



November 2016



DEMENTIA IN CANADA:

A National Strategy for Dementia-friendly Communities

Standing Senate Committee on
Social Affairs, Science and Technology

The Honourable Kelvin Kenneth Ogilvie, *Chair*

The Honourable Art Eggleton, P.C., *Deputy Chair*



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Order of Reference

Extract from the *Journals of the Senate* of Tuesday, February 23, 2016:

The Honourable Senator Ogilvie moved, seconded by the Honourable Senator Patterson:

That the Standing Senate Committee on Social Affairs, Science and Technology be authorized to examine and report on the issue of dementia in our society;

That the committee review programs and services for people with dementia, the gaps that exist in meeting the needs of patients and their families, as well as the implications for future service delivery as the population ages;

That the committee review strategies on dementia implemented in other countries;

That the committee consider the appropriate role of the federal government in helping Canadians with dementia;

That the committee submit its final report no later than January 31, 2017, and that the committee retain all powers necessary to publicize its findings until 180 days after the tabling of the final report.

After debate,

The question being put on the motion, it was adopted.

Clerk of the Senate

Charles Robert

Members

The Honourable Senators who participated in this study:

Kelvin Kenneth Ogilvie, Chair
Art Eggleton, P.C., Deputy Chair
Linda Frum
Pana Merchant
Chantal Petitclerc
Nancy Ruth
Nancy Greene Raine
Judith G. Seidman
Carolyn Stewart Olsen

Ex Officio Members:

The Honourable Senators Peter Harder, P.C.
(or Diane Bellemare) and
Claude Carignan, P.C. (or Yonah Martin).

Other Senators who have participated from time to time in the study:

The Honourable Senators Beyak, Doyle, Gagné, Marshall, Munson, Omidvar, Neufeld and Patterson.

Parliamentary Information and Research Services, Library of Parliament:

Sonya Norris, Analyst

Senate Committees Directorate:

Keli Hogan, Clerk of the Committee
(until April 2016)
Shaila Anwar, Clerk of the Committee
(from April 2016)

Debbie Larocque, Administrative Assistant
(until April 2016)

Tracy Amendola, Administrative Assistant
(from April 2016)

Introduction

On February 23, 2016, the Senate adopted an Order of Reference authorizing the Standing Senate Committee on Social Affairs, Science and Technology (“the committee”) to examine and report on the issue of dementia in Canadian society. The committee held 14 meetings between March 9 and June 2, 2016 and heard from a broad range of experts whose testimony addressed the nature of dementia, the burden of the conditions both at a personal and societal level, prevention and treatment, caregiver issues, housing, research, as well as national strategies to

improve the care available to patients. Over the course of the study, the committee heard from officials from the Canadian Institutes of Health Research and the Public Health Agency of Canada as well as witnesses representing health professional organizations; dementia and mental health advocacy organizations; research programs; seniors’ residential housing groups; long-term care and palliative care associations; home care and caregiver groups; national dementia strategies; and, finally, the Assembly of First Nations.



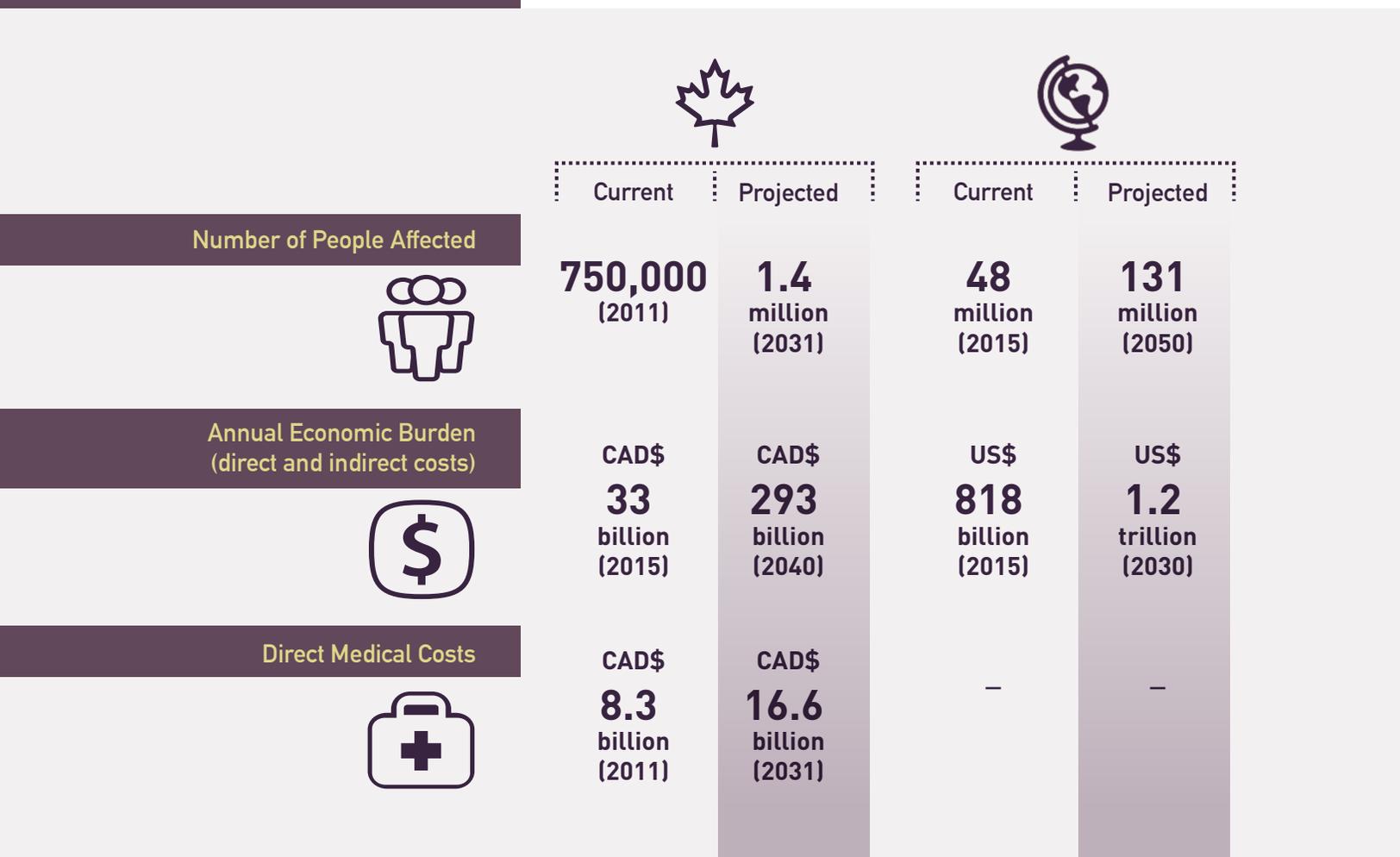
Context

“I can think of no other disease that has such a profound effect on loss of function, loss of independence, and the need for care. I can think of no other disease so deeply dreaded by anyone who wants to age gracefully and with dignity.

I can think of no other disease that places such a heavy burden on families, communities, and societies. I can think of no other disease where innovation, including breakthrough discoveries to develop a cure, is so badly needed.”

— Margaret Chan, Director General, World Health Organization
(Opening remarks at the First WHO Ministerial Conference on Global Action against Dementia, 17 March 2015)

The Impact of Dementia in Canada and Worldwide



Canada, like most industrialized countries in the world, has an aging population. In 2010, the first of the “baby boomers” turned 65 years of age. Although the proportion of seniors has been increasing for decades due to longer life expectancy, the proportion of seniors has been increasing even faster since 2010. According to the Canadian Institute for Health Information’s *Health Care in Canada, 2011: A Focus on Seniors and Aging*, the proportion of the Canadian population aged 65 years and older increased from 10% in 1986 to 14% in 2010. The report projects that between 2011 and 2031, during which time all baby boomers will turn 65, the proportion will continue to rise to almost 25%.¹ This means that within the next 15 years, one in four Canadians will be over the age of 65.

According to data from Statistics Canada, that projection is being realized. Population estimates for July 2015 indicated that “for the first time, the number of persons aged 65 years or older exceeded the number of children aged 0-14 years.”² The proportion of children aged 0-14 years was estimated to be 16.0% while seniors aged over 65 years was 16.1% of the population. This proportion varies somewhat among jurisdictions, with the Atlantic provinces having the highest percentage of residents aged 65 years and older; at 19%, New Brunswick has the highest proportion of residents aged 65 and older of all the provinces.

Dementia is a progressive and degenerative condition that robs an individual, over the course of many years, of the ability to live and function independently. The primary risk factor for dementia is age, and this proportion of individuals with dementia increases with age. That is, approximately 7% of people over the age of 65 is affected, but this proportion increases to 35 or 40% for individuals aged older than 85 years, according to testimony offered by the Canadian Institutes of Health Research (CIHR). As such, the number of Canadians living with dementia is expected to grow along with the proportion of the population aged 65 years and older.

Persons affected by dementia can continue to live independently for some time; however, as their condition progresses, they require increasing levels of care, first within their home but usually ending within a long-term care setting.

It was within this context — increasing numbers of Canadians affected with dementia requiring considerable health and social service support — that the committee undertook this study to determine the actions that should be taken to most effectively and efficiently meet this challenge.

1 Canadian Institute for Health Information, “*Health Care in Canada, 2011: A Focus on Seniors and Aging*,” 2011.

2 Statistics Canada, “*Canada’s population estimates: Age and sex, July 1, 2015*,” *The Daily*, 29 September 2015.

Background

1. Dementia Described

Witnesses explained that dementia is not a normal part of aging, although aging is a major risk factor for developing dementia. Rather, it is a slow and progressive condition that involves impairment in memory and other cognitive functions including mood, speech, behaviour and the ability to perform basic daily activities. There are a number of types of dementia, all characterized by a similar collection of symptoms, but all progress over the course of several years.

A. TYPES OF DEMENTIA

The most common type of dementia is Alzheimer's Disease, which accounts for about 60-70% of all dementia cases. A small proportion of individuals with Alzheimer's disease, less than 5%, develops the disease earlier in life, on average around the age of 50 years. This condition is called early-onset Alzheimer's disease. Late-onset Alzheimer's disease accounts for about 95% of Alzheimer's disease cases and is diagnosed after the age of 65 years. According to testimony from the Alzheimer Society, women account for more Alzheimer's disease cases than men, making up about 72% of all late-onset Alzheimer's disease diagnoses.

Vascular dementia is the second most common type and it can be caused by strokes that impair blood flow to the brain, which in turn results in oxygen deprivation

and cell death. This form of dementia accounts for 15-20% of dementia cases. Some individuals may be afflicted with both vascular dementia and Alzheimer's disease.

Other types of dementia include Lewy body dementia in which protein deposits called Lewy bodies form in the areas of the brain used for movement and thinking. This type of dementia, which makes up 5-15% of dementia cases, is associated with Parkinson's disease and can also occur along with Alzheimer's disease. Frontotemporal dementia accounts for 2-5% of dementia cases and usually occurs in individuals younger than 65 years of age. This form of dementia affects the front and side lobes of the brain, areas primarily associated with speech and behaviours.

Because the type of dementia is not always specifically diagnosed and because Alzheimer's disease makes up the majority of dementia cases, the term identifying these conditions that is often used in the literature is "Alzheimer's disease and related dementias."

B. SYMPTOMS, DIAGNOSIS AND PROGRESSION OF DEMENTIA

Dementia causes the slow and progressive deterioration and loss of brain function. The Alzheimer Society of Canada (ASC) has developed a list of **10 warning signs**³ that is used by health professionals across the country:

1. memory loss affecting day-to-day abilities;
2. difficulties performing familiar tasks;

3 Links relating to programs and initiatives that appear in bold type are listed in Appendix 1.

[4] *Dementia in Canada: A National Strategy for Dementia-friendly Communities*

3. language difficulties;
4. disorientation in time and space;
5. impaired judgement;
6. problems with abstract thinking;
7. misplacing things;
8. changes in mood and behaviour;
9. changes in personality; and,
10. loss of initiative.

The ASC emphasizes that anyone concerned about themselves or a loved one with respect to the signs listed above should see a doctor. It is also important to note that factors other than dementia may produce one or more of these symptoms, such as medication, depression and stress.

