

Canadian Academy of Health Sciences  
Académie canadienne des sciences de la santé



Commissioned Reports

Addendum to the CAHS Assessment on

# IMPROVING THE QUALITY OF LIFE AND CARE OF PERSONS LIVING WITH DEMENTIA AND THEIR CAREGIVERS



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**Addendum to the CAHS Assessment on**

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The commissioned papers were read by the CAHS Expert Panel and informed their work. Components were integrated within the final report, but the commissioned papers are separate documents and reflect the opinions of their authors, not necessarily the CAHS. These commissioned papers are presented in the language they were received by the panel. They are listed in the order in which they appear in the assessment report.

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## APPENDIX A

# Rural Dementia Care

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With a higher proportion of seniors in rural areas compared to urban<sup>1</sup> and increasing risk of dementia with age, more people in rural communities are at risk for dementia. Yet rural and remote communities face significant challenges in meeting the needs of people and their caregivers, as a result of geographic, demographic, social, and economic factors (see Table 1). Although consideration of rural and remote issues applies to all the topics included in the CAHS report outline, in-depth coverage of all relevant research is not feasible in this summary.

The need to specifically address the unique challenges of dementia care in rural and remote communities has been recognized in the Alberta Dementia Strategy, the Nova Scotia Dementia Strategy, and the Senate Report on Dementia in Canada.<sup>2</sup> The Senate Report includes a recommendation that the Canadian dementia strategy include the assessment and promotion of specific models for rural and remote communities.

Two systematic reviews of rural dementia care research are available. A review of formal service provision for dementia in rural and remote settings identified lack of access to timely diagnosis and management, service delivery challenges (distance, shortage of skilled staff, limited specialist access, lack of services for people with early onset dementia and minority groups), and lack of educational opportunities for health care providers.<sup>3</sup> A review of informal/family dementia care in rural and remote settings found low service use, gaps in service provision, and available services not meeting needs.<sup>4</sup> Challenges included lack of community-based services, time and cost of travel to services, stigma and isolation, lack of privacy, poor coordination of services, and lack of education and support for caregivers.

Most research on rural dementia care to date has been small-scale descriptive studies focused on understanding the experiences, use, and barriers to accessing formal services.<sup>4</sup> These studies provide important information on gaps and needs that can inform policy, practice, and research. There are few intervention/evaluation studies to address identified gaps, but research is growing and there are emerging best practices. Three key issues can be identified that, if addressed, could significantly improve dementia care in rural settings.

## KEY ISSUES

### Access to Timely Diagnosis

Obtaining a dementia diagnosis is often challenging for rural people.<sup>5-7</sup> Although Canadian guidelines indicate that initial assessment should be conducted by the primary care provider, many family physicians do not feel confident in making a dementia diagnosis.<sup>8</sup> Potential strategies for improving access to timely diagnosis in rural settings include: increasing the capacity of rural PHC providers; developing interdisciplinary rural PHC teams; increasing remote education and support to PHC providers by specialists; increasing PHC provider access to decision support tools; and developing rural memory clinics. Some examples of published approaches for improving access to diagnosis in rural areas include:

- In Saskatchewan, an urban-based interdisciplinary one-stop Rural and Remote Memory Clinic provides specialist diagnosis of complex, atypical dementias for individuals living in rural and remote areas of the province.<sup>9</sup> Follow-up is provided via telehealth videoconferencing.<sup>10</sup>
- In Ontario, a primary health care model is helping to build capacity in primary care teams to support diagnosis, treatment, and care for people with in their community. This model is being expanded to rural and remote communities in the province.<sup>11</sup>

- In Austria, Rural Dementia Services Centres provide screening and referral for dementia diagnosis; 80% of those receiving a baseline evaluation subsequently received a diagnosis.<sup>12</sup>
- A scoping review of technology-based interventions for remote dementia screening concluded that telephone screening can be used to refer people with suspected dementia for diagnostic workup and that videoconference approaches could be used to diagnose dementia.<sup>5</sup> The review identified only two RCTs and most studies were small.
- The role of primary health care (PHC) is critical in rural settings because of lack of access to specialist and other services.<sup>13</sup> The role of coordination of health and social care is best embedded at the level of PHC, where providers know the person with dementia, the family, and the rural context.<sup>13</sup>
- Studies conducted in rural northern Ontario found that informal social networks help to sustain people with dementia in their homes but they do not replace the formal support systems,<sup>20</sup> and identified a need for access to a wider range and frequency of services, and more awareness of available supports.<sup>15,21</sup>

### **Support and Education for Individuals with Dementia and Caregivers**

Lack of access to post-diagnostic support services and education, and lack of coordination and integration of existing services are consistent findings in rural dementia studies.<sup>13-15</sup> Case management and system navigation are especially critical in rural settings, but there is limited research to date on rural-specific strategies.

- In Austria, Rural Dementia Services Centres have been successful in providing locally accessible screening and referral for diagnosis; post-diagnostic education, counselling, programs, support groups, and care coordination for people with dementia and families.<sup>12</sup>
- In Australia, a Dementia Outreach Service has provided services to people with early-stage dementia and their caregivers for over 10 years. Key principles include early intervention, outreach, clinical expertise, multidisciplinary team, and building a cohesive dementia sector by linking clients and health care providers, and linking community partners.<sup>16</sup>
- The Alzheimer Society First Link program provides important coordination and navigation functions.<sup>17</sup> Providing and accessing the service in rural areas can present additional challenges, including higher costs in time and human resources.<sup>18</sup>
- An evaluation of a telehealth support group for spouses of early onset, atypical dementias found that this approach was feasible and effective<sup>19</sup> and was subsequently adopted by the Alzheimer Society of Saskatchewan.

### **Access to Education and Specialist Support for Rural Health Care Providers (Building Capacity)**

Given the limited access to specialized dementia services in rural areas,<sup>3</sup> developing the capacity of rural providers is key to increasing their comfort and competency in delivering high quality care. Remote education and case-based support could improve rural access but there is limited evaluation research to date. A recent systematic review<sup>5</sup> identified several approaches to provide dementia education and support to rural providers:

- an online tool to guide dementia assessment and diagnosis is currently being evaluated.<sup>22</sup>
- distance learning to train rural primary care providers in dementia screening and assessment resulted in increased screening, moderate increase in diagnoses, and improved confidence in diagnosing.<sup>8</sup>
- 3-day in-person training program for rural health care professionals showed increased use of screening tools, and increased knowledge and confidence to diagnose and treat dementia.<sup>2</sup>

**Table 1: Some Unique Rural Dementia Care Challenges**

**Low Population Density**

- economies of scale make it difficult for communities to offer specialized services
- limits individual anonymity
- decreases opportunities for socialization
- increases possibility of social isolation
- Older population (with cognitive and functional limitations)
- hinders ability to travel outside of community for services

**Limited Transportation Options**

- hinders access to health and social services

**Limited Social Support**

- adult children/relatives may live in a different community
- peers are also aging and may move to long-term care in different community
- local health and social services may not have the capacity necessary to provide additional support

**Limited Health and Social Service Resources**

- specialists are mainly urban-based
- choice of primary care provider is limited
- home care limited to basic services and may not be available as often as needed
- limited institutional care (day programs, night respite, long-term care)
- limited social services and community programs, e.g., Alzheimer Society programs are not available in every community and not offered as frequently as some may like. There are few opportunities to increase awareness and education

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## APPENDIX B

# Literature Review: Alzheimer's Disease Policies in OECD Countries: Executive Summary and Key Learnings

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Alzheimer's disease (AD) and other major neurocognitive disorders (NCDs) pose significant challenges as the number of people living with Alzheimer's disease is rapidly increasing. Alzheimer's disease is incurable and has biopsychosocial implications for those affected. This obviously raises a multitude of issues for persons with AD and their families, but from a societal point of view, these issues require developing collective solutions by transforming communities, developing better organizational practices and adopting renewed public policies. It is in this spirit that since the early 2000s some governments have adopted action plans for these diseases.

