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Policy Update:
Improving the Lived Experience
of People with Dementia

A Policy Paper by BC's Doctors
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**doctors
of bc**
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The Doctors of BC's Council on Health Promotion (COHP) reviews and formulates policy through the use of project-oriented groups of practising physicians and professional staff.

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POLICY STATEMENT

Building on our 2004 policy paper, [*Building Bridges - A Call for a Coordinated Dementia Strategy*](#), Doctors of BC is reconfirming and expanding on its calls to actions and commitments to support efforts to reduce stigma and improve the quality of life for all British Columbians living with dementia, regardless of age or stage of disease.

In addition to our previously stated calls to action and commitments and with the continued aim of reducing stigma and improving quality of life for people living with dementia, Doctors of BC supports:

- Prioritizing prevention activities, particularly modifiable lifestyle behaviours, for all age groups across all aspects of health policy.
- Increasing availability of dementia training and education programs for physicians and other health care providers, and for caregivers and the public.
- The provincial government's plan to increase funding for long-term care facilities to meet the provincial guideline for direct care hours.
- Efforts to increase understanding among the public, caregivers, and health care providers about the benefits of the palliative approach to care, for all people with dementia.

INTRODUCTION

In 2004, Doctors of BC published [*Building Bridges – A Call for a Coordinated Dementia Strategy*](#). In that policy paper, Doctors of BC (then the BC Medical Association) called on the provincial government to develop and implement a coordinated dementia strategy, and made recommendations across six key areas.

Since 2004, the BC government has developed and then refreshed its dementia strategy. In 2012, the provincial government released [*The Provincial Dementia Action Plan*](#), which was refreshed in 2016 with the [*Provincial Guide to Dementia Care in British Columbia*](#). Additionally, the provincial government created the Office of the Seniors Advocate in 2014. There has also been movement at the national level, with the federal government’s commitment to develop a National Dementia Strategy in 2018.*

Doctors of BC appreciates that there has been significant progress towards many of the recommendations in *Building Bridges*, and commends the provincial and federal governments for their continued efforts in this area. Recognizing that significant efforts have been made, challenges remain. British Columbians will continue to be diagnosed and live with dementia, especially as the population ages. The greatest challenge will likely be reducing stigma and improving the lived experience of people with dementia. It is with this intent that Doctors of BC has developed this policy update which renews existing recommendations and introduces additional new recommendations.

Reiterating recommendations from our *Building Bridges* policy paper, Doctors of BC continues to recommend that:

- Health Authorities continue to work to implement and/or expand a range of respite services, including emergency support, planned short-term respite programs, and day programs.
- The Ministry of Health continues to improve prioritization mechanisms to ensure equitable access to long-term facilities.
- Government and physicians work together to ensure that patients are able to access a family physician and appropriate speciality care.

Further to the recommendations made in *Building Bridges*, in 2016 Doctors of BC published [*Circle of Care: Supporting Family Caregivers in BC*](#), which recognizes family caregivers as key partners in health care delivery for patients with chronic conditions. Because family caregivers play a critical role in supporting people with dementia, the commitments and recommendations made in *Circle of Care* are complementary to and supported by this policy update.

* In addition to these shifts in policy, there have been changes to the diagnostic criteria for dementia. The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*, published in 2013, introduced the terms Mild and Major Neurocognitive Disorder to replace dementia. Doctors of BC recognizes that while these terms are used in clinical settings, dementia remains more commonly used among the public and will be used throughout this policy update.

In addition to the issues considered in *Building Bridges* and *Circle of Care*, there are a number of key policy areas that have not yet been considered, but present opportunities for action. Doctors of BC has identified prevention, education and training opportunities, direct care hours in long-term care facilities, and the palliative approach to care as key opportunities to improve the lived experience of people with dementia in BC. To address these areas, Doctors of BC supports:

- Prioritizing prevention activities, particularly modifiable lifestyle behaviours, for all age groups across all aspects of health policy.
- Increasing availability of dementia training and education programs for physicians and other health care providers, and for caregivers and the public.
- The provincial government's plan to increase funding for long-term care facilities to meet the provincial guideline for direct care hours.
- Efforts to increase understanding among the public, caregivers, and health care providers about the benefits of the palliative approach to care, for all people with dementia.

Dementia in British Columbia | 2018

26,987

Approximate number of people between the ages of 65 and 84 living with dementia in BC.

24,763

Approximate number of people over the age of 85 living with dementia in BC. These numbers are expected to continue increasing, especially when the oldest Baby Boomers start to turn 85 in 2031.



The prevalence rate of dementia in BC at the end of 2017/18 in people between the ages of 40 and 64 was 0.30%.



The prevalence rate of dementia in people between the ages of 65 and 84 was 3.72%.



The prevalence rate increased to 23.11% for people over age 85.