Following the elimination of other causes such as those listed above, usually by a family physician, through physical examinations, blood tests, medical history reviews and mental health assessments, screening for dementia involves assessment of cognitive ability, or mental acuity. This type of test assesses the ability to recall words, draw simple shapes, spell dictated words, answer questions, make simple calculations, etc. If dementia is suspected, the physician may refer the patient to a specialist, such as a geriatrician or neurologist, who will likely conduct additional mental acuity questionnaires as well as order various types of imaging such as X-rays, electroencephalograms (EEGs), computerized tomography (CT) scans, magnetic resonance imaging (MRI) scans, and positron emission tomography (PET) scans, to try to isolate the affected areas of the brain. Research using some of these types of neuroimaging techniques has shown that physiological evidence of damage can be seen up to 25 years before the onset of symptoms.

Once diagnosed, individuals affected by dementia can continue to live independently during the early stages of their disease, and with the appropriate support can continue to live in their home until the later stages. Over the course of many years, individuals with dementia will no longer be able to live at home as they become unable to perform the activities of daily living such as dressing, eating, toileting and bathing and will often display behaviours that caregivers may find difficult to address. In the last stage of dementia, individuals lose the ability to convey when they are in pain, as well as to walk, talk, chew and even swallow.

C. PREVENTION OR DELAY OF DEMENTIA

The cause or causes for the majority of dementia cases are not known. Genetics and heritability of the condition do not appear to play a major role in this regard. While some genes have been identified that are associated with dementia, there is a multitude of interacting factors that appear to increase or decrease a person's chances of developing the condition. These factors also affect the age of onset and the rate of progression of dementia. While genetics and age are risk factors that cannot be modified, many other risk factors are within the control, to some degree, of each individual.

In this regard, several lifestyle factors have been identified as being protective against developing dementia, or to delaying its onset or speed at which it progresses. These factors include physical exercise, a healthy diet, proper management of chronic disease, moderate alcohol consumption, not smoking, intellectual stimulation and social engagement. As well, avoiding brain injury, stress and depression, to the extent possible, can also delay the onset or progression of dementia.

D. TREATMENT AND SUPPORT

Currently there are no effective drugs to cure or to stop the progression of dementia. Some dementias present specific symptoms that can be treated with drugs but they do not reverse, slow down or stop the neurological damage within the brain. Rather, various non-pharmaceutical approaches have been and continue to be developed that aim to stimulate the brain, provoke memories and induce calmness and peacefulness. Many of these methods are described later in this report.

2. Economic Cost of Dementia

As described above, most types of dementia are age-related. As a result, countries around the world will experience a surge in the number of individuals affected by dementia as the proportion of the population aged 65 years and older continues to grow for the next 15 to 20 years. Chris Simpson, past president of the Canadian Medical Association, provided some information to the committee on rising healthcare costs as a result of the increasing proportion of people over 65 years of age. Currently, just one-sixth of the population is over 65 years of age and this group accounts for half of public health expenditures. Within 20 years, more than one in four Canadians will be over 65 years of age and 62% of the healthcare budget will be dedicated to the care of seniors.

A. CANADA

The Alzheimer Society of Canada's (ASC) most recent estimate suggests that 747,000 people were suffering from dementia in 2011. This number is expected to almost double in the next 15 years to 1.4 million, alongside the doubling of the number of people over the age of 65 years. Accordingly, the Public Health Agency of Canada (PHAC) told the committee that the direct health costs associated with the care of individuals with dementia is expected to also double from \$8.3 billion in 2011 to \$16.6 billion annually by 2031. The ASC informed the committee that the burden on the Canadian economy would increase from \$33 billion annually to \$293 billion annually by 2040 when both direct medical and indirect costs associated with social services and lost earnings of caregivers and dementia sufferers are combined.

B. INTERNATIONALLY

Alzheimer's disease International stated that dementia affects 48 million people worldwide currently and this number is expected to rise to 131 million by 2050. While the number of dementia cases is expected to double in Canada and other high-income countries by 2031, low- to middle-income countries are expected to see greater increases. Globally, the economic cost of dementia in 2015 was US\$818 billion, and this cost is expected to soon reach US\$1.0 trillion annually. The World Health Organization indicated that the economic burden would reach US\$1.2 trillion by 2030. These amounts include direct medical costs, direct social sector costs as well as indirect costs associated with informal care.

Current Efforts and Innovative Programs

1. In Canada

Over the course of the committee's study, members heard of the considerable amount of work on dementia currently underway across the country and by a multitude of stakeholders. Below is an overview of the many projects, programs and technologies that were discussed.

A. FEDERAL INITIATIVES

In September 2014, the Minister of Health announced the launch of the *National Dementia Research and Prevention Plan* (NDRPP)⁴ in response to the December 2013 G8 Dementia Summit Declaration.⁵ The aspirational goal set at that summit was to find a cure or disease-modifying treatment for dementia by 2025. Rodney Ghali, Director General at PHAC's Centre for Chronic Disease and Prevention, told the committee that the NDRPP provides the foundation on which the federal government's collaboration with other governmental stakeholders can help to make dementia a public health issue and to ensure that dementia remains a national and international priority.

Yves Joannette, Scientific Director of CIHR's Institute of Aging stated that the research component of the NDRPP is the CIHR Dementia Research Strategy, while the Institute of Aging also funds a number of other related initiatives.⁶ He indicated that the federal government had invested over \$183 million in dementia research over the past five years, including \$41 million in fiscal year 2014-2015. The strategy facilitates collaboration among researchers, promotes the sharing of research platforms and the dissemination of results in three areas of research, or themes: dementia prevention; improving diagnosis as well as treatment to delay the onset or stop the progression of dementia, and improving the quality of life for Canadians afflicted with dementia as well as their caregivers. He further detailed that the CIHR Dementia Research Strategy includes two components: domestic and international.

The domestic component is the Canadian Consortium on Neurodegeneration in Aging (CCNA). The committee was told that CIHR and its partners will invest \$32 million over five years in the CCNA. Partners include national, provincial and industry organizations.⁷ This consortium was launched alongside the NDRPP and comprises 350 researchers, working among 20 teams within the three themes listed above.⁸ There are eight national platforms within the CCNA

4 Government of Canada, *National Dementia Research and Prevention Plan*. 2014.

5 Government of the United Kingdom, "G8 Dementia Summit Declaration," 11 December 2013.

6 Canadian Institutes of Health Research (CIHR), *IA Initiatives*.

7 CIHR, CCNA, *Partner Organizations*.

8 CIHR, *Canadian Consortium on Neurodegeneration in Aging (CCNA)*.

to “facilitate research and create opportunities for collaboration by pooling and drawing on big data,” such as a “brain bank” and a cohort of volunteers suffering from dementia who may wish to participate in ongoing research.⁹ Finally, the CCNA incorporates four cross-cutting programs that must be applied to all research teams; ethical, legal and social issues, training and capacity building, knowledge translation and exchange, and women, gender, sex and dementia. This structure ensures that issues such as gender disparity in dementia are incorporated into all areas of dementia research funded through CIHR’s CCNA.

The international component of CIHR’s Dementia Research Strategy allows Canadian researchers to collaborate with their international colleagues. For example, the European Union Joint Programme — Neurodegenerative Disease Research supports multinational teams researching neurodegenerative conditions including Alzheimer’s and related dementias. Canada is one of 30 countries involved in this joint venture.

While PHAC revealed that the research component of the NDRPP is the central pillar of that plan, committee members were told that PHAC has a responsibility to carry out activities in three areas, namely surveillance and monitoring, improving quality of life and, promoting awareness to reduce stigma.

In terms of surveillance and monitoring of dementia, PHAC has invested \$50 million in a four-year, national population health study co-led by the Neurological Health Charities of Canada. As a result of this study, PHAC is now working with provinces and territories to establish surveillance of dementia along with epilepsy, multiple sclerosis

and Parkinson’s disease. The expectation is to include these four conditions within PHAC’s existing Canadian Chronic Disease Surveillance System¹⁰ by spring 2017.

In terms of quality of life, members were told that PHAC has a role in identifying the risk factors for developing dementia and to help mitigate the impact of these risk factors. For example, research is showing that many of the risk factors for developing several other age-related chronic conditions are likely also associated with the development of age-related dementias. In this regard, conditions such as Type 2 diabetes, cardiovascular disease, hypertension and some cancers, to which many lifestyle behaviours have been linked, also appear to be associated with a higher risk of developing dementia. Poor diet, sedentary lifestyle, smoking and alcohol abuse appear to increase the risk of developing these chronic diseases as well as dementia, and PHAC has a role in promoting the lifestyle behaviours that can help to contribute to healthy aging. While PHAC did not indicate any ongoing efforts in this regard, members were told that the agency is assessing opportunities in this area. However, the committee was told of collaborations between PHAC and organizations such as the Canadian Centre for Aging and Brain Health Innovation. Through these collaborations, the federal government is investing in the development of innovative technologies aimed at optimizing the quality of life of individuals with dementia by helping them to maintain their independence for as long as possible.

Finally, in terms of promoting awareness to reduce stigma, the committee was told of the initiative **Dementia Friends Canada**, which was launched in June 2015 and is a collaborative effort of the federal government

9 CIHR, CCNA, *National Platforms*.

10 Public Health Agency of Canada (PHAC), *Surveillance*.

and the Alzheimer Society of Canada. The initiative is a digitally based awareness program aimed at providing Canadians with information about dementia and how each of us can be supportive of affected individuals.

B. RESEARCH PROGRAMS

Research was not a primary focus of the committee's study because the federal NDRPP already places a strong emphasis in this area. CIHR has implemented the CCNA which has a comprehensive and integrated approach to dementia research. The CCNA was cited repeatedly by witnesses as an important and innovative research funding model that can help to propel the understanding of dementia and lead to effective treatments and models of care. As such it is important to acknowledge some of the important research that is being conducted in Canada, largely within the team structure of the CCNA. Additional CCNA-funded research has already gone on to become practice within some communities and will be described further below.

The CCNA funds research teams to look at different models of primary care for dementia patients. Primary care is essentially the healthcare provided in the community, traditionally by a general practitioner but can incorporate other health practitioners as well. For example, health teams may be led by nurses or nurse practitioners, or there may be initial patient screening by a geriatric assessor. The committee was told that research into different models of primary care is necessary in order to effectively meet the individual needs of different communities and populations.

Dementia research specific to the Aboriginal population is another area of funding from

CCNA. Research has shown that the rate of dementia in the First Nation population is 34% higher than in the non-First Nation population and that the age of onset is about 10 years younger than it is in the non-Indigenous population. As well, research has established that, in contrast to the general population, the rate of dementia among men in Aboriginal communities is higher than it is among women.

Outside the CCNA, members heard about an investment of \$123.5 million to establish the Canadian Centre for Aging and Brain Health Innovation within Baycrest Health Sciences in Toronto. PHAC's contribution to this investment was \$42 million. The centre is working on such innovations as the Virtual Brain, which would provide an integrated computer model on which experimental drugs could be tested, as well as telehomecare¹¹, which would improve access to geriatric care for homebound seniors.

C. CARE AND CAREGIVER SUPPORT

Throughout the study, witnesses emphasized the need for early diagnosis of dementia. However, they also acknowledged the difficulty of encouraging early diagnosis when there is currently no cure for dementia and little treatment available to slow the progression of the condition. Nevertheless, several witnesses stated that early diagnosis is important because there is evidence to suggest that progression of the disease can be delayed with lifestyle changes. In this regard, eating well, keeping physically and socially active and engaging in activities that are intellectually stimulating are all believed to extend the early phase of dementia during which an individual can maintain an independent lifestyle.

11 Telehomecare refers to the delivery of telehealth services within a patient's home rather than within a healthcare facility.

As mentioned above, one of the cross-cutting programs that supports CCNA-funded research is “Knowledge Translation and Exchange.” This term refers to facilitating the dissemination of research results and to translating research results into practice. In this regard, the committee was told about a number of new technologies, programs, diagnostic tools, primary care models, etc. that were held up by witnesses as examples of best practices across Canada.

Recent research has contributed to expanding the screening and diagnostic tools available to practitioners. One CCNA-funded research project was highlighted as an advance in screening tools for assessing individuals suspected of having dementia. The **Montreal Cognitive Assessment tool**, or **MoCA**, is a questionnaire that helps health practitioners assess short-term memory, language, ability to focus, delayed recall, visuospatial ability by drawing, and ability to name pictures of common items. William Reichman, from Baycrest Health Services, described a self-assessment tool called the **Cogniciti Brain Health Assessment** that measures brain health based on age and education level.