We conducted a literature review with the objective of understanding the social dynamics that led to the adoption of public policies, identifying their main areas of action, and exploring how these measures are actually implemented. This report presents the results of the literature review in four main sections:

### The Literature Review Strategy

We used three types of documentary data: 1) 57 scientific articles that focused on the process of recognizing the social problem of AD and NCDs, the political agenda, content, implementation and effects<sup>1</sup>; 2) two reports published by international organizations; and 3) action plans for these diseases which have been adopted by eight of the ten Canadian provinces. We analyzed these documents using a grid based on a public policy analysis model, and the main areas of public policy as identified by the World Health Organization (WHO).

### How AD and NCDs Came to Appear on the Political Agenda, Their Emergence as a Social Problem and the Adoption of Dedicated Public Policies

From 1900 to 1970, AD and NCDs were mainly perceived as a state of madness associated with old age. The boom in medical research in this area in the following decades changed the social representations and contributed to the recognition of the pathological nature. The dissociation of normal aging from cognitive disorders has contributed to the development of associative movements along with increased media attention. Although AD and NCDs emerged as a social problem in the second half of the 20<sup>th</sup> century, the importance of the psychosocial needs of those living with their impact was diminished in public policy and in the care provided. However, recognition of these needs has grown since the early 2000s, and many governments have adopted action plans. Several scientific

1 The majority of articles focuses on the content of action plans.

articles propose that the participation of people with Alzheimer's disease, their families and the organizations that make their voices heard in the policy making process, is a particularly favourable condition for the recognition of their needs and their expertise. Governments must, however, develop mechanisms that effectively support the ability of these actors to act, rather than simply delegating responsibilities to them.

The key learnings in this section are:

- Between 1900 and 1970, Alzheimer's disease (AD) and other major neuro-cognitive disorders (NCDs) were the subject of very few social and political concerns. The medicalization of these diseases and the rise of the associative movement during the years from 1970 to 2000, contributed to their recognition as a social problem. However, psychosocial needs were sparsely addressed until around the year 2000, when these diseases became part of the political agenda.
- Since the early 2000s, 27 national governments have adopted action plans for AD and NCDs, not to mention the plans adopted by subnational governments. For example, in Canada, eight of the ten Canadian provinces have adopted action plans. The province of Ontario was the first to adopt a plan, in 1999.
- In 2017, the Canadian government passed legislation requiring the adoption of a national strategy in this area. Sustained collaboration between the federal and provincial governments will be required to avoid potential duplication.
- Several scientific articles show that the participation of civil society facilitates the development of an action plan. Seeking out and recognizing the expertise of people living with AD and their families, enables the design of public policies that are better adapted to the needs of the people concerned.

## Action Plans - Comparison and Identification of Predominant Trends

In a report by the WHO, seven main areas were identified: 1) dementia as a public health priority; 2) dementia awareness and friendliness; 3) dementia risk reduction; 4) dementia diagnosis, treatment, care and support; 5) support for dementia carers; 6) information systems for dementia; and 7) dementia research and innovation (World Health Organization, 2017). These areas transcend action plans for AD and other major NCDs, and are thus broadly convergent, although WHO recommends that governments operationalize them in concrete measures adapted to their political, sociosanitary, population and territorial realities. We observed that measures to improve early phases of the care and service trajectory, such as improved diagnosis, are the focus of the action plans. Improved diagnosis is usually put in place too late, constituting a major obstacle to the implementation of follow-up adapted for people living with the repercussions of these diseases. This explains why diagnostic measures are almost universally promoted in public policies, under various conceptual arrangements. However, several action plans have not given the same importance to the development of care and services, following diagnosis, and this can generate feelings of helplessness. A holistic approach to the needs of people living with AD and NCDs, requires public policies to reflect the same intensity in all of the main areas. This can be achieved using the concepts of dementia capable, dementia friendly and dementia positive. These shared concepts are useful in functional components, in transforming the physical and social environment, and in recognizing that people with Alzheimer's disease deserve to live a fulfilling life. This approach is key for people living with these diseases, and their loved ones, to fully exercise their remaining abilities and live with dignity.



The key learnings in this section are:

- The main areas of the various action plans are broadly convergent. The experience of other jurisdictions is very useful in inspiring interested governments to develop an action plan. Many experts and studies recommend that policymakers draw a portrait of the situation in their jurisdiction, and translate and operationalize the major normative orientations into concrete measures, adapted to their political, social, population and territorial realities.
- The measures in the action plans most widely promoted are diagnosis, workforce training, and access to care. Action in these three areas is an obvious prerequisite for implementing adapted follow-up care, yet follow-up is at times overlooked in these plans.
- Despite the fact that the psychosocial needs of people living with the repercussions of AD and NCDs are better recognized now than in the 20<sup>th</sup> century, some action plan measures focus on the cure and the biomedical model. In Canadian provincial action plans, the biopsychosocial aspects are generally well thought-out. The concepts of dementia capacity, dementia friendly and positive dementia are particularly interesting for a holistic approach that fully considers the needs of people living with these diseases.

## Policy Implementation Process

The first characteristic of effective implementation of an action plan is the adequate investment of financial resources. The second determinant is the development of a national steering committee, which serves to coordinate numerous departments and partners in various levels of government involved in the implementation of change. The committee helps plan activities implemented, address issues encountered, and monitor and follow up on changes made. The third determinant is the development of a strategy to support change. Several governments have developed projects that experiment with change in practices. Projects that stand out are identified and the conditions of change and implementation are understood, with a view to scaling up. Based on learnings from the literature review, governments need to consider four major aspects when engaging in this type of strategy: 1) mobilizing local actors

is crucial to rooting change in local realities; 2) change needs to be flagged and actors must be supported to fully achieve the fundamental objectives of public policy; 3) experimental projects must be rigorously evaluated to draw meaningful learning from them; and 4) large-scale dissemination of innovative practices must mobilize the same type of implementation strategy and maintain the importance of the conceptual foundations on which the experimental projects were based. The policy implementation process must be a priority for governments since the real action to effectively improve the quality of life of people living with the repercussions of AD and NCDs can be realized only by the effective implementation of the measures proposed in the action plans.

The key learnings in this section are:

- Several scientific articles reveal that implementation of an action plan is greatly facilitated if the targeted actions are precise and well-embodied in the populational particularities of the jurisdiction, and if the various stakeholders are actively involved in the realization of these projects.
- Many governments have adopted action plans on AD and NCDs, in a context of national and international mobilization, although implementation varies widely. Scientific articles identify three major measures to facilitate the implementation of action plans: 1) allocation of sufficient financial resources that are well-distributed in the action areas; 2) set up of a committee to pilot the implementation; and 3) development of implementation strategies to support changes in practice.
- Regarding implementation strategies, some governments have developed experimental projects to determine best practices and implementation conditions, followed by national dissemination of results. Scientific articles indicate four major aspects that policymakers need to take into account when undertaking this strategy: 1) the mobilization of local actors is crucial to root the changes in local realities; 2) the changes must be tagged and local actors must embody the fundamental objectives of public policy; 3) these experimental projects must be rigorously evaluated to draw meaningful learnings from them; and 4) the large-scale dissemination of innovative



practices must mobilize the same implementation strategy and maintain the importance of the conceptual foundations on which the experimental projects were based.

- Two scientific articles have shown a positive influence resulting from the implementation of action plans. In England, the number of people diagnosed has increased significantly and in France, both diagnoses and the number of scientific publications have increased significantly. This makes it possible to precisely demonstrate that the anticipated effects of certain action plans translate into real effects.
- Several studies have compared the content of the action plans. To our knowledge, no study has compared the evaluation of plans between the countries of the Organization for Economic Cooperation and Development, or between Canadian provinces. Such a study would promote a better understanding of the types of evaluations mobilized by governments, the actual measures that were implemented, and the conditions which favoured their implementation.