Source: Population Health Surveillance & Epidemiology (PHSE), V2017 Alzheimer & Dementia Registry and V2017 Client Roster.

PRIORITIZE PREVENTION

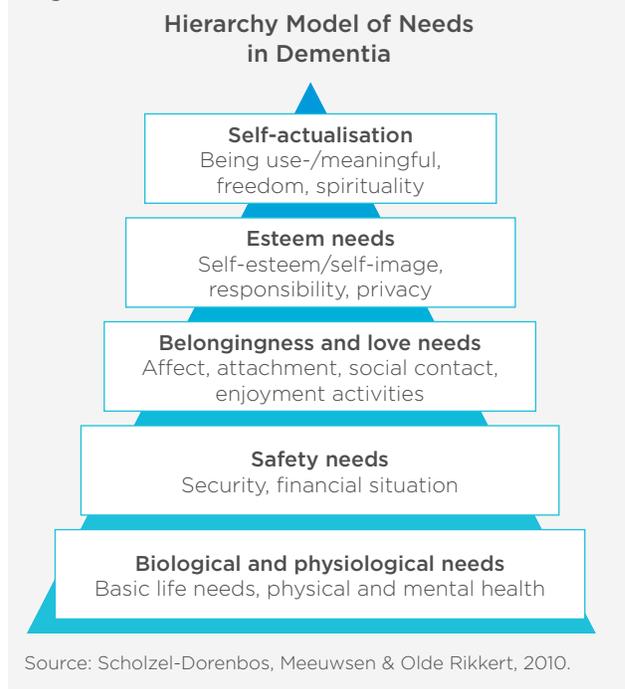
In *Building Bridges*, Doctors of BC recommended that prevention activities be encouraged. Since then, there has been considerable progress towards better understanding the prevention of dementia.

Theoretical modelling estimates that factors such as low education, hypertension, obesity, hearing loss, depression, diabetes, physical inactivity, smoking, and social isolation contribute to approximately 35% of dementias.¹ There is also evidence that moderate to severe, or repetitive mild head trauma, contributes to dementia risk.^{2,3} Polypharmacy, the use of multiple medications in people with multiple conditions, can result in cognitive impairment and has been associated with a greater risk of dementia.⁴

Studies have demonstrated that dementia risk can be reduced through the active treatment of hypertension in middle-aged people. Further, preliminary evidence suggests that increasing physical activity levels, maintaining social engagement, reducing smoking, and managing hearing loss, depression, diabetes and obesity in middle-aged and older people, and improving access to early education for children may also reduce dementia risk.¹ Healthy lifestyle behaviours, particularly when combined in a multimodal approach, have the potential to significantly reduce the incidence of cognitive impairment in the aging population.⁵ Lifestyle changes should be adapted to fit the social, cultural, geographic, and economic context of individuals in order to ensure they are effective and sustainable. Further, system wide efforts to promote inclusive communities that allow individuals to age in place will better allow for seniors to remain physically active and promote social engagement.

While Doctors of BC recognizes the importance of continued scientific attention to diagnosis and treatment, prevention activities are currently the most effective way to reduce the impact of dementia on individuals, caregivers, and the health system. Prioritizing prevention for all age groups will have the greatest impact in terms of preventing or delaying the onset of dementia and promoting healthy ageing. Further, healthy lifestyle behaviours such as aerobic exercise, mental activity, including socializing, and cardiovascular risk factor control may help people manage mild cognitive impairment and help to improve quality of life by improving overall mental and physical health.⁶

Figure 1.



EDUCATION AND TRAINING PROGRAMS

Dementia, by nature, is progressive so many people struggle with continuous change to their cognitive capacity and emotions, as well as complex physical and psychosocial symptoms.⁷

Because of these changes, people with dementia may be unable to independently meet their own needs or express their needs to caregivers. As a result, they may experience physical discomfort, social isolation, and other challenges, all of which contribute to a lower quality of life and have serious consequence for people with dementia. While rare, unmet needs may lead to violent behaviour. There were about 550 incidents of resident-on-resident aggression in BC long-term care homes in 2014/15.⁸ Negative mental health outcomes are far more prevalent. Depression and mental illness are common among people with dementia, with one study estimating the prevalence of depression in people with dementia at 77%.⁹

The Hierarchy Model of Needs in Dementia (the “Hierarchy”) illustrates the complex needs of people with dementia.¹⁰ At the bottom of the Hierarchy are the most basic needs, with the most complex needs at the top. To ensure these complex needs are met, education and training opportunities should be made available to physicians, allied health professionals, and staff who work with people with dementia in all health care settings, including home care, long-term care facilities, emergency departments, and private practices. Further, training opportunities should also be made available to caregivers, as research has shown that education on recognizing and addressing the symptoms of dementia can reduce caregiver distress.¹¹

One example of an excellent education program that has been used in BC since 2012 is P.I.E.C.E.S.TM It provides health care professionals with the knowledge and tools to develop individualized care plans for people with dementia to address complex symptoms.¹² The program also provides opportunities to include family caregivers in the development of care plans for their loved ones.