Without follow-up support, a diagnosis of dementia can leave a person feeling very isolated and can lead to depression. Several witnesses endorsed the Alzheimer Society of Canada’s (ASC) **First Link**® early intervention program. This referral program is offered by several ASC chapters across the country and it provides recently diagnosed dementia individuals and their families with information, including ASC’s First Steps for patients and families, and connects them to a variety of support services within their respective communities.

Memory Cafés are for people suffering from dementia and their caregivers. The Memory Café concept was born in the Netherlands

in the 1990s and quickly spread to several European countries. Ken McGeorge of the Alzheimer Society New Brunswick informed the committee that eight Memory Cafés have been launched in that province. The initiative involves providing a safe, friendly environment, often a church basement or community hall, where people can gather on a regular basis. While the gathering is informal, there is some structure and planning involved. For example, it includes a set start time when attendees hear from an invited lecturer or watch an informative video. Following a social break, there may be a question and answer period for discussion of issues of interest to dementia sufferers or their caregivers. This format has proven to be popular and provides individuals with a supportive environment for social engagement that is free from stigma.

Several chapters of the ASC also offer the **Minds in Motion** program. This program offers physical activity, intellectual stimulation and social engagement for people with early or mid-stage dementia along with their informal caregiver, or care partner. The program usually consists of two-hour sessions offered once a week over an eight-week period.

Access to healthcare in rural and remote communities, including Aboriginal communities, is a well-known challenge, and access to dementia diagnosis and follow-up services is no exception. The committee was told about the **Rural and Remote Memory Clinic** in Saskatoon, Saskatchewan developed by **Rural Dementia Action Research**, or **RaDAR**, which facilitates a one-day memory assessment clinic for people in rural and remote communities. For individuals diagnosed with dementia, follow-up services consist of telehealth clinics, which reduce travel distances considerably. This model received CCNA funding and successfully demonstrated that the follow-up care

offered through telehealth was just as effective and efficient as in-person care.

With respect to First Nation communities, Health Canada's First Nations and Inuit Health Branch has delivered the Home and Community Care Program over the past ten years. This program aims to work with these communities to develop appropriate home and community care services. The model of home care delivery can vary from one community to the next across Canada. Norma Rabbitskin, a Senior Health Nurse with Sturgeon Lake First Nation Health Centre, explained that home care services can be delivered by tribal council, in which case it comprises only home nursing care. Alternatively, it can be delivered at the community level and include home nursing assessment, case management and personal care including personal aides. However, members were told that the program requires additional resources as its budget has not been

increased since the program's inception and remains based upon 1997 population statistics.

Members also heard about an innovative approach to dementia care within a First Nation community. Isadore Day, National Health Portfolio Holder and Assembly of First Nations Regional Chief for Ontario with the Assembly of First Nations, described the JOY Program, joining old and young, where elders spend time in the day care community alongside children. Structured programming helps keep skills elevated for seniors and maintains social cohesion. This program uses community resources, looks at the life-long learning continuum and is a culturally based model.

For the majority of individuals suffering from dementia in Canada, primary care takes place within a number of healthcare silos, which involves different specialists attending to a patient's specific ailments or



conditions. The committee was told that a recently developed model of primary care memory clinics in Ontario, called Linda Lee clinics, aims to remove these silos. These clinics use a collaborative approach where the primary care team is linked to specialists in geriatric medicine and geriatric psychiatry. There are over 70 of these clinics across Ontario. Similarly, members were told of the **GEM Plus** program in Ontario. As part of Ontario's Aging at Home Strategy, the program integrates geriatric nurses within hospital emergency departments. Finally, **New Brunswick's Home First Strategy** has attempted to remove some of the silos and offers a range of supports in order to keep seniors in their own homes as long as possible and discourages hospital admissions.

Dementia sufferers are often able to stay in their home, with the proper supports, until the later stages of the condition, and as much as 90% of individuals with dementia live within the community. While maintaining independence in the home is usually the best option, this situation can place a lot of responsibility and stress on family and friends to provide informal care. It also presents a challenge in terms of providing formal home care services. Dementia in its early stages can still require vigilance on the part of informal caregivers who must be alert to memory lapses that can create safety or security concerns. Examples include leaving the stove on, water running or doors unlocked. The role of informal caregivers also includes providing reminders about dressing properly, eating meals and keeping appointments.

As the disease progresses, changes in behaviour and personality can be particularly difficult for caregivers and can, at times, present a danger. Many dementia sufferers exhibit a wandering tendency at this stage as well, requiring the caregiver to always be on the alert. The committee was told

that family caregivers provide an average of 8.2 hours of support a day. As a result, caregiver burnout is the principal reason for dementia patients being hospitalized or placed prematurely in long-term care facilities. The committee was told of the **C.A.R.E. tool** which is a questionnaire that helps to identify the needs of family caregivers so that burnout can be avoided.

Informal caregivers sacrifice their time, their social life, their jobs and often their good health to provide care to their loved ones and several witnesses noted that 80% of informal caregivers are women. One way in which informal caregivers can get the respite they require in order to avoid burnout is through increased access to home care services. The committee was told that the demand for home care had increased 55% in just the past seven years in Canada, with few if any new resources over that same period.

Although members heard only anecdotally of programs that provide respite to caregivers by offering Adult Day programs to dementia sufferers, they did hear testimony regarding various technologies available that can help to reduce some of the burden. Sensor technology in the form of wearable devices or motion sensors in the home can be used to alert a caregiver or emergency response to unusual or abnormal situations. Wearable GPS technology can be used for individuals who are at risk of wandering. Medication reminder prompters can be programmed into watches, TVs or phones to help caregivers adhere to dosing schedules.

D. HOUSING AND COMMUNITY MODELS

As dementia progresses, affected individuals often move into assisted-living facilities. This move may be by choice in order to ease the caregiving responsibilities of informal

caregivers, or it might be because there are no long-term care options available. Assisted-living facilities can also be referred to as seniors housing, retirement residences or retirement communities. As well, some seniors already living in this type of facility may develop dementia during their stay.

Assisted-living residences may house as few as four or as many as several hundred residents. However, most provinces do not subsidize these facilities so individuals who live in these facilities are responsible for the cost, which can be as high as \$5,000 per month. Witnesses testified that as much as 70% of the residents in assisted-living residences have various stages of dementia. These facilities are responding to the increasing number of dementia cases by creating secure memory care units within existing assisted-living accommodations. Memory care units are areas of a retirement home that have been separated from the rest of the building by the use of passcode protected access. This security limits the entry of non-dementia residents and others into the units and prevents residents with dementia from wandering away and becoming lost. These memory care units remain under the management of the assisted-living facility and the cost is the responsibility of the resident. This approach addresses the long wait times for long-term care beds, which can be in the order of months to a few years. It also provides an alternative to moving, which can be very disruptive and can potentially accelerate decline in dementia patients, and also allows resident couples, who might otherwise have to be separated, to remain close.

Members were told that one of the benefits of caring for individuals with dementia within assisted-living homes, both in the memory care units and within the main facility, is that care is not institutionalized but rather can

be tailored for a person-centred approach. The committee was told about programs that have been implemented that aim to improve overall quality of life. In this regard, members were intrigued by the **Butterfly model**. This approach was created in the U.K. by David Sheard, the founder of Dementia Care Matters. It strives to make the living environment for dementia sufferers as familiar as possible and to make it feel more like home rather than an institution. It is based on the concept that “feelings matter most” and that although a resident may not remember the people around them or recent events, they will respond to their environment because of how it makes them feel. Irene Martin-Lindsay, Executive Director of Alberta Seniors Communities & Housing Association, stated that this approach allows residents to thrive as they become more sociable and active and medications are sometimes reduced as a result.

Several witnesses mentioned the **dementia village** model developed in the Netherlands. Dementia villages are entire communities specifically designed for individuals with dementia and their caregivers. The communities provide a safe and secure environment while encouraging full social engagement and a high quality of life. The dementia village concept includes grouping residents with similar interests and backgrounds and creates an environment to suit each of these groupings. The buildings that make up each village are surrounded by a wall, and all pathways lead back to a central area. This approach encourages residents to remain active, both physically and mentally.

Long-term care includes both privately and publicly run facilities, but all are subsidized by provincial or territorial governments. As such, long-term care is not as costly to residents as assisted living but residents must still assume some costs if they are able to pay. Long-term care offers 24 hour a day

medical and supportive care. The committee was told that because seniors with dementia are now staying in their homes or retirement community longer than ever before, they are now coming in to long-term care at a later stage of the disease than has been the case in the past and therefore their needs are greater. Candace Chartier, Chief Executive Officer of the Ontario Long Term Care Association, stated that 62% of long-term residents have dementia but emphasized that innovative practices are also being adopted in some long-term care facilities, despite the institutional setting that is restricted by regulations. These practices include doll therapy which provides a patient with a doll to care for, the ipod (music) program, and pet therapy. The committee was told that programs like these can reduce the stress and anxiety in dementia patients responsible for producing behaviour that can increase the chance of harm to themselves or others. As a result these programs have a positive influence on behaviours and potentially reduce the use of medications, such as antipsychotics and benzodiazepines (eg., valium) that are used to reduce aggression and agitation.

Integrating appropriate palliative and end-of-life care has become an important component of the care offered, regardless of where dementia patients live out the last of their days. Louise Hanvey of the Canadian Hospice Palliative Care Association noted that the federal government provided the association with funding to create a national framework for integrating a palliative approach to care across Canada called **The Way Forward**. She explained that the approach focuses on meeting the full range of needs of both individuals and their families, including physical, psychosocial and spiritual needs and spans all stages of illness, not just the end of life. Part of the palliative approach involves advance care planning and members were told of the **Speak Up:**

Start the conversation about end-of-life care awareness campaign, which came out of the Advance Care Planning in Canada project. This campaign provides information and assistance on issues such as substitute decision makers and personal directives.

In addition to the innovative practices evolving among seniors' residences and long-term care facilities across Canada, other initiatives have taken on a larger scope. In this regard, the committee found the concept of **dementia-friendly communities** to be very compelling. This approach refers to communities at large that are inviting and supportive of individuals with dementia as well as their caregivers. One element of this approach involves reducing or eliminating the stigma associated with dementia through increased awareness and education campaigns as well as the uptake of specific initiatives by business operators and other service providers to deliver dementia-friendly interactions.