## APPENDIX C

# Current Evidence on Alzheimer's Disease and Its Related Dementias (ADRD) and Indigenous Populations in Canada

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### HIGHLIGHTS

- The available evidence suggests that when compared to the majority population, dementia is 34% higher in First Nations populations, increasing at faster rates, has a 10-year earlier/younger age of onset, and males have higher rates of diagnosis.
- An aging Indigenous population is an important factor in the increasing incidence of dementia, however, the dementia equity gap is widened by several contributing intermingling risk factors including high rates of related chronic diseases and increased vulnerability to the impacts of social determinants of health, including poverty, lower levels of formal educational attainment, low rates of health literacy, and potentially increased rates of post-traumatic stress.
- Indigenous cultural understandings of dementia differ from mainstream biomedical understandings and approaches. Cultural values emphasize acceptance and inclusion and can foster a strong community-based caregiving model when adequately resourced and supported.
- Mainstream (i.e., western biomedical) health services and approaches to care are most often culturally unsafe spaces for older Indigenous adults, especially for those with dementia, which results in delays seeking diagnosis and/or services and supports.
- Informal caregiving is the most common response to dementia in Indigenous communities. There is a preference to remain in the community setting, with family and friends, and engaged in community life.
- Informal caregivers often have not been trained in providing care to a PWD, and formal health care providers are rarely trained in cultural safety or culturally sensitive dementia care.
- Long-term care facilities are considered a last resort and can be associated with traumatic memory of residential school, and other institutional experiences (jails, TB sanatoriums).
- Indigenous people in Canada are faced with inequitable access to health care. Services specific to dementia are rare. Availability of specialists varies by place, but First Nations peoples in rural and remote communities have reduced access for accurate diagnosis, follow-up, and care.

- Culturally-grounded, strength-based approaches are appropriate. Indigenous people with dementia will benefit from information, programming and services respectful of their personal histories, community context, and culture. In particular, culturally adapted health promotion materials and programming, screening and diagnostic procedures, and care are needed.
- Greater investments in Indigenous dementia research are warranted. There are considerable gaps in all research areas for Indigenous peoples including, but not limited to: epidemiological, health services (especially culturally appropriate diagnosis and care and strength-based approaches), policy, intergenerational studies, multi-level intervention, social determinants of health, and research specific to Inuit and Métis populations.

## BACKGROUND

In recent years there has been an increased emphasis on the acknowledgment of a destructive history of relations between Indigenous<sup>1</sup> peoples and non-Indigenous peoples in Canada. Dating back to 1991 the Royal Commission on Aboriginal Peoples (RCAP) was established in Canada to investigate the history of relations between Aboriginal and non-Aboriginal peoples, policies and programs that harmed those relationships, and the consequences of these actions on Indigenous peoples and communities (1; 2). The Commission detailed the gross inequities in health and social-economic conditions for Indigenous peoples and recommended a political framework grounded in empowerment and self-determination in order to repair relations and improve outcomes. In 2008, the Canadian government formally apologized for the specific policy known as the Indian Residential School policy which led to the separation of Indigenous children from their families and communities resulting in a century long struggle to regain and reignite Indigenous culture and community in Canada (3). The government admitted this was one of the state's formal policy attempts to forcibly assimilate Indigenous peoples. A class action suit against the Government of Canada resulted in the Indian Residential School Settlement

Agreement, which allocated funding for the creation of a Truth and Reconciliation Commission (TRC). The TRC resulted in years of research and the collection of testimonials aimed at documenting and understanding how Canada's assimilationist policies have harmed and continue to impact Indigenous peoples. This commission culminated in a series of reports and recommendations that have compelled Canadian agencies and private citizens to take concrete actions to improve relationships with Indigenous people in Canada, improve services and service provision and increase the knowledge of everyday Canadians about this difficult history. Specifically, in relation to healthcare, the TRC called on governments, organizations, and institutions to "acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies", some of which are ongoing, and calls upon medical and nursing schools to require "skills-based training in intercultural competency, conflict resolution, human rights, and antiracism" (4).

Now more than ever, Canadians are compelled to work in partnership with Indigenous people and communities to ensure services and policies are culturally safe (see Important Concepts section). Partnerships with Indigenous peoples and communities must move beyond consultation to collaboration where Indigenous empowerment and self-determination are the goals.

## THE INDIGENOUS POPULATION IN CANADA – AGING AND DEMENTIA

As the world population continues to grow older, Alzheimer's disease and its related dementias (ADRD's) have been identified as a public health priority across the globe (5), with advanced age being the number one risk factor to developing Alzheimer's Disease (6). The Indigenous population in Canada increased 42.5% from 2006–2016 more than four times the growth rate of non-Indigenous Canadians, and is projected to exceed 2.5 million people in the next twenty years (7; 8). Indigenous Canadians are living longer lives than in the past, and the population is aging, a trend that is expected

1 The terms 'Indigenous' and 'Aboriginal' are used to describe the collective group of First Nations, Inuit and Métis Peoples, the original inhabitants of Canada and their descendants.

to continue in coming decades (7-9). For example, in the First Nations population, it is estimated that those aged 60 and older are expected to increase in number by 3.4 times between 2006 and 2031 (9). This shifting population age structure will likely have a large impact on the prevalence of dementia in Indigenous populations.

Dementia has been identified as an emerging health issue in Indigenous communities (10-12). Indigenous epidemiological data for ADRD is sorely lacking worldwide (13), and epidemiological data on prevalence of ADRDs in Indigenous Canadians as a collective group of First Nations, Inuit and Métis does not exist (14). The available published data suggests that prevalence in Indigenous populations in Canada and Australia are 3-5x national averages with a younger age of onset (10; 15; 16). No prevalence data is available for American Indian/Alaskan Native (AI/AN) populations in the United States (17); however, incidence in the AI/AN populations is reported to be 13.6% higher than the White population (18).

The most recent estimates in Canada are based on administrative health care data in Alberta (10) and British Columbia (19) and provide information on the treated prevalence of dementia based on a recorded physician diagnosis. These reports indicate that the age-standardized prevalence of dementia in the registered First Nations population is 34% higher than the non-First Nations population (10); increasing more quickly than the rate for the non-First Nations population; there is a younger age of onset for First Nations peoples diagnosed with dementia; and there are a higher proportion of males diagnosed with dementia in First Nations compared to the general population.

## RISK OF ADRD IN INDIGENOUS POPULATIONS

Biomedical research has identified several risk factors and prevention strategies concerning dementia. The Alzheimer Society of Canada describes two categories of risk factors: modifiable, which may be influenced by individuals' behaviours or life circumstances, and non-modifiable, which cannot be changed. The primary non-modifiable risk factors for dementia are age and genetics (20). Genetic factors in the development of dementia has not been extensively researched among Indigenous

populations in North America. One study documented a case of early onset familial AD in an Indigenous extended family in British Columbia (21), and one published research note suggests lower frequencies of Apolipoprotein E (ApoE) among Choctaw populations in Oklahoma (22).

While aging contributes to increasing rates and risk for the development of ADRD, it has been shown that aging alone does not account for the recent increasing incidence of ADRD in Indigenous populations (10). Instead, it is suggested that Indigenous people have a markedly increased risk for dementia associated with related health disparities such as high rates of multiple, complex health conditions at younger ages compared to other populations (23-26), and a disproportionate share of individual, community, social, historical, and colonial risk factors (10; 27; 28). MacDonald and colleagues (29) explored Alzheimer's disease risk prevalence among Indigenous Canadians and found that modifiable risk factors may account for more than 75% of cases of AD among this population, suggesting a portion of the cases may be preventable (29).

Many specific risks include those which are most often labeled "modifiable" and include higher rates of smoking, obesity, and associated diseases such as diabetes, hypertension, stroke, and heart disease (24; 25), along with increased vulnerability to the impacts of social determinants of health including poverty, lower levels of formal educational attainment, low rates of health literacy, and potentially increased rates of post-traumatic stress disorder caused by residential school/Indian boarding school trauma (10; 27; 30).

