease Management Care Program, starting with the development of a provincial registry for dementia.
- That the Ministry of Health Services develops and distributes clinical guidelines for the diagnosis and management of dementia. The BCMA will support this endeavor through the Guidelines and Protocol advisory committee.
- That appropriate preventive activities (attention to diet, exercise, alcohol consumption, and drug abuse) for dementia continue to be promoted and advocated to the public.

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<sup>46</sup> BC Ministry of Health Services, Chronic Disease Management - [http://www.healthservices.gov.bc.ca/cdm/cdminbc/chronic\\_care\\_model.html](http://www.healthservices.gov.bc.ca/cdm/cdminbc/chronic_care_model.html) "The B.C.'s Expanded Chronic Care Model identifies essential elements in a system that strives for enhanced chronic care management. These include, the community, the health system, self-management support, delivery system design, decision support, clinical information systems."

### **3) Support the provision of comprehensive care**

The Government of British Columbia should increase its efforts to recruit, train, and retain an appropriate mix of skilled health professionals in order to provide the level of dementia care that will be needed in the years ahead.

#### **Recommendations**

- That government and physicians work together to ensure that patients with dementia are able to access a family physician and appropriate specialty care.
- That a community group, such as the Alzheimer Society of British Columbia, be funded to participate in the provision of coordinated care through education, information and support services for the patients and their families at the health authority level.
- That the BCMA will produce a patient pamphlet on dementia available for distribution to physician offices.
- That dementia is reviewed as a prospect for inclusion under the BCMA/Ministry of Health Full Service Family Practice Incentive Program.
- That undergraduate and post-graduate medical and nursing education programs in the province reflect the importance of dementing illnesses in our society.

### **4) Match residential and community services with needs**

Dementia will be a significant factor driving the need for community and residential services. The government of British Columbia and the Health Authorities need to ensure a match between the needs of people affected by dementia and the services offered. Efforts must also be made to ensure appropriate resources and support is available for the families of people with dementia. These services (including home-based diagnostic and treatment services where possible) should seek to enable people with dementia to remain in their home (their residence or assisted living) according to their wishes and their caregivers' capacity.

#### **Recommendations**

- That the Ministry of Health review disability adjusted standards for the provision of community and residential services for people with dementia.
- That the assisted living model be adapted appropriately to meet the needs of people with dementia on key issues such as medication management, nutrition, safety and supervision.
- That Health Authorities work to implement and/or expand a range of respite services, including emergency support, planned short-term respite programs, and day programs.
- That the Ministry of Health in conjunction with Health Authorities conduct an evaluation of existing and planned long-term care resources and assisted living based on the projected distribution of seniors by RHA, and this review be made public.
- That the Ministry of Health continues to improve the prioritization mechanisms to ensure equitable access to long-term care facilities.

## **5) Improve the coordination of services**

We envision that British Columbia will be a Canadian leader in the provision of comprehensive coordinated dementia care by 2010. Providing effective and efficient care and services for dementia requires a dynamic and flexible system. BC needs to develop a system that anticipates the needs of dementia patients that will arise over the course of the disease, and by early intervention prevent unnecessary disability, dependency and cost to the health care system. This includes improving the tracking and availability of information related to dementia care. These efforts should be coordinated with other efforts in the development of electronic medical and health records.

### **Recommendations**

- That government and Health Authorities work to provide incentives to improve linkages between family physicians and long-term case managers and other care providers and coordinators.
- That a clinical information summary (paper or electronic) for patients with dementia be developed that is accessible to health care professionals across the health care system.
- That the Ministry of Health and Health Authorities work with practicing physicians, long-term care facilities and other agencies 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.

## **6) Provide coverage for dementia medications**

British Columbia needs to catch up to the rest of Canada in providing coverage for dementia related medications. Currently available medications - cholinesterase inhibitors, such as donepezil, rivastigmine and galantamine, are approved for use in Canada but are not insured by BC Pharmacare. These medications have the potential to reduce overall care costs by preserving functional capabilities and improving the quality of life for patients and their families. It is unacceptable that dementia treatment considered standard in other provinces in Canada is not covered in British Columbia. At the time this report was being prepared, newer medications were approved in other jurisdictions and others are in development. If these are also approved, this will potentially increase the level of disparity between BC and other systems even further.

### **Recommendations**

- That Pharmacare expand coverage to include dementia medications.
- That maintenance or a slowing in the rate of decline of cognition or function be accepted as a standard of efficacy in the pharmacological treatment of dementia in BC.
- That BC physicians (through guidelines and protocols) are provided with ongoing information on dementia pharmacotherapy.

## **6.0 Conclusion**

The British Columbia Medical Association is calling on the provincial government to commit to developing and implementing a dementia strategy for British Columbia. There will be at least 55,000 people with dementia in BC by 2011, an increase of 10,000 in less than seven years. Our system is not adequately prepared to provide the wide range of services they and their families will need. As the disease progresses, the burden on BC families will also substantially increase. It is unavoidable.

A clear advantage for BC is that several provinces and countries have already taken many of the first and most difficult steps. BC can build on these efforts and adapt their successes to meet our own needs. This document has outlined six challenges that BC must address as a first step. This list is not exhaustive and there are other challenges. The BCMA has provided recommendations in each of these areas to begin addressing these challenges:

- 1) Make caring for dementia a BC priority**
- 2) Include dementia in chronic disease management**
- 3) Support the provision of comprehensive care**
- 4) Match residential and community services with needs**
- 5) Improve the coordination of services**
- 6) Provide coverage for dementia medications**

The first step must be to establish a dementia task force in order to bring the key stakeholders to the table. This must be done in order to include all the necessary elements of the strategy. If a strategy is to be successful, dementia needs to be included under BC's efforts in chronic disease management. Given that dementia will have significant human resource and financial impact over the next decade, it must have a higher priority than it does now.

We must ensure that the proper incentives and support structures regarding dementia care are in place for primary care physicians. This is part of the larger challenge of BC's growing shortage of family physicians. These support structures must also extend to other health care providers, agencies and especially the families of those suffering from dementia. In this light, the BCMA sees a greater role for agencies such as the Alzheimer Society of British Columbia.

BC also needs to do a better job of collecting, analyzing and sharing information on dementia. This will assist in delivering more efficient care, but will also assist in dementia research. As we move forward, the province and health authorities must look at where seniors, particularly those with dementia are choosing to live.

Lastly, BC needs to catch up to the rest of Canada in terms of providing coverage for medications for dementia. It is recognized that guidelines and protocols must be in place to ensure appropriate use of these medications. However, it is unacceptable that BC, unlike other provinces, has chosen to cover medications for other chronic conditions, but not for dementia.

The BCMA is committed to a constructive dialogue on dementia, and will be actively engaging government, other health care providers and key agencies in developing this strategy. People with early stage dementia and their families should also be engaged through the Alzheimer's Society of British Columbia. There is a considerable amount of hard work being done to care for British Columbians with dementia, and it is now time to bring these pieces together.