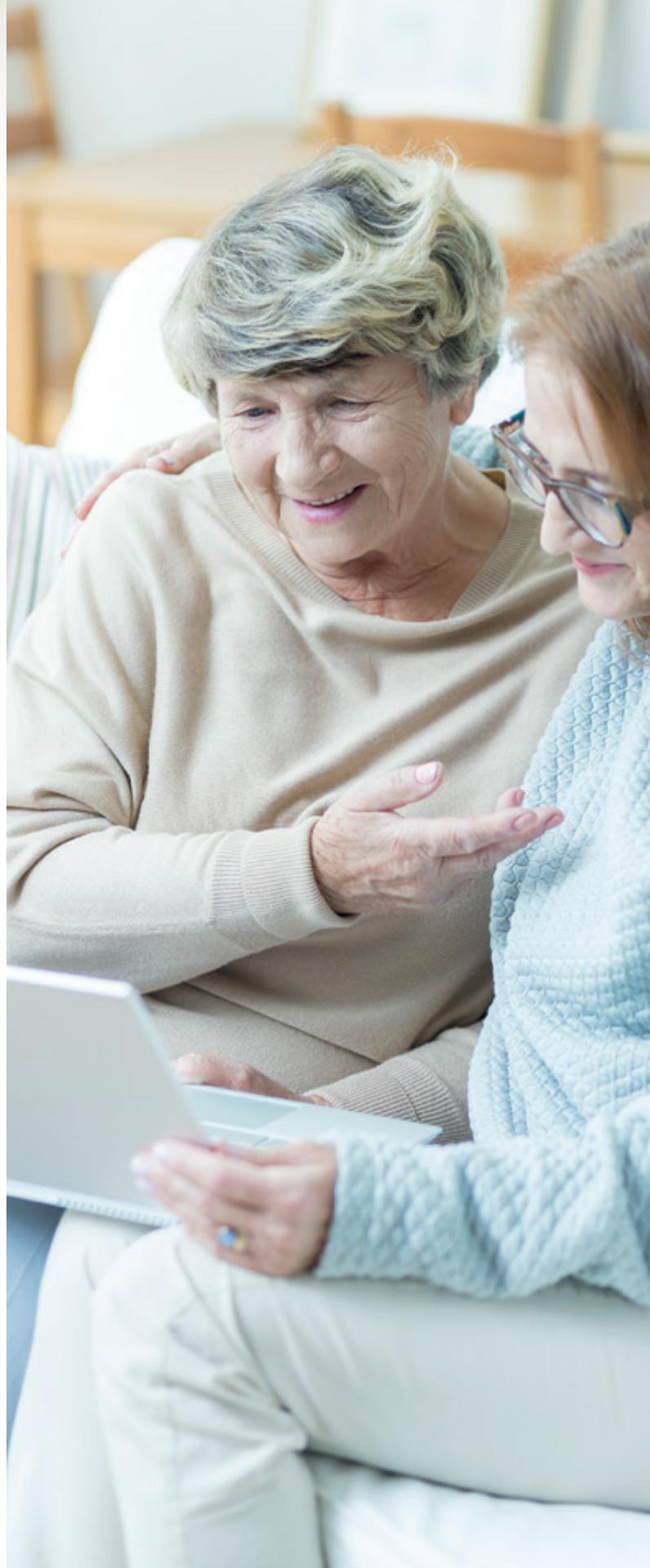
One initiative of dementia-friendly communities is the **Blue Umbrella** program. This program allows businesses to place a blue umbrella symbol in their window to signal that their employees have been provided with training so that they can provide dementia-friendly service. Individuals with dementia can similarly wear a blue umbrella pin on their clothing so that employees can easily identify them. The specific approach would depend on the nature of the business. A cashier may be trained on how to offer help to a customer who is having trouble counting money. A clerk in a busy store may realize that a customer should be re-directed to a quiet area. A salesperson may helpfully make suggestions to someone having difficulty naming an item that they are looking for. Regardless of the approach taken, the goal is the same: create a safe and inviting environment in which dementia sufferers and their caregivers feel welcome.

2. Global Initiatives

Shekhar Saxena from the World Health Organization and Marc Wortmann of Alzheimer’s Disease International provided some details to the committee about global efforts to address the challenge of rising dementia cases. The World Dementia Council, currently chaired by CIHR’s Yves Joanette, was recently created as a result of a commitment made at the 2013 G8 Dementia Summit. This entity aims to help make dementia a public health priority in countries across the world and to advocate for innovation and development of treatment options for dementia.

The committee learned that the World Health Organization is creating a “Global Dementia Observatory” projected to be functional later this year, for the collection and dissemination of dementia data and that Canada has been chosen to be one of the pilot countries. As well, the World Health Organization is developing an online platform called “iSupport” designed to provide information and support to people with dementia as well as their caregivers.

Alzheimer’s Disease International has created a virtual Alzheimer’s University that provides training to people who work in Alzheimer associations and societies around the world. The program offers basic training for newly created Alzheimer associations as well as more advanced training in public policy.



More Efforts and Coordination are Needed

1. Increased Investment in Research

As mentioned earlier, CIHR has placed significant focus on dementia research. CIHR's Canadian Consortium on Neurodegeneration in Aging (CCNA) was lauded by several witnesses who appeared during this study. As noted earlier, as much as 72% of dementia sufferers are women. The reason, or reasons, for this are not yet known. Whether this is a result of women living longer than men, or a consequence of hormonal changes at menopause, lifestyle differences, a combination of these issues or something else entirely, has yet to be determined. Committee members are pleased that CIHR has included a requirement that a gender lens must be applied to all CCNA-funded research and expect that such an approach will help to quickly resolve this mystery.

However, some witnesses questioned whether sufficient resources have been invested in dementia research given the number of people affected and the economic burden it will produce in the coming years. Lynn Posluns of the Women's Brain Health Initiative noted that dementia is now the third leading cause of death in Canada and is rising while the death rates for cancer, heart disease and stroke and HIV/AIDS have been declining.

These diseases have benefitted from greater research investment than dementia research is currently receiving. While research on Alzheimer's disease and related dementia received \$41.1 million in funding from CIHR in 2014-15, cancer, heart disease and stroke and HIV/AIDS received \$150 million, \$96.2 million and \$49.2 million, respectively.

Members were told by Ronald Petersen, Director of the Mayo Clinic's Alzheimer's Disease Research Center in Rochester, Minnesota that dementia research funding in G8 countries should be 1.0% of the cost of dementia care. Direct medical costs are currently in the order of \$10 billion annually for dementia care in Canada and, as mentioned earlier, the federal government invested \$41 million in dementia research in 2014-2015. An investment of 1% of direct medical costs would translate to a research budget of about \$100 million, more than twice the current CIHR investment. The committee was told that this level of investment would likely permit researchers to find a disease-modifying treatment by 2025.

2. Improved Public Awareness to Reduce Stigma

“We must broaden society’s perspective of the lived experience of Alzheimer’s beyond the last few years of its course.”

— Lynn Posluns, President,
Women’s Brain Health Initiative

Witnesses frequently emphasized the hope that dementia-friendly environments can be achieved. However, it was also frequently noted that there is significant stigma attached to dementia and that in order to achieve dementia-friendly neighbourhoods, communities, housing, etc., much more work needs to be done to reduce that stigma. Reducing the stigma starts with a greater emphasis on public awareness.

Although members heard from the Public Health Agency of Canada that the federal government has a responsibility in this area, the launch of the **Dementia Friends Canada** website, without any public awareness component to direct Canadians to it, is not sufficient. Similarly, the Alzheimer Society of Canada’s **Still Here Campaign** does not appear to have captured the attention needed to reduce the stigma around dementia.

Currently, the level of stigma attached to dementia results in a reluctance by individuals to seek additional information. As such, considerably more effort needs to be dedicated to informing the public of the practical realities as well as to dispelling fears and anxiety. However, efforts to improve public awareness and reduce stigma should not be initiated in isolation but rather alongside the many other issues

that need to be strengthened to effectively support individuals with dementia and their caregivers, as discussed below.

Improved public awareness will also have an effect on public policy in general so that existing community services become adapted to the needs of dementia sufferers. For example, the committee was told that public transportation that is made available to the disabled is sometimes restricted to the physically disabled, rather than the cognitively disabled. Implementation of dementia-friendly policies will be more inclusive of the needs of dementia sufferers.

3. Enhanced Health Human Resources: Training and Education

“Our current healthcare workforce is not prepared to provide dementia care, and I don’t think the curriculum in the majority of those professional groups is there.”

— Bonnie Schroeder, Executive Director,
Canadian Coalition for Seniors’ Mental Health

Members were told that the nursing curriculum is regularly modified to keep pace with the needs and demands of the population. Carolyn Pullen, a director with the Canadian Nurses Association, emphasized that the first clinical rotation for student nurses is usually a long-term care setting, which gives them early exposure to the unique health needs of this population, the majority of which suffers from dementia.

With respect to physician training however, members were surprised to hear that there is little focus in medical curricula about geriatric medicine in general or dementia in particular. The committee was told that there is poor integration of senior care in medical schools and that there is a disconnect between the curriculum content and society's needs. On one hand, members heard that all medical students do a clinical rotation in paediatrics, despite the statistic that only 2% of physicians will enter that specialty. On the other hand, there is no requirement to do a rotation in geriatrics even though most physicians will provide care to seniors at some point in their careers.

There has been some focus on providing training in the area of geriatrics to newly graduated physicians who begin their residency programs. Francine Lemire, Executive Director of the College of Family Physicians of Canada, indicated that the two-year family medicine residency training requires that residents acquire core competencies in the care of the elderly including the diagnosis and management of dementia. Similarly, physicians entering the psychiatry residency program must undertake a geriatric psychiatry rotation. However, the residency program for internal medicine¹² does not require a geriatric rotation.

In addition to the lack of required geriatric training, the committee was also told that there has been a financial disincentive to enter that specialty. Physicians entering internal medicine, a three-year residency program, tend to receive higher compensation than those doctors who go on to enter the geriatric specialty which requires an additional two-year residency after the internal medicine program. While further testimony revealed that

this disparity has been largely addressed in Ontario, the problem has not been addressed in other provinces. Members were told that as a result, it is difficult to attract new physicians to the field of geriatrics, which leaves Canada poorly equipped to provide specialized geriatric care to its aging population.

4. Early and Improved Diagnosis

Members heard that estimates suggest that only 50% of dementia cases in the community have been diagnosed. While stigma and fear of the diagnosis partially accounts for this low rate, some witnesses suggested that the medical community could be more proactive in assessing patients as they age. In this regard, the committee heard that regular screening of mental acuity should be considered. Other witnesses noted that dementia diagnosis often takes too long as family physicians refer them to specialists, which frequently entails a long wait for an appointment. Other witnesses mentioned the need to ensure validation of the screening and diagnostic tools that are available to both physicians and individuals for self-screening because there are many tests and questionnaires available that have not been validated and could provide false results.

A number of witnesses emphasized the observation that physical evidence of damage in the brain can be identified many years before the onset of dementia symptoms using neuroimaging technology. While individuals may question the value of

¹² Internists are physicians who care for adults with complex multi-system diseases. (Canadian Society of Internal Medicine (CSIM), *About CSIM*.)

knowing this information decades before the inevitable decline into dementia, it was pointed out that early detection could be beneficial in modifying lifestyle in order to delay the onset of symptoms as long as possible. Improving diet, increasing physical activity, engaging socially and expanding cognitive reserve through intellectual stimulation can all contribute to extending the years of good mental health.

Although several witnesses agreed that early diagnosis is preferable, testimony also confirmed that improved diagnosis cannot happen in isolation. Rather, it must be addressed in tandem with the gaps identified below. They emphasized that patients who are handed this difficult diagnosis must be offered a range of supports at the time of diagnosis, which is the case for other types of diagnoses, such as cancer or heart disease. Diagnosis should mark the beginning of a process of healthcare management rather than an end point where a newly diagnosed individual is left to find his or her own way through a complex system.

5. Greater Support for Informal Caregivers

“The biggest challenge in caregiving is avoiding caregiver burnout, when a caregiver can no longer perform their role.”

— *Angus Campbell, Executive Director,
Caregivers Nova Scotia*

The progression of dementia spans many years and for most of those years a person can maintain some level of independence. The optimal situation for most people affected by dementia is to remain in their homes and this is usually possible until the later stages of the condition, when the needs of dementia sufferers often surpass the capacity of informal caregivers and home care providers.

Informal caregivers, most of whom are women, sacrifice their own time, finances and health in order to care for a loved one with dementia. Caregivers shoulder a tremendous responsibility as they strive to provide the attention and care that is necessary. As a result, caregivers are vulnerable to health problems. As the committee heard from Jo-Anne Poirier of VON Canada, informal caregivers are Canada’s silent patients. She noted that one-third of the caregivers for dementia sufferers report symptoms of depression. Members also heard that the stress and anxiety of providing care can lead to premature dementia in the caregiver.

Caregiver burnout often results in premature hospitalization of dementia patients. As Katherine McGilton, a senior scientist at Toronto’s University Health Network, described, premature hospitalization can precipitate further cognitive decline and result in the patient having to stay in hospital to await placement in a long-term care facility. Members were told that on average across Canada, 15% of people in acute-care hospitals are waiting for placement in long-term care.

Witnesses emphasized that society should offer a range of supports for caregivers in order to lengthen the time that dementia patients can stay in their homes while also reducing the burden on the caregivers. Suggestions for needed support included

adult day programs that provide supervised activities for dependent adults in order to provide some respite for caregivers; overnight stays for dementia patients in residential care facilities; additional tax incentives; extended Employment Insurance benefits under the Compassionate Care program; a caregiver allowance; flexible work conditions; training and information; support groups; and, improved home care services, discussed below.

6. Integration of Health Services

“Dementia is the godfather of chronic diseases in that it will lead to an ongoing litany of many other diseases.”

*— Chris Simpson, Past-president,
Canadian Medical Association*

As mentioned above, there is a need to address the number of health professionals with specialized training in geriatric and dementia care. In addition to that challenge, however, is the need to adjust the current model of healthcare delivery. Elderly Canadians are the most likely sector of the population to suffer from multiple chronic conditions requiring multiple prescriptions. Patients suffering from dementia present an additional challenge in chronic disease management as they are limited in their ability to describe symptoms, relay medical history and, if not properly supported by caregivers, may not be adhering to their medication regimen.