It is important to emphasize that many of these modifiable risks are intergenerational, and stem from the history of Indigenous peoples being marginalized, disenfranchised, and oppressed as a result of colonialism and government policy and are difficult for most to conceptualize as modifiable (31). This points to the need for programs, policies and approaches tailored to Indigenous circumstance and context and an intensive research strategy focused on multilevel interventions.

## INDIGENOUS UNDERSTANDINGS OF AGE-RELATED DEMENTIAS

Social science research with Indigenous peoples to date has found that the biomedical construct of dementia, in which dementia is perceived as a disease, is not the predominant understanding of dementia in this population (see Cultural Frameworks of Illness and Disease in Important Concepts section). In general, dementia is looked upon as an accepted part of a person's path and is often not viewed as a disease by Indigenous peoples. Available published research describes an Indigenous framework for understanding AD/DRD.

Participants in national and international studies described dementia as a "natural" part of the "circle of life". Elders from the Secwepemc communities in British Columbia held understandings that included beliefs that dementia was a part of "going through the full circle of life" (32). In Saskatchewan, Grandmothers described dementia as going "back to the baby stage" and part of the "circle of life" (33). Similarly, in a study among Ojibwe in northern Minnesota female caregivers explained "part of her life was just part of the circle of life; she became a little child again" (34). The cultural understanding of dementia as "normal" and as part of "the circle of life" was consistent among diverse Indigenous communities in Ontario, including the Haudensaunee people of Six Nations of the Grand River Territory in Southern Ontario, and the seven rural Ojibwa, Odawa, and Pottawatomi First Nations of Manitoulin Island in Northeastern Ontario (35-37). In the studies involving Indigenous peoples cited above, the cultural framework of the medicine wheel and the circle of life provide context for Indigenous understandings of age related dementias. For instance, the understanding of the connections between the Spirit world and the physical world at the intersection of birth, infancy old age, and death, help explain "childlike" behaviour and communication with the deceased. Hallucinations are described as visions and as gifts and are considered important opportunities to learn and communicate (37-39). Dementia has been described as a "second childhood" and a time when one is "closer to the creator" by Indigenous people (40).

Despite those who view dementia as normal, dementia could still be feared by many, and caring for someone with dementia was sometimes viewed as extremely difficult (32). In some cases, communities reported feeling unprepared and poorly equipped to deal with someone in the later stages of the illness (12; 32; 37).

## AWARENESS AND HEALTH PROMOTION EFFORTS

It is reported that Indigenous persons with dementia and informal care providers often lack knowledge about dementia, including information about risk factors, symptoms, progression, and treatments (37; 41). Patients and caregivers report a discomfort with mainstream services, and a reliance on cultural teachings and spirituality (37). An environmental scan of published and unpublished literature accessible via the internet found a dearth of Indigenous specific dementia resources worldwide and none in Canada with one exception (42). Researchers associated with the Canadian Consortium on Neurodegeneration in Aging (CCNA) Team 20, with funding from Health Canada, recently released a series of Indigenous specific dementia health promotion and awareness materials (Fact Sheets) on the Indigenous Cognition and Aging Research Exchange (I-CAARE) website hosted by Dr. K. Jacklin: [www.I-CAARE.ca](http://www.I-CAARE.ca) (39; 40; 43-45).

## DIAGNOSIS

Diagnosis of dementia is reliant on the administration of cognitive assessments, which have been shown to be less accurate and reliable in Indigenous contexts (46-49). Accurate diagnosis is inextricably linked to effective dementia care and access to services for people and families. Although researchers have flagged the appropriateness of mainstream cognitive screening tools for use with Indigenous people in North America as a diagnostic issue for over twenty years (47; 50-52), the need for culturally appropriate assessment processes and screening tools remain. Inaccurate diagnosis also impacts our ability to accurately track epidemiological and health service use trends. A recent worldwide

systematic review led by de Souza and colleagues (53) related to dementia, cognitive impairment prevalence, and associated factors in Indigenous populations revealed, “The most relevant limitation indicated by the selected studies was the degree of validity of the neuropsychological tests in relation to their lack of cultural adaptation to the Indigenous population” (p. 285).

The lack of accurate detection of dementia at the individual level translates to major gaps in health information systems vital to health care resource allocations, policy and planning for Indigenous organizations, and First Nations communities in Canada.

There is a current effort underway funded by Canadian Institutes of Health Research (CIHR) and facilitated by the CCNA Team 20 to adapt and validate an Indigenous-specific cognitive screening tool (54) based on the Kimberly Indigenous Cognitive Assessment developed in Australia (55; 56). Progress on this work is updated regularly on the [www.I-CAARE.ca](http://www.I-CAARE.ca) website.

## ACCESS TO CARE AND CAREGIVING

Noted barriers to timely, accurate dementia diagnosis and care in Indigenous populations living in Canada include: 1) differing and culturally specific understandings of dementia which may delay health care visits and diagnosis (10; 37; 47; 57); and 2) structural barriers which impact a multitude of age-related chronic illnesses in Indigenous populations. Structural barriers include access to health care facilities and specialist services (58; 59); socioeconomic barriers include costly travel to urban centres for those living in rural and remote communities, and jurisdictional issues (10); clinical barriers include negative encounters with health care providers, lack of continuity (60; 61), fear of a dementia diagnosis, mistrust (41), lack of relatability, and feeling that their concerns were dismissed (62); and the perception of the medical system as an institution (63). The complexity of these barriers, results in multiple system navigation challenges for PWD and their caregivers.

## Formal Caregiving

The evidence suggests a reluctance and aversion to accessing formal health care services along the illness trajectory of AD RD. Many of the barriers outlined above serve as deterrents until symptoms and caregiving become more severe and supports are required. For these reasons most come to formal services late in their journey (58).

There is often a deep aversion to the use of long-term care facilities. This is sometimes related to cultural family values around caregiving, but also because removal of an elder from a community to obtain care at a nursing home or hospital is viewed as inappropriate, and as a last resort (58; 64). Long-term care is most often not available on First Nations reserves requiring elders to be removed from the community for care. Some have commented that removal of elders from the community is seen to further disrupt traditional modalities for the passing on of knowledge, (i.e., preventing the teaching and learning of culture, and the passing on of Indigenous knowledge), and has been described as “forced disengagement” (65).

From the limited studies available, suggestions to strengthen care in the community include: sustainable programming, improved home care; supporting traditional caregiving values; more culturally congruent and safe care from service providers; and nursing homes that more closely resemble assisted living facilities under the ownership and operation of the tribe or First Nation which better reflect Indigenous culture, language, and values (66-69).

## Informal Caregiving

In Indigenous communities, the family is often viewed as the primary or sole provider of care (47; 58; 67; 70-73). This stems from necessity in some cases, but more often because of a cultural emphasis on familial interdependence (74; 75), and the cultural values of reciprocity (76), and respect (58). However, the dependence on family for the provision of care is sometimes the only option as many First Nations reserves do not have trained home care staff that can properly care for people at later stages of dementia or residential care facilities (58).



Informal caregivers in Indigenous communities are reported to find caregiving rewarding but also experience stress in the form of anxiety related to the quality of care they are providing (58; 76), the psychosocial aspects of care, strains on family relations, and negative effects on personal well-being (72).

In one multi-community study, Indigenous dementia caregivers expressed feelings of frustration, anger, and stress associated with their caregiving responsibilities but felt committed to and rewarded in their role. Many in this study attributed their commitment to Indigenous values of respect, reciprocity, and love; reporting that they drew strength from their spirituality (58). Some caregivers have relocated, changed their children's schools (34) or set aside their own career and education goals in order to fulfill their caregiving duties (58).