Beyond addressing the recognition and management of complex symptoms, education should include concepts such as cultural safety and trauma-informed care, as well as recognizing the diversity of people with dementia. This will ensure First Nations and other cultural groups, people with disabilities, and those with early onset dementia also receive appropriate, individualized care that improves their quality of life. Further, providing education to the public and community partners can encourage people to take concrete actions to make their communities more inclusive for people with dementia and allow them to age in place for as long as possible.

There are a number of dementia-friendly initiatives across the province that help people to develop a deeper awareness and understanding of dementia and the people affected by it.

DIRECT CARE HOURS IN LONG-TERM CARE FACILITIES

The challenges associated with meeting the needs of people with dementia are amplified in long-term care facilities.

Residents depend on staff who are trained to provide a supportive, culturally-appropriate, inclusive environment that allows people with dementia to continue to live meaningful lives.¹³ According to data from the Office of the Seniors Advocate, in BC 51% of residents in long-term care facilities have mild to moderate cognitive impairment and 30% have severe cognitive impairment.¹⁴ Because of this, it is important that long-term care facilities be resourced to meet not only the physical needs of residents, but the more complex needs identified across the top three tiers of the Hierarchy (see Figure 1).

Unfortunately, only 15% of BC long-term care facilities met the provincial guideline of 3.36 hours of direct care per resident day in 2016/17.¹⁴ The provincial government committed to meeting the provincial guideline of 3.36 hours of direct care per resident day in the 2018 provincial budget. Doctors of BC applauds this commitment and supports the continued implementation of this funding as quickly as possible to improve the quality of life for people with dementia living in long-term care facilities. In addition to funding for direct-care staff, it is important that long-term care facilities have the appropriate mix and number of staff, including specialist physicians and nurses to address all of the complex needs of people with dementia, including mental health.



PROMOTE A PALLIATIVE APPROACH TO CARE

The life expectancy for a person with dementia is highly variable. It is important to recognize that people with dementia can continue living fulfilling lives after their diagnosis.

A palliative approach to care helps people maintain a high quality of life when they have been diagnosed with a terminal illness, including dementia, by identifying and treating pain and other physical, psychosocial and spiritual challenges as soon as they arise. It is important to note that the palliative approach to care can be delivered concurrently with therapy for acute illness. This approach has benefits for all people with dementia, from the time of diagnosis until death.¹⁵

While a palliative approach that reduces burdensome and futile treatments for people with advanced dementia is becoming increasingly common, this approach for early stage dementia remains rare. There is a misconception among patients, their families, and many health care providers that palliative care is only provided to patients in the last weeks or days of life. It is important to note that the palliative approach to care goes beyond pain management at the end of life.

A palliative approach to care in the early stages of terminal illness focuses on prognosis awareness and potential life changes, advance care planning, psychosocial and spiritual support for the patient and their family, and symptom management.¹⁶ There are many elements of the palliative approach that can be provided to a person with early stage dementia, even if they have many years to live, that will improve their lived experience. For example, advance care planning, when provided soon after a dementia diagnosis as part of a palliative approach, can improve quality of life by establishing a care plan that reflects the person's values and goals.*

Support programs for patients and their caregivers, such as the programs provided by the Alzheimer Society, allow people with dementia to remain socially engaged, and live a meaningful life.

A variety of supports, including adequate funding, awareness and education, and access to providers, are required to ensure physicians are able to provide timely access to palliative care for all people with dementia.

* Doctors of BC published the policy paper [It's Time to Talk: Advance Care Planning in British Columbia](#) in 2014. The Association supports physician-initiated advance care planning as a standard of care for all patients, regardless of age, life stage, or health status. Further, at the time of writing, advance directives for Medical Assistance in Dying (MAiD) is not available to people with dementia. The discussion of advance directives for MAiD is outside the scope of this policy paper.

CONCLUSION

Dementia continues to impact a growing number of British Columbians.

Action is needed to ensure those diagnosed with dementia do not face unnecessary stigma and have access to the knowledge, tools and resources that allow them to live a fulfilling life.

While there has been progress in a number of areas to improve dementia care since *Building Bridges* was published in 2004, barriers remain. In addition to the recommendations made in 2004, Doctors of BC also supports prevention, education and training opportunities, funding for direct-care hours in long-term care homes, and a palliative approach to care.

We look forward to continuing to work with people with dementia, caregivers, government, the Office of the Seniors Advocate, and other health care providers to address these continuing and emerging challenges in order to improve the lived experience of people with dementia.

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