Frank Molnar of the Canadian Geriatrics Society noted that 90% of dementia patients who live in the community have at least two other chronic conditions. Currently, healthcare delivery, both primary care physicians and acute-care hospitals, emphasize treatment of a single issue at a time. However, individuals with multiple chronic conditions would be better served by a healthcare delivery model that can manage all of these conditions together, instead of individually. In this regard, it was suggested that a “dementia-plus care” model would be a fully integrated chronic disease management system that would permit all the required specialists to work together to determine the most effective treatment approach. It was noted that such an approach would help to improve the monitoring of patients taking multiple medications, sometimes called polypharmacy, which is associated with increased adverse reactions, drug-drug interactions and reduced compliance. Similarly the committee heard from Veronique Boscart of the Canadian Gerontological Nursing Association that the complexity of caring for a dementia patient requires the integration of health as well as social services.

Without the population base to support the significant presence of health professionals or services, rural, remote and First Nations communities present challenges with respect to healthcare delivery. For dementia care, Andrew Kirk of the Rural Dementia Action Research described the innovative Rural and Remote Memory Clinic at the University of Saskatchewan, which requires rural and remote patients to travel to a one-day memory clinic for diagnosis but then provides effective follow-up care remotely. However, funding is stretched for this innovative program, and it seems to have little capacity to promote this model to other communities across Canada. Perhaps more importantly, Wayne Warry from the Centre

for Rural and Northern Health Research at Laurentian University noted that access to broadband services is inconsistent across the country, especially in rural and remote areas. The committee was told that the limited connectivity significantly restricts the capacity for telemedicine.

7. Emphasized Home and Community Care

“If we get this right, we can postpone or avoid the need for people to move into that institutional care that is on no one’s bucket list.”

*— Irene Martin-Lindsay, Executive Director,
Alberta Seniors Communities &
Housing Association*

In addition to the healthcare challenges presented by dementia patients, primarily due to the co-morbidities of other chronic conditions, dementia patients require increased supervision and assistance with activities that are both health-related and non-health related as their dementia progresses. While these issues are often assumed by informal caregivers, as discussed above, there is an increased need to provide these services in-home.

With respect to healthcare services that could be made available through home care, the committee heard about the importance of rehabilitation, especially following a hospital visit. Rehabilitation services help to prevent the sudden decline that often accompanies health crises in dementia patients. In-home

nursing care was also held up as an important component of home care for dementia sufferers to ensure that medications are taken properly and that prescriptions are up to date. Nurses could also help to identify evolving health issues before they necessitate a hospital visit, could consult with physicians as needed and could keep the health team updated on health status. The committee was also told of the Home-Care-Plus model which includes specialists in dementia care as part of the home care model. As explained by Nadine Henningsen of the Canadian Home Care Association, expanded use of innovative technologies within the home can further improve care, including self-care, reduce emergency room visits and admissions to hospital as well as reduce medication errors.

Personal support workers are equally important in a comprehensive home and community care approach. With appropriate training to support individuals with dementia, personal support workers can help to provide many social services, depending on the level of care required, including meal preparation, house cleaning, laundry, shopping, dressing, bathing, toileting, feeding, skin care, etc. The committee was cautioned, however, that the provision of home care services to dementia patients is challenged by the observation that these individuals often do not want strangers in their homes. It is essential, therefore, to start home care services as early as possible in order to build relationships with the patients.

Some witnesses questioned whether volunteers could help to address the needs of dementia sufferers, whether in their home or in other settings. It was pointed out that specialized training is essential and that these dementia patients are particularly sensitive to changes in personnel. For these reasons the committee was told that it would be difficult to rely on volunteers in the area of dementia care.

The provision of home and community services is particularly important in rural and remote communities where other housing options are likely to be very far away, which would remove the dementia sufferer from a familiar environment and away from their loved ones. Suzanne Dupuis-Blanchard, President of the Canadian Association on Gerontology, described a program in New Brunswick which permits a geriatric assessment team to travel from Fredericton to rural parts of that province. Despite the success of this program it has not been adopted elsewhere. Marie-France Tourigny-Rivard, from the Canadian Academy of Geriatric Psychiatry, discussed her experience with geriatric mental health teams that consult with rural physicians, either in person or via telehealth. In addition, this component of care is critical for First Nations communities where alternative housing options may not be culturally acceptable.

Several witnesses noted that effective provision of home and community services to individuals affected by dementia will require a re-structuring of the current approach in order to allow for the integration of health and social services. The committee was told about and applauds the efforts of the Canadian Nurses Association, the College of Family Physicians of Canada, the Canadian Home Care Association and other key stakeholders to come together to discuss the policy and practice implications for transitioning from traditional primary care and acute care to community-based care. Witnesses cautioned that this approach would result in an initial increase in costs but that, if the change is properly managed, the new system would produce cost savings.

8. Affordable Housing

“Despite all the investments, acute care hospitals are being overwhelmed by the care of persons with dementia. We do not have the resources to meet their needs. We are losing ground and need immediate help.”

*— Frank Molnar, Vice-president,
Canadian Geriatrics Society*

Dementia patients who can no longer remain in their homes have essentially two housing options as described earlier, assisted living and long-term care. While assisted-living facilities have the capacity to provide care to most dementia patients and some have integrated special memory care units, this option is only available to individuals who can afford the cost, which can be as high as \$5,000 per month. Sadly, some seniors, including dementia patients, are being transferred to subsidized long-term care residences prematurely if they are no longer able to be cared for at home but cannot afford assisted

living. This situation is detrimental to the individual, whose health will deteriorate more quickly in the long-term care environment, it is a costlier alternative than providing the supports needed to keep the person in their home, and it takes a long-term care bed away from someone who may be more in need.

Laurie Johnston of the Ontario Retirement Communities Association stated that Canada is one of the few Western countries that does not provide any flexible funding for seniors’ housing, an approach that would address the affordability issue as well as the waiting lists for long-term care. She suggested that flexible funding would allow greater access to assisted-living facilities and could include, for example, subsidies provided directly to individuals so that they can choose the housing or services that best suit their situations, or could be in the form of mandatory long-term care insurance. The Canadian Medical Association suggested that the federal government should make a capital investment of about \$540 million, with funding awarded on a cost-share basis with applicants, to renovate and retrofit existing infrastructure as a means of quickly increasing the number of available long-term care beds.

The Patient Perspective

Of all the expert testimony offered throughout this study, none was more compelling than that which was given by members of the Ontario Dementia Advisory Group, Mary Beth Wighton, Phyllis Fehr, Bill Heibein and Bea Kraayenhof. This group represents individuals suffering from dementia and is committed to being an influential participant in policy making, research projects and education initiatives in Ontario.

“We are parents, grandparents, spouses and friends. We have had long and successful careers. When we were diagnosed with dementia, these experiences did not disappear; they are and will always be a part of us.”

*— Mary Beth Wighton, Member,
Ontario Dementia Advisory Group*

Members heard first-hand experience of the current disjointed approach to dementia care, beginning with the reluctance or inability of healthcare providers to provide supportive and helpful advice so as to minimize the devastation of this diagnosis or how to maintain a good quality of life.

“You get your diagnosis and when you get your diagnosis, I will honestly say, you get prescribed disengagement...People are prescribed disengagement. They’re sent home to sit in that chair and do nothing. We need to keep them engaged and active.

That is not happening.”

*— Phyllis Fehr, Member,
Ontario Dementia Advisory Group*



Committee members were moved by the strength and determination of these individuals who have been let down by a compartmentalized system that is ill-equipped to integrate the range of services needed to properly address the needs of individuals with dementia. It is clear, they deserve nothing less than a dementia-friendly Canada in which they are not only accepted but embraced.

“The more we can be seen and heard in public the better. One of the reasons I say that is I know when I was first diagnosed, the first thing you want to do is just withdraw and hide. The more we can be seen, the more people who have just been diagnosed and start to pay attention to what’s happening, hopefully they’re going to get their self-confidence back to be able to go out and participate.”

*— Bill Heibein, Member,
Ontario Dementia Advisory Group*

Finally, the committee was reminded that the United Nations Convention on the Rights of Persons with Disabilities ensures that persons with dementia, as with other disabilities, are entitled to participate as equals in discussions about the programs and services that affect them. As members listened to their personal stories, it became not only obvious but imperative that Canadians living with dementia must be included in all aspects of a coordinated approach to dementia care in Canada.

“Don’t ignore us, because we still have so much to offer. As with the dementia strategy program, we could be the experts because we live with it.”

*— Bea Kraayenhof, Member,
Ontario Dementia Advisory Group*



Recommendations for a National Dementia Strategy

“All over the world there is a need for national dementia strategies, and 24 countries have done that now.”

— Marc Wortmann, Executive Director,
Alzheimer’s Disease International

It became clear to members from listening to the testimony of multiple experts on the issue of dementia over the course of 14 meetings that there is a considerable amount of excellent work being done by a vast number of dedicated individuals and groups in Canada. However, as noted by Mimi Lowi-Young of the Alzheimer Society of Canada (ASC), we are far behind other countries in our approach to this challenge, being one of only two G7 countries (along with Germany) that do not have a comprehensive national dementia strategy. This observation is of particular concern given the warning by some witnesses that the nearly doubling of dementia cases in the next 15 years will overwhelm Canada’s healthcare system unless the country addresses the situation head on with targeted programs, clear goals and proper monitoring and accountability.

In Canada, the direct provision of health and social services is primarily under the authority of the provinces and territories, with the exception of certain populations for whom the federal government is responsible including First Nations. While this situation may limit the nature of the direct interventions promoted under a national strategy, members were told

that such a jurisdictional arrangement is not unusual among countries that currently have national dementia strategies, Australia and the United States are examples. In fact, the committee notes that national strategies have been implemented in Canada for other health-related issues. These strategies include the Canadian Diabetes Strategy, the Canadian Strategy for Cancer Control and the Integrated Strategy on Healthy Living and Chronic Disease¹³ and additional strategies have existed in previous years. Finally, members were told that Canada supported the 2015 “Strategy and Plan of Action on Dementias in Older Persons” developed by the Pan American Health Organization, which listed five areas of action to address dementia:¹⁴

- Promote plans, policies and programs for risk reduction, prevention, quality of life and care;
- Establish interventions for prevention and care;
- Implement a long-term care system that addresses the needs of the patients as well as their caregivers;
- Strengthen health human resources training; and,
- Improve research and surveillance.

In order to more effectively address the surge of dementia cases in Canada, the committee believes that a comprehensive approach must be taken and agrees with testimony

13 Public Health Agency of Canada, *Chronic Disease Initiatives, Strategies, Systems and Programs*.

14 Pan American Health Organization, *Strategy and Plan of Action on Dementias in Older Persons*, 29 September 2015.

from the World Health Organization that dementia must be given a higher priority.

As discussed earlier, the federal government has implemented the “National Dementia Research and Prevention Plan,” however, only the research component of this plan appears to be comprehensive. In fact, many witnesses congratulated the Canadian Institutes of Health Research (CIHR) on its work in this area. Despite the strong research focus, all witnesses called on the federal government to assume a leadership role to establish a strategy that; brings together all of the great work being done; facilitates the scaling up of promising practices in healthcare, home care, housing and social services; promotes the translation of successful research into policy and programs; encourages the uptake of guidelines and standards across the country for dementia care; provides assistance to improve access to home care services and alternative housing options; and supports informal caregivers.

In terms of structure and accountability of the dementia strategy, the committee heard about the “U.S. National Plan to Address Alzheimer’s Disease,” which is under the authority of the U.S. Department of Health and Human Services and involves partnerships among several federal agencies and departments. An Advisory Council on Research, Care and Services was established to create a national strategic plan to address the increasing prevalence of dementia and to coordinate efforts across the federal government. The committee was informed that the U.S. plan must be evaluated, reported on and updated annually.