In Ontario, Indigenous people shared how specific historical policies of the federal government, such as the residential school policy, have led to post traumatic stress in the older Indigenous population, and intergenerational trauma in the younger generations. This trauma greatly affects the ability of families to function in a caregiving role without a healing process (64). Yet, enabling community and family caregiving is viewed as culturally appropriate whereas long-term care facilities are viewed as a "death sentence" (12) or a place people are sent to die (77).

Despite caregiving obstacles, such as time commitments, financial hardships, competing familial obligations, and overcrowding, many Indigenous caregivers described reluctance towards long-term care and nursing home facilities, and felt they could provide comparable care for their elder at home (76; 77).

## Technology

The use of technology in the diagnosis and care of older Indigenous adults with dementia is relatively unexplored. A recent literature review on the topic suggests that technological solutions may be welcomed if Indigenous communities are sufficiently empowered to participate in their design and delivery (78). The same review cautions that there remains a digital divide in Canada that prevents equitable access to health technologies for many rural and remote First Nations communities and for individuals without adequate financial means to acquire technology.

## SUPPORTING CULTURAL APPROACHES AND COMMUNITY SOVEREIGNTY

### Community Caregiving

There are a handful of studies describing the role of the community in caregiving. Research with a remote First Nation in British Columbia found that the community participated in dementia caregiving in two distinct ways; first, Elders from the community became involved in decision making in cases where the person with dementia had no family; and second, community members participated in monitoring people with dementia who were known to wander. In the latter case, caregivers sent letters to other community members to alert them to the person's behaviour (79). The role of community members in locating the wandering elderly was also mentioned in an Ontario study where one caregiver explained how everyone in her community knew where she worked and knew that her loved one wandered so those who located her always knew where to bring her (58).

Community caregiving was also noted to have potential therapeutic advantages. A caregiver in a remote First Nation community explained that the community is the best place for someone with Alzheimer's disease because the individual is surrounded by all of their memory triggers. They expressed that placing someone with dementia in a hospital setting would result in the loss of those cognitive stimuli (58). Among the Secwepemc in British Columbia, it was suggested that community caregiving is not just therapeutic but also culturally appropriate: "... as part of a community whose member support one another through the life course, an Elder would continue to be supported and to support others while completing their journey through the full circle of life" (32). This group suggested that the words "Supporting one another" best reflected the participant's ideals concerning caregiving for dementia such as family relationships, wholistic health and community (32). On a cautionary note, Indigenous grandmothers in Saskatchewan discussed the increased pace of life and changing family structures as being related to less community helping, and more isolation for elders (33).

## Indigenous Medicine

Plant based remedies and ceremonies are important aspect of healing from past traumas and medical conditions. The inclusion of traditional medicine and ceremony in dementia care is a re-occurring theme in the literature (11; 32; 36; 47; 58; 80; 81). These studies suggest that the incorporation of Indigenous medicine is an important part of providing culturally appropriate care and improving outcomes. In Northwestern Ontario, a study that included Alzheimer's disease in its categorization of "acquired brain injury" found that spirituality and access to traditional care were deemed essential (80). It was emphasized that the Ojibwa approach to wellness does not focus on fixing the illness, rather wellness is wholistic, and improvements in cognitive function can be best accomplished when biomedical health care teams work with traditional healers to promote wellness (80).

## TRAINING AND RESEARCH

ADRD has only recently emerged as a significant health concern in Indigenous populations. Not surprisingly there are many knowledge gaps. Significantly, epidemiological data that would allow policy makers and communities to understand trends in dementia rates is absent, as are data allowing the examination of health service use. While the number of social science contributions to Indigenous dementia research is growing, there is yet to be a critical mass of studies that could inform scalable interventions. Notably research concerning dementia in Métis and Inuit populations is almost non-existent.

Taken as a whole, the research studies on dementia in Indigenous populations is increasingly disproportionate to the population and the expanding needs. There is much to be done in all academic disciplines to address a growing dementia equity gap for Indigenous people in Canada. Studies aimed at patient experiences along the illness trajectory, appropriate diagnosis and care, and prevention and intervention studies are needed.

Greater investments are needed generally, but particularly those that include capacity building for research at the community level and community partnerships or control. All research concerning Indigenous populations are compelled to respect the principles of OCAPTM Ownership, Control, Access and Possession (82), the Tri-Council Policy Statement: Ethical conduct for research involving humans, Chapter 9: Research involving the First Nations, Inuit and Métis Peoples of Canada (83), and the CIHR Guidelines for Health Research Involving Aboriginal Peoples (84).

## IMPORTANT CONCEPTS

### Cultural Frameworks of Illness and Disease

It is well established that culture influences an individual's understandings and behaviors around illness. This includes what an individual believes has caused their illness, how they think it should be treated, health care seeking behaviors, decision making models, and what are considered appropriate models of care (85-88). Culture is an adaptive system of meaning: a system of ideas, values, and symbols that are consciously, and unconsciously used or enacted by people in their everyday lives (89). Culture organizes "our conventional common sense about how to understand and treat illness; thus we can say the illness experience is always culturally shaped" (90). Medical anthropological and, more generally, qualitative approaches, are essential in order to discover and deconstruct patient and caregiver health and illness narratives which are critical aspects of health seeking behavior (87; 90). The terms 'disease' and 'illness' are viewed by medical anthropologists as overlapping explanatory models. Biomedicine focuses on the biological (pathological) treatment of various diseases (dementia, diabetes). Illness, in contrast, is the subjective experience of individuals and those around them, to disease. Illness experiences comprise not only the actions of individuals, but of larger systems of family, clinical, and community care. The relationship between culture and health is such that illness symptoms vary across different cultural and ethnic groups, and are often at odds with the culture of western biomedicine, significantly impacting diagnosis, treatment and care.



**Cultural safety**, a concept originally defined by New Zealand Maori nurse educators, addresses structural inequalities and power relationships between health care providers and patients that influence equitable access to care, and produce inappropriate health care encounters (91). The concept is increasingly used to speak more specifically to the need to address lingering colonial policies and account for intergenerational trauma in care approaches. The colonial legacy has been responsible for cultural discontinuity, dissimulation of family structure, and is compounded by oppression, abuse, and trauma (92; 93). This legacy continues with Indigenous peoples' common mistrust of the health care system where care is often provided by the dominant culture perpetuating the "burden of history" that shapes everyday interactions (61; 94). Cultural safety retains but expands the cultural domains previously associated with cultural competence and sensitivity allowing for more critical awareness of residual structural violence in our health care systems; that is, the way health institutions may harm people by preventing them from attaining appropriate, safe health care, and positive health outcomes (95; 96).

Cultural safety and culturally safe care are approaches that have emerged as strategies to address disparities in Indigenous peoples' health and health care, respectively. Community-based, culturally safe interventions provide an appropriate framework for dementia care to be delivered in a culturally relevant manner respecting the values, beliefs, and traditions of the individual (77; 97). Appropriate delivery of dementia care in a culturally safe way, requires that care providers be trained on the colonial and sociohistorical factors affecting Indigenous Peoples; Indigenous explanatory models of dementia, including linguistics; appropriate approaches to the clinical encounter; dementia care and prevention; reducing barriers, and improving access to appropriate care and support (97).

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## APPENDIX D

# Current Knowledge on Alzheimer's Disease or Related Disorders Among Ethnic Minorities and Recent Immigrants

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The Canadian population is simultaneously aging and diversifying. In 2016, visible minorities represented 22.3% of the population.<sup>1</sup> Immigrant older adults reside primarily in Metro Toronto, Montreal and Vancouver, arrive from South Asia and East Asia, do not speak either of Canada's official languages, and remain in the labour force longer than their Canadian-born counterparts.<sup>2,3</sup> Older adults who are recent immigrants as well as racialized minorities who have aged in Canada experience health inequities.<sup>4-9</sup> In particular, immigrant seniors with cognitive impairments have been described as facing a 'quadruple jeopardy' of dementia, age, ethnic minority status and low socioeconomic status.<sup>10</sup> Some of the more common risk factors for developing Alzheimer's Disease and Related Disorders (ADRD)—such as hypertension, stroke, and diabetes—are more prevalent among certain ethnocultural communities,<sup>11</sup> yet ethnic minority older adults (EMOA) are under-represented amongst ADRD (or dementia) service and support users.<sup>12,13</sup>

There is an urgent need to improve our understanding of the experiences of EMOA and their families to inform policy initiatives and best practice.<sup>11</sup> In addition to the complex and diversely experienced notion of ethnicity we also need to consider how factors such as immigration, health beliefs, and socioeconomic status intersect to create unique experiences in the dementia journey.<sup>11,14-17</sup>

This review includes studies on immigrants and refugees to western countries—primarily Canada, the United Kingdom (U.K.), and the United States (U.S.)—from multiple origins, most especially South Asia, Korea, China and Hong Kong, the Caribbean, Latin America, the U.K., the U.S., and Europe. Also considered are Black minorities living in Canada and the U.S. from multiple origins. This literature has been synthesized in parallel with the seven priority actions developed by an expert panel convened to inform the emergent Dementia Strategy for Canada<sup>18</sup> with the goal of optimizing planning and delivery of effective dementia services to ethnic minorities and recent immigrants, curbing health costs, and ensuring that *all* individuals impacted by dementia are equitably supported.

### Awareness, Information, and Mobilization

Lack of knowledge about dementia can result in delays in diagnosis among EMOA.<sup>19,20</sup> Alternative understandings of health and illness, which are overlooked by service models, contribute to a failure of EMOA to identify as service users.<sup>21</sup> For example, 'dementia' and associated concepts are not part of the vocabulary of South Asian languages<sup>22</sup> and Chinese origin older adults often lack sufficient Western vocabulary to describe their symptoms.<sup>23</sup> Normalization of symptoms is also common among older South Asians.<sup>10,24,25</sup> Chinese-Canadians from diverse educational and professional backgrounds also normalized the symptoms of dementia,<sup>19</sup> but socioeconomic status and education may influence such perceptions within this group.<sup>11</sup> Symptoms may also be misattributed to long-standing personality traits,<sup>20</sup> physical



illness, and life transitions such as retirement.<sup>26</sup> Traditional religious and spiritual beliefs about the cause and nature of dementia may also prevent EMOA from seeking help.<sup>11,15,17,23</sup>

Often these beliefs mistakenly portray dementia as a mental illness, which in turn is highly stigmatized since it is often thought to be the result of past deeds.<sup>10,11,27-29</sup> Concealing dementia from one's community may be a coping mechanism to preserve dignity, 'save-face' and avoid gossip.<sup>10,14,28,30,31</sup> EMOA may hide symptoms from family members when familial responsibilities take precedence<sup>32</sup> or for fear of negative consequences such as institutionalization.<sup>17,33,34</sup> Caregivers may also be reluctant to discuss symptoms in order to avoid family conflict, viewing dementia as a personal or family matter rather than a medical concern.<sup>26</sup> However, social pressure from family can also encourage help-seeking.<sup>35</sup> Reframing help-seeking as a way to enable families to support EMOA with dementia to live as well as possible may be a helpful intervention.<sup>36</sup>

Access to dementia information in one's own language is lacking.<sup>19,37</sup> Evidence points to the need for multipurpose leaflets provided by a trusted source (e.g. general practitioners or community figures) that outline symptoms as having a physical cause (versus mental illness), and indicate when to seek help and what supports are available.<sup>36,38</sup> Also recommended are informative talks that are ethno-linguistically targeted and presented at community and religious centres or on local ethnic TV and radio stations to increase knowledge and awareness of dementia as a health issue.<sup>15,17,38,39</sup>

### **Access to Personalized, Coordinated Assessment and Treatment Services for People with AD and Their Family/ Informal Caregivers**

The Public Health Agency of Canada (PHAC)<sup>40</sup> attributes responsibility for limited access to appropriate health care by marginalized populations to a dominant socio-economic environment that perpetuates marginalization, stigmatization, and loss of culture among minority groups. Accessing dementia care is a complex process compounded by key social determinants of health, which have a bilateral relationship with health policy, service delivery and clinical practice.<sup>3,41-43</sup>

Immigrant families are disadvantaged by a relative lack of knowledge about the Canadian health care system.<sup>44</sup> Regardless of length of time in Canada, immigrant status and compounding responsibilities (such as work and/or caregiving) can isolate individuals who thus have little awareness of services or how to access them.<sup>19</sup> Service access is also impacted by location of clinics, transportation options, hours and language of operation, required levels of health literacy, and funding models that limit the time health practitioners have per patient.<sup>17,44</sup> A study of South Asians in Toronto suggests the time between symptom recognition and consultations with a general practitioner vary from one to four years.<sup>20</sup>

Older immigrants and their caregivers are sometimes disinclined to use services when there is language and cultural incongruity with available health care providers.<sup>19,38</sup> Even when congruity is possible, some EMOA still feel uncomfortable in medical environments,<sup>45</sup> and harbour beliefs that they do not need help, do not know how to talk to a doctor, or that the doctor will not disclose diagnosis.<sup>19,23</sup> Some studies related cases where the physician overlooked dementia symptoms, possibly due to differences in presentation, or the insensitivity of diagnostic tools to such differences. In these instances, diagnosis and/or care was delayed until the EMOA experienced a crisis event,<sup>19,26,27</sup> or received treatment for other medical conditions.<sup>10,14,19,20,26</sup> Communication skills of both patients and providers thus shape symptom presentation.<sup>19,46</sup> Literature describes instances of disregard for patients' concerns by physicians and poor communication skills among specialists, as well as a failure to inform EMOA and their carers about the diagnosis and medications.<sup>14,19,27</sup> Experiences of racism, discrimination and power imbalances are also noted.<sup>26,28</sup> Building trust with EMOA is key to communication and is facilitated by the provider's knowledge of cultural conventions, such as how to address someone, and non-verbal communication including eye contact and gestures.<sup>28,38</sup>

For many minority groups, diagnostic processes are complicated by a lack of culturally sensitive assessment tools.<sup>10,11,14</sup> Existing tools are developed from studies on the general population and may skew estimates of dementia among EMOA.<sup>38</sup> Physicians are likely to use observation, clinical experience, biomedical testing, and information from family caregivers during assessments.<sup>14</sup>

Technology applications such as decision support software for primary care physicians may improve the diagnostic process for dementia in this group,<sup>29</sup> but assessment approaches must also account for migration and cultural influences on the experience of dementia.<sup>47</sup> It is often critical for family members to be present during assessment<sup>19</sup> so that EMOA are offered appropriate treatment options when communication due to ethnolinguistic incongruence (and not dementia) is the issue.<sup>48</sup> Use of family members as interpreters is not advised, however, when there is a potential for miscommunication and embarrassment between family members,<sup>16</sup> or a risk of abuse and neglect of the older adult, susceptibility to which is exacerbated by dependency borne of sponsorship status.<sup>49</sup> This potential can be mitigated by recruiting culturally diverse staff with proficiencies in multiple languages.<sup>15</sup>

### **Promotion of Quality of Life and Access to Home-Support Services and to a Choice of High-Quality Alternative Living Facilities in the Advanced Stages of AD**

Acceptance of care by EMOA with dementia and their families is influenced by the degree of alignment between supports offered and the recipient's health beliefs, cultural suitability and social determinants of health.<sup>44</sup> Health and social services with a 'person-centred care' agenda, need to create a non-discriminatory environment responsive to the uniqueness of individuals from diverse ethnic backgrounds, ages and cognitive abilities.<sup>50</sup> Dementia care services are more commonly informed by Eurocentric values (i.e. in staff distribution, language spoken, food options, decor and recreation activities).<sup>48</sup> Culturally misaligned services such as day programs and long-term care may thus be seen as inappropriate by EMOA.<sup>10,15,17,30,51</sup> Culturally sensitive services may offer activities related to religious practices (e.g. prayer, ritual washing)<sup>14</sup> or family mealtimes<sup>52</sup> to maintain quality of life.