In establishing a dementia strategy for Canada, the committee supports the model proposed by the ASC that calls for the creation of a partnership,¹⁵ an adaptation of the approach taken in the Canadian Strategy for Cancer Control. That strategy is the responsibility of the Canadian Partnership Against Cancer, which is made up of representatives from cancer and health organizations; federal, provincial and territorial government agencies and departments; patient organizations; individuals and families affected by cancer; clinicians and healthcare providers; researchers; and the Aboriginal community. The work of the Canadian Partnership Against Cancer spans prevention and screening; diagnosis and clinical care; person-centred perspectives; First Nations, Inuit and Métis; system performance; knowledge management; and public engagement and outreach. The Canadian Partnership Against Cancer receives \$50 million annually from the federal government and is currently operating under its second five-year mandate. The ASC proposes that a similar partnership be established to develop and implement a national dementia strategy that is “built on the collective vision, expertise and firsthand experience of dementia leaders, researchers, experts, practitioners, caregivers and those living with the disease from across the country.”¹⁶ The ASC proposes annual federal funding of \$30 million.

“Hundreds of thousands of Canadians living with dementia are counting on the Government of Canada to lead the way.”

**— Ken McGeorge, Acting Executive Director,
Alzheimer Society of New Brunswick**

15 ASC, *The Canadian Alzheimer’s Disease and Dementia Partnership: Strategic Objectives*, September 2015.

16 *Ibid.*, page 2.

RECOMMENDATION 1:

The committee therefore recommends that the federal government immediately establish the Canadian Partnership to Address Dementia with a mandate to create and implement a National Dementia Strategy.

RECOMMENDATION 2:

The committee further recommends that the federal government, when establishing the Canadian Partnership to Address Dementia, take into consideration the structure and function of the Canadian Partnership Against Cancer, however the new organization must:

- **include representation from, but not be limited to, federal, provincial and territorial governments, dementia and other health-related organizations, individuals affected by dementia and their caregivers, healthcare professionals, housing organizations, researchers and the Indigenous community;**
- **be required to evaluate, report on and update the strategy annually; and,**
- **receive adequate federal funding of at least \$30 million annually.**



RECOMMENDATION 3:

The committee further recommends that the federal government adjust the annual funding provided to the proposed Canadian Partnership to Address Dementia in response to annual evaluations and strategy updates.

The committee agrees that the federal government’s “National Dementia Research and Prevention Plan” is not sufficient to address the increasing demands for dementia care in Canada and would like to see the establishment of a more comprehensive strategy. In developing the National Dementia Strategy, the Canadian Partnership to Address Dementia should take advantage of the good work conducted by the ASC in its proposed model and as well as the strategies that have been implemented in countries around the world. In this regard, Alzheimer’s Disease International produced the 2013 report “Improving Dementia Care Worldwide: Ideas and Advice on Developing and Implementing a National Dementia Plan,” which provides an assessment of several national dementia strategies.¹⁷

RECOMMENDATION 4:

The committee therefore recommends that the proposed Canadian Partnership to Address Dementia, in its development and creation of Canada’s National Dementia Strategy, be guided by the following documents:

- *The Canadian Alzheimer’s Disease and Dementia Partnership: Strategic Objectives (Alzheimer Society of Canada); and,*
- *Improving Dementia Care Worldwide: Ideas and Advice on Developing and Implementing a National Dementia Plan (Alzheimer’s Disease International).*

As recommendation 4 illustrates, the committee prefers not to be overly prescriptive in this report in the description of a National Dementia Strategy and leaves many of the particulars up to members of the proposed partnership. Rather, the committee would like to emphasize some of the components that must be included within the new strategy. Some aspects specifically include a role for the federal government while still respecting jurisdictional limitations. Other aspects of the strategy, where the federal role is smaller, require that the partnership’s collaborative structure promote and facilitate uptake across jurisdictions for a uniform approach to dementia care across the country.

17 A.M. Pot and I. Petrea, *Improving Dementia Care Worldwide: Ideas and Advice on Developing and Implementing a National Dementia Plan*, London: Bupa/Alzheimer’s Disease International, October 2013.

A. RESEARCH

“Research on dementia ranging from prevention to living with dementia to a cure must be encouraged, along with continued research funding.”

— *Suzanne Dupuis-Blanchard, President,
Canadian Association on Gerontology*

The Canadian Institutes of Health Research’s Institute on Aging, which currently invests \$41.1 million annually in dementia research, has implemented the Canadian Consortium on Degeneration in Aging (CCNA), which was applauded by many witnesses. In particular, the committee commends CIHR’s requirement that all CCNA-funded research include gender-based analysis. While the committee is of the view that Canada can be very proud of its dementia research efforts, it questions the level of investment. Dementia is now one of the leading causes of death and one of the most costly medical conditions in terms of care and housing. As well, members note that Canada supported the 2013 G8 Dementia Summit Declaration from which the proposal for a research investment level at 1% of dementia care costs was derived.

RECOMMENDATION 5:

The committee therefore recommends that the federal government allocate to the Canadian Institutes of Health Research’s Dementia Research Strategy, as a component of the proposed National Dementia Strategy, 1% of current direct dementia care costs, or approximately \$100 million annually.

B. PUBLIC AWARENESS

“Dementia is a growing cause of death in this country and we need to pay attention to it.”

— *Louise Hanvey, Project Manager,
Canadian Hospice Palliative Care Association*

More effort must be placed on public awareness. While the Public Health Agency of Canada emphasized stigma reduction, it appeared to play only a passive role in this regard through the creation of Dementia Friends Canada. In addition, members are concerned that the federal government has not fully embraced its responsibility for increasing public awareness about dementia. That is, public awareness campaigns should not be restricted to stigma reduction, but rather, should include prevention strategies, the importance of early diagnosis, symptom recognition, reassurance that a good quality of life can be maintained for years with the proper supports, and information about the supports available and organizations to contact for more help.

RECOMMENDATION 6:

The committee therefore recommends that the Public Health Agency of Canada create and implement, within the National Dementia Strategy, a comprehensive public awareness campaign that includes promotion of the Dementia Friends Canada website as well as high-visibility/high-impact approaches regarding prevention, early diagnosis, symptom recognition, quality of life, and services and supports.

RECOMMENDATION 7:

The committee further recommends that, with respect to prevention strategies, the federal government implement recommendations 20 and 21 of the Standing Senate Committee on Social Affairs, Science and Technology's 2016 report entitled *Obesity in Canada: A Whole-of-Society Approach for a Healthier Canada*, by:

- designing and implementing a public awareness campaign on healthy eating based on tested, simple messaging, and
- implementing a comprehensive public awareness campaign on healthy active lifestyles in collaboration with other relevant departments, agencies, experts and trusted organizations.



C. SURVEILLANCE

The committee is concerned that the surveillance model that the Public Health Agency of Canada has indicated should be operational by 2017 may not be resourced sufficiently to meet the needs of the National Dementia Strategy.

RECOMMENDATION 8:

The committee therefore recommends that the federal government ensure that Public Health Agency of Canada receive adequate resources for the Canadian Chronic Disease Surveillance Program so that it can provide robust, timely and accessible dementia surveillance data beginning in 2017.

to be filled with the proper follow-up supports that these individuals need and deserve.

In this regard, the committee heard from David Berry, from the Dementia Policy Unit, Government of Scotland. He emphasized that the Scottish dementia strategy has recently been updated with a guarantee of follow-up care for people who have received a diagnosis of dementia. Scotland is now undertaking the third iteration of its national dementia plan, which is updated every three years. He explained that the new strategy will offer a year of person-centred support, coordinated through a trained “link worker” to any newly diagnosed person who wishes to take advantage of the supportive care. The individual can choose to engage with the coordinator at the time of diagnosis or at some time later on. This approach is similar to the ASC’s **First Link**[®] early intervention program, which the committee was told has not been effectively communicated to, or taken up by, all health providers.

D. DIAGNOSIS AND FOLLOW-UP

“This will become one of the great public health challenges of our time.”

*— William Reichman, President,
Baycrest Health Sciences*

Testimony from individuals affected with dementia revealed that pursuing and receiving a diagnosis of dementia must be improved. Some of the inadequacies will be addressed through issues described below, such as improved training, better access to specialists, and improved access to healthcare services for rural and remote regions. However, the committee also heard that once a diagnosis has been made, it creates a vacuum which needs

RECOMMENDATION 9:

The committee therefore recommends that the proposed Canadian Partnership to Address Dementia ensure that Canada’s National Dementia Strategy encourages the implementation of the Alzheimer Society of Canada’s **First Link[®] early intervention program across Canada, adapted as necessary to be appropriate and culturally sensitive to each community.**

E. SUPPORT FOR INFORMAL CAREGIVERS

“The tipping point for placement in long-term care is most frequently caregiver burnout.”

— Candace Chartier,
Chief Executive Officer,
Ontario Long Term Care Association

Members heard repeatedly that informal caregivers shoulder a tremendous responsibility when caring at home for a person suffering from dementia. As a result, caregivers sacrifice income, job security, and their own good mental and physical health. Committee members agree with the sentiment expressed, for example, by Bonnie Schroeder of the Canadian Coalition for Seniors’ Mental Health, that these caregivers need support to maintain good physical, emotional, social and financial health. In fact, financial challenges were put forth by Angus Campbell of Caregivers Nova Scotia as one of the primary concerns expressed by caregivers. In addition, the committee notes the work of the Employer Panel for Caregivers, which was established under Employment and Social Development Canada in 2014. This panel engaged with employers to assess practices and policies that support caregivers in the workplace and encourage their full participation in the workforce. In 2015 it released its report entitled *When Work and Caregiving Collide: How Employers Can Support Their Employees Who Are Caregivers*.¹⁸

“The problems seem huge and complex, but the solutions can be very simple.”

— Jo-Anne Poirier, President, VON Canada

RECOMMENDATION 10:

The committee therefore recommends that the federal government explore fiscal options to reduce the financial stress on informal caregivers including:

- expanding the Employment Insurance compassionate care benefit beyond palliative care; and,
- amending the Caregiver Tax Credit and the Family Caregiver Tax Credit to make them refundable in order to benefit lower income Canadians.

RECOMMENDATION 11:

The committee further recommends that the federal government promote the workplace best practices identified in the 2015 report commissioned by Employment and Social Development Canada entitled *When Work and Caregiving Collide: How Employers Can Support Their Employees Who Are Caregivers*.

18 Government of Canada, *When Work and Caregiving Collide: How Employers Can Support Their Employees Who Are Caregivers*, 2015.

RECOMMENDATION 12:

The committee further recommends that the proposed Canadian Partnership to Address Dementia ensure that additional caregiver supports be promoted through the National Dementia Strategy including:

- **education and training;**
- **respite services; and,**
- **a web resource portal that provides access to information about these programs and initiatives.**

F. HOME CARE SERVICES

“The idea of home care and aging at home not only supports patients’ self-determination and aging with dignity but is generally considered less costly than institution-based care.”

— *Francine Lemire, Executive Director,
College of Family Physicians of Canada*

Testimony throughout this study indicated that access to home care services is a critical element of a national dementia strategy. Not only do individuals generally prefer to stay in their homes as long as possible, but this approach is better in terms of the progression of dementia and is less expensive than the publicly funded acute-care hospital setting,

publicly subsidized long-term care setting or the privately paid assisted-living setting.

Comprehensive coverage of home care services should include visits by health providers for care as well as rehabilitation, and personal support workers or social workers for meal preparation, assistance with transportation, and house cleaning, maintenance, etc. This support reduces the burden on informal caregivers, allows patients to remain in a familiar environment and reduces demand for other housing options.

The committee notes that the Minister of Health has a mandate to “support the delivery of more and better home care services. This includes more access to high quality in-home caregivers, financial supports for family care, and, when necessary, palliative care” and to include this within the upcoming Health Accord.¹⁹ The government has indicated its intention to invest \$3 billion over four years in home care,²⁰ however, there has been no government announcement to date on this issue. The committee notes that implementation of a home care strategy is a critical element for all seniors who would like to age at home, not only for those with dementia. In fact, comprehensive coverage for home care services would help to keep seniors who are not suffering from dementia at home longer, which would free up beds in long-term care facilities for dementia patients who require the round-the-clock care offered at these facilities. These individuals would then not be forced to stay in hospital or pay the high costs associated with memory care units in assisted-living facilities. In order to encourage innovation and implementation of publicly-funded home care, the committee suggests that the level of funding be adjusted annually using

19 Prime Minister of Canada, *Minister of Health Mandate Letter*.

20 Liberal Party of Canada, *Investing in Health and Home Care*, 2015.

a reward mechanism that acknowledges positive outcomes within each jurisdiction.