Community organizations such as local Alzheimer's Society Resource Centres and peer support programs, can play a significant role in supporting EMOA.<sup>19,27</sup> Targeted outreach to establish relationships with ethnocultural groups, such as organizing 'roadshows' at community centres and religious establishments, is especially important.<sup>38,53,54</sup> Bicultural support workers (who are culturally and linguistically competent) may be instrumental in helping EMOA and their families to identify symptoms, navigate mainstream services, and facilitate confidentiality between clients and health providers.<sup>53</sup> However, the effectiveness of this approach depends on the degree of diversity among ethnic minority groups in various cities and regions.<sup>15</sup> The development of equitable partnerships between mainstream services and ethno-specific agencies is a valuable approach to addressing the challenge when diversity is high.<sup>10,55</sup>

Immigrant older adults are under-represented in long-term residential care facilities,<sup>10,30</sup> sometimes due to eligibility criteria that exclude immigrants still dependent on their sponsors<sup>49,56</sup> and/or limited financial resources.<sup>19,57,58</sup> Home care is highlighted as the service option preferred by South Asians.<sup>10,28</sup> Remaining in the family home may be imperative both emotionally and practically for EMOA with dementia, but a reluctance to allow strangers, even home care providers, into one's home can impede access.<sup>10</sup> Caregiver respite, with day programs (rather than home-based respite or short-stays in care homes) are thus recommended,<sup>38</sup> as is flexible service offering multifaceted support such as regular phone calls and home visits.<sup>53</sup>

## **Promotion of High-Quality, Therapeutically Appropriate End-of-Life Care that Respects People's Wishes, Dignity, and Comfort**

Health disparities experienced by EMOA throughout the life course also influence their access to end-of-life (EOL) services. Research has documented how EMOA, especially those with dementia, have difficulty accessing palliative care<sup>59-62</sup> and advanced care planning.<sup>63,64</sup> First and foremost, they are often not aware of palliative care and other available EOL services, and hence have low rates of self and professional referrals.<sup>65</sup>

Western constructions of a 'good death' and hospice care philosophies<sup>65,66</sup> are often at odds with EMOA and their families.<sup>67,68</sup> Minority groups may hold alternative views concerning orientation to the future and beliefs about control, fate, miracles and higher power, and with respect to the role of the family versus the dying individual around EOL decision-making.<sup>69-71</sup> Family members, not the person who is dying (especially when dementia is present), are more often consulted about EOL decisions.<sup>63,70,72-74</sup> Importantly, family may include large extended and international networks that must be consulted or who need to be present in the final hours.<sup>72,75</sup> Talking about death in the presence of the dying individual is considered abhorrent and even harmful in many cultures.<sup>70,73,76,77</sup> In some cultural traditions, families go to great lengths to reduce pain and suffering, whereas others feel that the mind must be clear at death, so avoid pain medications that dim consciousness.<sup>76,78</sup> Cultural and religious discrepancies from the host country's culture may vary across generations within families, with spouses more divergent than offspring, for example.<sup>61,73,76,79</sup> In some communities, trust in the health care system in general may be low:<sup>73,80</sup> individuals who feel they have been denied treatment (personally or historically) may be less inclined to accept EOL care.<sup>73,81</sup> yet disease and ethnicity interact and create a higher likelihood of utilization of life-sustaining interventions among African-Americans with dementia.<sup>82</sup> Finally among some groups, limited social and financial resources contribute to a low sense of entitlement to formal EOL services.<sup>73</sup>

In sum, providing EOL care in a way that respects dignity and comfort to EMOA requires a person-centred and culturally responsive approach. Health care providers must educate themselves about the beliefs and values of the groups they serve, including cultural practices and rituals<sup>65</sup> but, most importantly, EOL care plans must be tailored to the unique needs of individuals and families to take into account the variation within cultural groups and even families.<sup>73</sup>

## **Treatment of Family/Informal Caregivers as Partners Who Need Support**

A significant portion of the literature focuses on the preference for ethnic minorities to 'care for their own' due to cultural norms and religious obligations surrounding filial responsibility.<sup>11,14,26,30,31,33,39</sup> Formal supports may be resisted since acceptance could imply that families are incapable of fulfilling their duty to care.<sup>39,49</sup> However, this relies on availability of family members, particularly women, who are increasingly involved in the labour force.<sup>19,83</sup> Moreover, not all EMOA have supportive extended families.<sup>10,46,50</sup> Family support may be additionally compromised by immigration laws, fragmented family networks, financial preferences, acculturation of subsequent generations, and changing social practices of marriage and divorce.<sup>16,32,38,46,49</sup> Family involvement may also be a source of stress for EMOA due to disagreements, dissatisfaction and unwanted advice.<sup>33</sup> The assumption by care providers that 'immigrant families take care of their own' can thus impede EMOA's access to needed services.<sup>84-86</sup>

Consistent with mainstream populations, family caregivers of EMOA may face difficulties responding to behavioural symptoms of dementia, whereby lack of knowledge about the disease compromises coping.<sup>33</sup> Educational resources are required to enable families to support persons with dementia, as EMOA often rely on family members to navigate to and access health services.<sup>20,32,87</sup> Families have also emphasized the need for tangible supports, such as financial aid and home and community care, as well as psychological support.<sup>10,27</sup> It is crucial to offer services that are led by staff and volunteers who speak community languages, are held at convenient locations and times, and consider practicalities such as transportation and childcare arrangements to facilitate uptake.<sup>38,39,88</sup>

## Developing and Supporting Training Programs

Person-centred dementia care as a practice model aligns with a culturally responsive approach in the provision of services, which emphasizes the importance of understanding diverse life histories in supporting EMOA to live well with dementia.<sup>14,38,50</sup> Individualized interventions must be informed by important facets of the life history of EMOA with dementia, such as their country of origin, age at immigration, migration route and reasons for migrating,<sup>16</sup> as well as their personal interests and valued roles.<sup>30</sup> Service providers who are preoccupied by cultural differences may have reduced confidence in properly responding to patients from ethnic minorities.<sup>10</sup> Cultural competence approaches have been criticized for problematizing interactions between *individuals*, where the impact of *systemic* racism in the post-colonial context should not be overlooked.<sup>4,83,89</sup> Providers must acknowledge power discrepancies with patients (especially recent immigrants)<sup>19,83</sup> and be aware of stereotyping (e.g., care preferences, the availability of family supports), which can delay access by EMOA to dementia care.<sup>14,21</sup> There is a clear need for dementia-specific training that includes but extends beyond culture to the provision of individually responsive care.<sup>10</sup>

## Research Effort of All Members of the University, Public, and Private Sectors

While research suggests that awareness campaigns can be useful to reduce stigma, more evidence is required to determine their effectiveness on actual help-seeking behaviour.<sup>29</sup> Systematic evidence and evaluations of approaches to service design and delivery for EMOA, such as needs-led service development based on community consultation, are also warranted.<sup>21</sup> For this to be possible, funding periods must allow for sufficient time to build trust and establish relationships within local communities before producing deliverables.<sup>21,90</sup> Further research on EMOA with dementia may consider innovative community supports and housing models, end-of-life care, and effective training programs tailored for different types of health workers. Finally, there is a need for technology development, such as creating valid and reliable diagnostic tools for health professionals.