“There is enormous potential for technology-enabled home care.

The time is right, the need is now and the opportunities are endless.”

*— Nadine Henningsen, Executive Director,
Canadian Home Care Association*

RECOMMENDATION 13:

The committee therefore recommends that the federal government provide, in the upcoming Health Accord, targeted funding of \$3 billion over four years for a comprehensive package of home care services.

RECOMMENDATION 14:

The committee further recommends that the federal government require that the targeted funding for home care services under the new Health Accord be subject to regular evaluation and reporting that demonstrates effective use of funds, which will provide the basis for annual, success-based adjustments to funding.

RECOMMENDATION 15:

The committee further recommends that the federal government assess the need for home care funding beyond the initial four-year period as provincial budgets for health services and social services develop and implement integrated models of care.

RECOMMENDATION 16:

The committee further recommends that the proposed Canadian Partnership to Address Dementia engage stakeholders in promoting innovative technologies and the Home-Care-Plus model that integrates specialists in dementia care into the home care model.

G. INTEGRATION AND COORDINATION OF SERVICES

“We have to deal with symptoms in a much more multidisciplinary approach...

We have to look at how to care for this population differently.”

— *Katherine McGilton,
Senior Scientist, University Health Network*

Witnesses were clear that better integration of all aspects of dementia care can improve access to care, allow for coordination with social services, provide for a continuum of care along the whole course of the condition, allow for the optimal use of professional skills and reduce hospital admissions. However, the current system limits the ability to truly achieve an integration of services because of the separate funding envelopes for all health providers and institutions. As a result, health and social services are offered

in silos, with little or no communication or cooperation between them. As well, palliative and end-of-life care should be a part of the integration of services regardless of the patient’s place of residence as it is an essential component of the continuum of care. Existing agencies including Canada Health Infoway and the Canadian Foundation for Healthcare Improvement could provide data and expertise to accomplish this goal. Members note that seamless integration of health services requires comprehensive implementation of electronic health records, which this committee recommended in its 2014 report *Prescription Pharmaceuticals in Canada — Unintended Consequences*.²¹

“Health services in Canada are organized around providers and siloed funding envelopes as opposed to around patients and programs of care.”

— *Carolyn Pullen, Director, Policy, Advocacy and Strategy, Canadian Nurses Association*



21 Senate, Standing Committee on Social Affairs, Science and Technology, *Prescription Pharmaceuticals in Canada — Unintended Consequences*, October 2014.

RECOMMENDATION 17:

The committee therefore recommends that the federal government in collaboration with provincial and territorial counterparts:

- assess the fiscal barriers currently preventing the integration of health and social services; and,
- implement the necessary changes in order to facilitate the re-structuring necessary for integrating health and social services.

RECOMMENDATION 18:

The committee further recommends that the federal government implement recommendation 1 of the Standing Senate Committee on Social Affairs, Science and Technology's 2014 report *Prescription Pharmaceuticals in Canada — Unintended Consequences*, regarding:

- establishing targets for the implementation of electronic health and prescription drug systems;
- promoting the use of and accelerating the uptake of electronic databases by health professionals through an aggressive targeted awareness campaign; and,
- public reporting on the progress of implementing electronic health and prescription drug systems.

RECOMMENDATION 19:

The committee further recommends that the proposed Canadian Partnership to Address Dementia, within the National Dementia Strategy, promote:

- **models of dementia care that integrate healthcare delivery, such as the Dementia-plus Care Model;**
- **integration of social services into dementia care; and,**
- **a continuum of care that includes advance care planning for integrating of palliative and end-of-life care.**

increases. While the committee is optimistic that improvements in home care services will result in fewer admissions to hospital and fewer premature moves into long-term care, the aging demographic makes it imperative that immediate action be taken to improve housing options for vulnerable dementia patients. The committee agrees that investment in long-term care infrastructure is necessary and it endorses the suggestion from the Canadian Medical Association in this regard. As well, members feel that there should be greater uniformity across Canada within seniors' residences regarding accommodation, care and staffing requirements. Finally, the committee agrees that a substantial investment in infrastructure is necessary to increase long-term care capacity, that is, the \$540 million awarded on a cost-share basis as recommended by the Canadian Medical Association. Finally, that options such as flexible funding for assisted living as well as long-term care insurance should be explored.

“We should ensure that Canadians with dementia, regardless of their socio-economic status, have access to appropriate housing.”

— *Veronique Boscart, President,
Canadian Gerontological Nursing Association*

H. HOUSING

“We all need to work collaboratively to find affordable solutions that are respectful of the choices, needs and dignity of seniors living with dementia in Canada.”

— *Laurie Johnston, Chief Executive Officer,
Ontario Retirement Communities Association*

The committee is concerned about the high number of people in acute-care hospitals waiting for a vacancy in long-term care and by the high cost associated with assisted-living options. The current housing situation for individuals with dementia who cannot remain in their homes is strained, and will continue to worsen as the population ages and the number of Canadians suffering from dementia

RECOMMENDATION 20:

The committee therefore recommends that the federal government invest \$540 million in continuing care infrastructure to increase the capacity for long-term care in provinces and territories.

RECOMMENDATION 21:

The committee further recommends that the proposed Canadian Partnership to Address Dementia ensure that the National Dementia Strategy includes efforts to:

- **examine and update as necessary the staffing, care and accommodation standards applied to seniors' residences, including legislation and regulations; and,**
- **explore and assess a range of opportunities to improve access to seniors' housing.**

The committee notes that access to health and social services in rural and remote communities is limited. This observation is particularly concerning given that rural and remote communities often have proportionally more seniors than urban centres, and seniors require more healthcare services than younger Canadians. Further, residents in these communities are less likely to choose assisted-living or long-term care residences since such a move would likely require them to be located quite a distance from family and friends and a familiar environment. For dementia patients in rural and remote communities, access to integrated services either at home or via telehealth or mobile health technologies should be enhanced. The committee notes that the Minister of Innovation, Science and Economic Development has a mandate to increase high-speed broadband coverage in Canada²² and that Budget 2016 announced an investment of \$500 million over five years, beginning in 2016-17, in this regard.²³

1. RURAL AND REMOTE COMMUNITIES

“Remote communities face incredible challenges when caring for older adults.”

*— Wayne Warry, Director,
Centre for Rural and Northern Health
Research, Laurentian University*

“With respect to First Nations being so disadvantaged and underdeveloped, with the Internet we have Telehealth in the North and it seems to be helpful.”

*— Isadore Day,
National Health Portfolio Holder,
Assembly of First Nations Regional Chief,
Ontario, Assembly of First Nations*

22 Prime Minister of Canada, *Minister of Innovation, Science and Economic Development Mandate Letter*.

23 Department of Finance, *Budget 2016: Growing the Middle Class, Chapter 2: Growth for the Middle Class*, Ottawa, 22 March 2016.

RECOMMENDATION 22:

The committee therefore recommends that the proposed Canadian Partnership to Address Dementia include within the National Dementia Strategy the assessment and promotion of specific models of dementia care for rural and remote communities including that of Rural and Remote Memory Clinics.

RECOMMENDATION 23:

The committee further recommends that the federal government expedite the funding of the new program to enhance high-speed broadband coverage throughout Canada.

general population. As mentioned earlier, the rate of dementia is significantly higher in the First Nation population and the rate is higher for men than for women in these communities. Committee members were told that the symptoms, experiences and disease progression of dementia are consistent with Indigenous culture, world view and of the circle of life and that dementia is accepted as a natural part of many individuals' life course. Members were told that being cared for by family and friends within the community is particularly important and that other housing options are not acceptable. Therefore, sufficient resources must be provided in order to deliver culturally appropriate home and community care. The committee is concerned that the federal government has not ensured that the funding for the Home and Community Care Program, run by Health Canada's First Nations and Inuit Health Branch, has kept pace with population levels of Indigenous communities.

"It's not the traditional way to place a family member in a nursing home. It's not something that was taught to us."

*— Norma Rabbitskin, Senior Health Nurse,
Sturgeon Lake First Nation Health Centre*

J. FIRST NATIONS COMMUNITIES

"In my experience, I find it's often the Aboriginal communities that are the most dementia friendly."

*— Andrew Kirk, Professor,
University of Saskatchewan*

Many First Nations communities are located in rural and remote areas and therefore have many of the same challenges as the communities described above. However, First Nations people are affected by and respond differently to dementia than the

RECOMMENDATION 24:

The committee therefore recommends that the Home and Community Care Program, delivered by Health Canada’s First Nations and Inuit Health Branch:

- **be funded to reflect current Indigenous population levels; and,**
- **permit and encourage innovative approaches to program delivery.**

equipped for dementia care and often have not provided their staff with the skills and information they need to provide such care.

RECOMMENDATION 25:

The committee therefore recommends that the proposed Canadian Partnership to Address Dementia work with Accreditation Canada, within the context of the National Dementia Strategy, to develop standards of dementia care for acute-care hospitals.

K. TRAINING OF HEALTH PROFESSIONALS

“There is a need for more training, and we need to make sure that the educational content of all university and college programs ...include caring for persons with dementia in their curriculum.”

*— Marie-France Tourigny-Rivard, Member,
Canadian Academy of Geriatric Psychiatry*

The committee is concerned that there will continue to be a lack of specially trained health professionals to attend to the need of Canada’s aging population. Not only are there insufficient numbers of health professionals being trained for geriatric specialties, but in some cases, basic education does not include elder care. As well, acute-care hospitals, where too many individuals are spending too much time waiting for a long-term care bed, are not

RECOMMENDATION 26:

The committee further recommends that the proposed Canadian Partnership to Address Dementia, within the context of the National Dementia Strategy, in collaboration with provincial governments, medical faculties, nursing programs, and their regulatory and licensing bodies, address health human resource capacity, training and professional development with respect to aging and dementia care.

L. BEST PRACTICES PLATFORM

“There is a lot of great work being done across the country, but there is nowhere to bring it together.”

— Mimi Lowi-Young, Chief Executive Officer, Alzheimer Society of Canada

The committee is encouraged by the considerable amount of great work on dementia that is going on all around the country. However, it is also discouraged by the lack of any coordinated effort to share best practices in this area. A considerable number of witnesses called for the creation of a best practices platform.

RECOMMENDATION 27:

The committee therefore recommends that the proposed Canadian Partnership to Address Dementia ensure the development, implementation and promotion of a secure Best Practices Portal available to health and social service providers of dementia care.

RECOMMENDATION 28:

The committee further recommends that the Canadian Partnership to Address Dementia consider the programs and practices listed in Appendix 1 for inclusion in the proposed Best Practices Portal.

M. A FINAL THOUGHT

“The person with dementia must be heard.”

— Shekhar Saxena, Director, Department of Mental Health and Substance Abuse, World Health Organization

RECOMMENDATION 29:

The committee therefore recommends that the proposed Canadian Partnership to Address Dementia ensure that persons with dementia are included in all aspects of its work.

Conclusion

Dementia currently affects close to one million Canadians, robbing them of their quality of life and stretching our social, health and housing resources. Decisive action by the federal government is urgently needed as the proportion of seniors continues to grow over the next two decades.

Now is the time for Canada to implement a National Dementia Strategy. An impressive amount of work has been done by healthcare professionals, researchers, dementia advocates, housing providers and governments of all levels. However, a greater coordination of efforts is essential to effectively meet the oncoming surge in dementia cases. The World Health Organization has labelled this

situation a public health priority. In response, the Government of Canada must lead the way by working with all jurisdictions and relevant stakeholders to implement a National Dementia Strategy. Such a strategy would help to ensure adequate care for individuals suffering from dementia, the availability of appropriate housing options, funding for research and innovation to develop treatments and disease management, and facilitate the translation of new discoveries into practice. This committee notes a lack of innovation in the delivery of healthcare and would like to see incentives such as performance-based funding to encourage changes in how the healthcare system approaches the evolving needs of Canadians.



APPENDIX 1: Programs and Initiatives Highlighted in this Report

Program/Initiative	URL to the program or for further information
Alzheimer Society's 10 warning signs	http://www.alzheimer.ca/en/About-dementia/Alzheimer-s-disease/10-warning-signs
Blue Umbrella	http://www.alzheimer.ca/~media/Files/chapters-on/pklnh/job%20posting/Release%2023%20Feb%202015%20%20Alzheimer%20Staff%20has%20New%20Role.pdf
Butterfly model	http://www.dementiacarematters.com/pdf/modern.pdf
C.A.R.E. Tool (Caregivers' Aspirations, Realities and Expectations Tool)	http://www.cihr-irsc.gc.ca/e/48555.html
Cogniciti Brain Health Assessment	https://cogniciti.com/
Dementia friendly communities	http://www.alz.co.uk/dementia-friendly-communities
Dementia Friends Canada	www.dementiafriends.ca
Dementia villages	http://dementiavillage.com/
First Link®	http://www.alzheimer.ca/~media/Files/national/Core-lit-brochures/ASC_first_link_e.pdf
GEM Plus	http://www.canadiangeriatrics.ca/default/assets/File/CJG-CME%20Vol4-2%20Wilding(3).pdf
New Brunswick's Home First Strategy	http://www2.gnb.ca/content/gnb/en/departments/social_development/promos/home_first.html
Memory Cafés	https://www.alzheimersspeaks.com/memory-cafes
Memory Cafés New Brunswick	http://www.alzheimer.ca/en/nb/We-can-help/Support/memory-cafe
Minds in Motion	http://www.alzheimer.ca/en/on/We-can-help/Minds-In-Motion
Montreal Cognitive Assesment tool (MoCA)	www.mocatest.org
Rural Dementia Action Research (RaDAR)-Rural and Remote Memory Clinic	http://www.cchsa-ccssma.usask.ca/ruraldementiacare/radar.html
Speak Up — Advance Care Planning	http://www.advancecareplanning.ca/resource/acp-workbook/
Still Here Campaign	http://www.alzheimer.ca/stillhere
The Way Forward-Integrated Palliative Approach	http://www.hpcintegration.ca/

APPENDIX 2:

List of Recommendations

RECOMMENDATION 1:

The committee therefore recommends that the federal government immediately establish the Canadian Partnership to Address Dementia with a mandate to create and implement a National Dementia Strategy.

RECOMMENDATION 2:

The committee further recommends that the federal government, when establishing the Canadian Partnership to Address Dementia, take into consideration the structure and function of the Canadian Partnership Against Cancer, however the new organization must:

- include representation from, but not be limited to, federal, provincial and territorial governments, dementia and other health-related organizations, individuals affected by dementia and their caregivers, healthcare professionals, housing organizations, researchers and the Indigenous community;
- be required to evaluate, report on and update the strategy annually; and,
- receive adequate federal funding of at least \$30 million annually.

RECOMMENDATION 3:

The committee further recommends that the federal government adjust the annual funding provided to the proposed Canadian Partnership to Address Dementia in response to annual evaluations and strategy updates.

RECOMMENDATION 4:

The committee therefore recommends that the proposed Canadian Partnership to Address Dementia, in its development and creation of Canada's National Dementia Strategy, be guided by:

- the Alzheimer Society of Canada's *The Canadian Alzheimer's Disease and Dementia Partnership: Strategic Objectives*, and
- Alzheimer's Disease International's report *Improving Dementia Care Worldwide: Ideas and Advice on Developing and Implementing a National Dementia Plan*.

RECOMMENDATION 5:

The committee therefore recommends that the federal government allocate to the Canadian Institutes of Health Research's Dementia Research Strategy, as a component of the proposed National Dementia Strategy, 1% of current direct dementia care costs, or approximately \$100 million annually.

RECOMMENDATION 6:

The committee therefore recommends that the Public Health Agency of Canada create and implement, within the National Dementia Strategy, a comprehensive public awareness campaign that includes promotion of the Dementia Friends Canada website as well as high-visibility/high-impact approaches regarding prevention, early diagnosis, symptom recognition, quality of life, and services and supports.

RECOMMENDATION 7:

The committee further recommends that, with respect to prevention strategies, the federal government implement recommendations 20 and 21 of the Standing Senate Committee on Social Affairs, Science and Technology's 2016 report entitled *Obesity in Canada: A Whole-of-Society Approach for a Healthier Canada*, by:

- designing and implementing a public awareness campaign on healthy eating based on tested, simple messaging, and
- implementing a comprehensive public awareness campaign on healthy active lifestyles in collaboration with other relevant departments, agencies, experts and trusted organizations.

RECOMMENDATION 8:

The committee therefore recommends that the federal government ensure that Public Health Agency of Canada receive adequate resources for the Canadian Chronic Disease Surveillance Program so that it can provide robust, timely and accessible dementia surveillance data beginning in 2017.

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The committee further recommends that the proposed Canadian Partnership to Address Dementia ensure that additional caregiver supports be promoted through the National Dementia Strategy including:

- education and training;
- respite services; and,
- a web resource portal that provides access to information about these programs and initiatives.

RECOMMENDATION 13:

The committee therefore recommends that the federal government provide, in the upcoming Health Accord, targeted funding of \$3 billion over four years for a comprehensive package of home care services.

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The committee further recommends that the federal government require that the targeted funding for home care services under the new Health Accord be subject to regular evaluation and reporting that demonstrates effective use of funds, which will provide the basis for annual, success-based adjustments to funding.

RECOMMENDATION 15:

The committee further recommends that the federal government assess the need for home care funding beyond the initial four-year period as provincial budgets for health services and social services develop and implement integrated models of care.

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The committee further recommends that the proposed Canadian Partnership to Address Dementia engage stakeholders in promoting innovative technologies and the Home-Care-Plus model that integrates specialists in dementia care into the home care model.

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The committee therefore recommends that the federal government in collaboration with provincial and territorial counterparts:

- assess the fiscal barriers currently preventing the integration of health and social services; and,
- implement the necessary changes in order to facilitate the restructuring necessary for integrating health and social services.

RECOMMENDATION 18:

The committee further recommends that the federal government implement recommendation 1 of the Standing Senate Committee on Social Affairs, Science and Technology's 2014 report *Prescription Pharmaceuticals in Canada — Unintended Consequences*, regarding:

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- public reporting on the progress of implementing electronic health and prescription drug systems.

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- a continuum of care that includes advance care planning for integrating of palliative and end-of-life care.

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The committee further recommends that the proposed Canadian Partnership to Address Dementia ensure that the National Dementia Strategy includes efforts to:

- examine and update as necessary the staffing, care and accommodation standards applied to seniors' residences, including legislation and regulations; and,
- explore and assess a range of opportunities to improve access to seniors' housing.

RECOMMENDATION 22:

The committee therefore recommends that the proposed Canadian Partnership to Address Dementia include within the National Dementia Strategy the assessment and promotion of specific models of dementia care for rural and remote communities including that of Rural and Remote Memory Clinics.

RECOMMENDATION 23:

The committee further recommends that the federal government expedite the funding of the new program to enhance high-speed broadband coverage throughout Canada.

RECOMMENDATION 24:

The committee therefore recommends that the Home and Community Care Program, delivered by Health Canada's First Nations and Inuit Health Branch:

- be funded to reflect current Indigenous population levels; and,
- permit and encourage innovative approaches to program delivery.

RECOMMENDATION 25:

The committee therefore recommends that the proposed Canadian Partnership to Address Dementia work with Accreditation Canada, within the context of the National Dementia Strategy, to develop standards of dementia care for acute-care hospitals.

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The committee further recommends that the proposed Canadian Partnership to Address Dementia, within the context of the National Dementia Strategy, in collaboration with provincial governments, medical faculties, nursing programs, and their regulatory and licensing bodies, address health human resource capacity, training and professional development with respect to aging and dementia care.

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The committee therefore recommends that the proposed Canadian Partnership to Address Dementia ensure the development, implementation and promotion of a secure Best Practices Portal available to health and social service providers of dementia care.

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The committee further recommends that the Canadian Partnership to Address Dementia consider the programs and practices listed in Appendix 1 for inclusion in the proposed Best Practices Portal.

RECOMMENDATION 29:

The committee therefore recommends that the proposed Canadian Partnership to Address Dementia ensure that persons with dementia are included in all aspects of its work.



APPENDIX 3: List of Witnesses

Wednesday, March 9, 2016	
Canadian Institutes of Health Research	Dr. Yves Joanette, Scientific Director of the CIHR Institute of Aging, Chair of the World Dementia Council
Public Health Agency of Canada	Rodney Ghali, Director General, Centre for Chronic Disease Prevention
Thursday, March 10, 2016	
World Health Organization	Dr. Shekhar Saxena, Director, Department of Mental Health and Substance Abuse
Wednesday, March 23, 2016	
Alzheimer Society of Canada	Mimi Lowi-Young, Chief Executive Officer
Canadian Coalition for Seniors' Mental Health	Bonnie Schroeder, Executive Director
Women's Brain Health Initiative	Lynn Posluns, Founder and President
Thursday, March 24, 2016	
Canadian Medical Association	Dr. Chris Simpson, Past President
Canadian Nurses Association	Carolyn Pullen, Director, Policy, Advocacy and Strategy
College of Family Physicians of Canada	Dr. Francine Lemire, Executive Director and Chief Executive Officer
As an Individual	Dr. Frank Molnar, Vice-President, Canadian Geriatrics Society
Wednesday, April 13, 2016	
Canadian Academy of Geriatric psychiatry	Dr. Marie-France Tourigny-Rivard, Geriatric Psychiatrist and Professor, Department of Psychiatry, Division of Geriatric psychiatry, Ottawa University
Canadian Association on Gerontology	Dr. Suzanne Dupuis-Blanchard, Professor
Canadian Gerontological Nursing Association	Veronique Boscart, President
Thursday, April 14, 2016	
Alzheimer's Disease International	Marc Wortmann, Executive Director
Wednesday, April 20, 2016	
Assembly of First Nations	Isadore Day, National Health Portfolio Holder, AFN Regional Chief, Ontario
	Norma Rabbitskin, Senior Health Nurse, Sturgeon Lake First Nation Health Centre
As Individuals	Dr. Andrew Kirk, Professor and Head, Division of Neurology, University of Saskatchewan, Rural Dementia Action Research Network (RaDAR)
	Wayne Warry, Director, Centre for Rural and Northern Health Research, Laurentian University

Thursday, April 21, 2016	
Canadian Home Care Association	Nadine Henningsen, Executive Director
	Susan May, National Director, GE Healthcare
VON Canada	Jo-Anne Poirier, President and CEO
Wednesday, May 4, 2016	
Alberta Seniors Communities & Housing Association (ASCHA)	Irene Martin-Lindsay, Executive Director
Ontario Retirement Communities Association	Laurie Johnston, Chief Executive Officer
Thursday, May 5, 2016	
Canadian Hospice Palliative Care Association	Louise Hanvey, Project Manager
Ontario Long Term Care Association	Candace Chartier, Chief Executive Officer
Wednesday, May 11, 2016	
Caregivers Nova Scotia	Angus Campbell, Executive Director
HealthCareCAN	Dr. William E. Reichman, President and Chief Executive Officer, Baycrest Health Sciences
As an Individual	Katherine McGilton, Senior Scientist, Associate Professor, Toronto Rehabilitation Institute – University Health Network
Thursday, May 12, 2016	
Alzheimer Society of New Brunswick	Ken McGeorge, Acting Executive Director
As an Individual	Dr. Frank Molnar, Vice-President, Canadian Geriatrics Society
Wednesday, May 18, 2016	
Ontario Dementia Advisory Group (ODAG)	Phyllis Fehr, Board Member
	Bill Heibein, Board Member
	Bea Kraayenhof, Board Member
	Mary Beth Wighton, Board Member
Thursday, June 2, 2016	
Government of Scotland (Edinburgh)	David Berry, Policy Officer, Dementia Policy Unit
As an Individual	Dr. Ronald C. Petersen, Chair, Advisory Council on Research, Care and Services for the US National Plan to Address Alzheimer’s Disease

APPENDIX 4: Briefs

- Alzheimer’s Disease International
- Assembly of First Nations
- Canadian Gerontological Nursing Association
- Canadian Medical Association
- Canadian Nurses Association
- Caregivers Nova Scotia
- HealthCareCAN
- Heart and Stroke Foundation
- Kirk, Dr. Andrew (as an individual)
- Molnar, Dr. Frank (as an individual)
- Ontario Dementia Advisory Group (ODAG)
- Parkinson Canada
- Rochon, Dr. Paula (as an individual)

Copies of the briefs submitted to the committee can be found on the committee’s website **here**.





CANADA

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