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## APPENDIX E

# Young Onset Dementia

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Widely considered a disease that only impacts older adults, there is growing discussion and emphasis on the supportive care needs of adults who are diagnosed with dementia in younger years. Young onset dementia, also known as early onset dementia or working-age dementia, is a condition that affects adults before the age of 65 years and impacts about 16,000 Canadians.<sup>1,2</sup> Relating to neurodegenerative conditions, young onset dementia is most commonly caused by Alzheimer's disease, vascular disease, or frontotemporal degeneration.<sup>1,3,4</sup> Most commonly, individuals diagnosed with young onset dementia will experience behavioural changes, psychiatric manifestations, and cognitive decline.<sup>1</sup> These symptoms lead to a deterioration in the day-to-day functioning of the often otherwise physically fit individual.<sup>1,4</sup>

For those individuals diagnosed with young onset dementia and receiving home care services, 27 percent have severe cognitive impairment, 35 percent have clinical depression, and 69 percent have a degree of medical instability<sup>1</sup> – demonstrating that for adults with young onset dementia, their symptomology and disease experience is equivalent or worse than that described for older adults with dementia. Available pharmacological treatment options, including the use of acetylcholinesterase inhibitors or the use of antidepressants, provide symptom relief from the disease, but do not modify the disease progression.<sup>4</sup> Non-pharmacological treatment options, viewed to be as important as the pharmacological therapies available, include: safety assessments and planning; environmental modification; occupational and speech language therapy; peer- and community-support group attendance; and legal counsel to support and protect financial and other decision making as the disease progresses.<sup>4,5</sup>

The literature exploring and evaluating interventions and services targeted for adults diagnosed with young onset dementia is limited.<sup>1,4</sup> Despite great emphasis on the needs of older adults with dementia and their caregivers in the literature, there exists no systematic syntheses that explores this phenomenon or the experience of adults with young onset dementia.<sup>7</sup> While fewer young Canadians are diagnosed with dementia compared to their older adult counterparts, their experience is significant and their health and social care needs are just as great.<sup>1,3</sup>

## KEY ISSUES

While young onset dementia impacts only about 3 percent of those diagnosed with dementia,<sup>1</sup> it presents unique and significant challenges for those affected.<sup>3,5</sup> If addressed, these key issues, related to the physical, social, and supportive care needs of the individual and their caregivers, would have significant impact for those diagnosed with young onset dementia. These issues include: the delayed or initial misdiagnosis of dementia among this population; the loss of connection, and thereby, resources; the need for both age specific and age appropriate supportive services; and the significant impact that the disease has on those providing informal care.

### Delayed or Misdiagnosis of Young Onset Dementia

Atypical in its presentation in comparison to dementias in older adults, young onset dementia is often initially misdiagnosed, resulting in delays in diagnosis and thus, delays in appropriate support.<sup>3,6</sup> It is estimated that it takes, on average, one and a half years longer to receive a diagnosis of young onset dementia than it does to receive a dementia diagnosis in older adult populations.<sup>6</sup> This is likely because dementia is often a diagnosis of exclusion, and in young onset dementia it primarily presents with behavioural changes and psychiatric

manifestations such as depressive or psychotic symptoms in the beginning.<sup>5</sup> These behavioural and psychiatric changes present much earlier in young onset dementia than symptoms of cognitive decline, and often mimic other social changes that could be attributed to age-appropriate stressors or life changes such as employment or child rearing.<sup>1,5</sup> Given the delayed nature of diagnosis in individuals experiencing young onset dementia, post-diagnostic community level support for this population is important.<sup>3-5</sup>

### Loss of Connection and Resources

At the time of diagnosis, individuals with young onset dementia are typically still employed, may be raising young children, providing care for aging parents, or have financial commitments such as mortgages or outstanding loans.<sup>4,5</sup> As the disease progresses, however, these points of social connectedness and responsibility are impacted. Consequently, the adult with young onset dementia may experience social isolation, role and relationship loss, an accelerated loss of autonomy, and a premature loss of income and employment benefits.<sup>4-6</sup> These disease consequences have significant impact on the person and their family and often add excessive strain on remaining relationships with friends and family, and their finances related to a loss of income and added care costs.<sup>8</sup> Peer- and community-level support for both the person and their caregivers, work- and volunteer-oriented activities for physically able individuals, as well as respite services may aid in the maintenance of social connection.<sup>4-6</sup>

### Need for Age-Specific and Age-Appropriate Services

Of particular challenge for the adult with young onset dementia is the lack of age-specific and age-appropriate services to support health and social care needs.<sup>9</sup> On average, adults with young onset dementia stay in hospital longer than their older adult counterparts<sup>1</sup> and have a more difficult time finding placement or acquiring services.<sup>9,10</sup> This is because adults with young onset dementia typically have more significant cognitive impairments early in the disease,<sup>1</sup> and due to their early age at diagnosis, are more physically fit in comparison to older adults with dementia.<sup>10</sup> Upon leaving hospital or upon diagnosis, many of the programs and services available both privately as well as at the community level

are based on needs that the adult with young onset dementia may not yet require. Dementia services and referral mechanisms are typically geared toward older adults with memory impairments and physical frailty.<sup>3,4</sup> In addition, adults with young onset dementia are less likely to use formal services as their caregivers often perceive these services to be inappropriate, too costly, or to have inconvenient hours for their lifestyle.<sup>8-10</sup> This need for age-specific and age-appropriate services that support both the adult and their caregivers is well articulated within the literature,<sup>4</sup> and yet, remains limited in practice.

### Impact on Caregivers

As young onset dementia is often diagnosed between the ages of 45 and 65 years,<sup>5</sup> the disease progression significantly impacts young caregivers. It is estimated that of the 31 hours of unpaid care work provided on average to adults with young onset dementia, 18 percent is provided by children, 44 percent is provided by a spouse, and 38 percent is provided by others who may include elderly parents.<sup>1</sup> These findings show that more hours of unpaid care provision are required for adults with young onset dementia in comparison to older adult presentations.<sup>1</sup> This is likely a result of the intensity of symptoms, inclusive of personality changes, lack of motivation, and challenging behaviour at a degree that the caregiver, at this phase in their life, is generally not prepared for.<sup>7,11-13</sup> As the adult with young onset dementia often has to stop working, their partner or children face the added challenge of working full- or part-time in addition to caregiving, decision making managing household responsibilities, and providing financial support.<sup>8,12,13</sup> Caring for an adult with young onset dementia can be challenging,<sup>3,4,6,7,14</sup> especially for young children,<sup>12,13</sup> and results in higher levels of stress, burden, burnout, and depression among caregivers in comparison to those who provide care for older adults with dementia.<sup>3-5,12-13</sup>

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## APPENDIX F

# Current Knowledge on Alzheimer's Disease or Related Disorders and Sexual minorities

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Over the past years, the Canadian government has taken huge steps towards the inclusion of the lesbian, gay, bisexual, transgender, queer, and two-spirit (LGBTQ2) communities. These commitments have notably led to the appointment of a Special Advisor on LGBTQ2 issues in 2016, in the person of Randy Boissoneault.<sup>1</sup> Through his formal apology in 2017, the Prime Minister further expressed Canada's willingness to become a "partner and ally to LGBTQ2 Canadians in the years going forward".<sup>2</sup> As the Alzheimer's Plan recommendations are now adapting to the pan-Canadian national level, taking action to reflect Canada's stance on the inclusion of sexual minorities will have a particular significance for our LGBTQ2 elders.

It was recently estimated that 13% of Canadians falls within the spectrum of LGBTQ2.<sup>3</sup> With the projected numbers of 1.1 million Canadians who will present Alzheimer's disease or related disorders (AD) in 2038,<sup>4</sup> this could account for as much as 143,000 cases from sexual minorities. Further, as some of the most common risk factors for developing AD are more prevalent among the LGBTQ2 communities,<sup>5</sup> the projected numbers could be even higher. Addressing the specific healthcare needs of this population through the previously identified seven priority actions<sup>6</sup> will therefore be essential for the Plan to have the greatest impact on the care of all Canadians.

### **Awareness, Information, and Mobilization**

Knowledge about AD could help against stigmatization, isolation and caregiver helplessness and could even reduce some of the barriers to a timely diagnosis and access to appropriate care.<sup>7-10</sup> LGBTQ2 individuals living with AD reported experiencing the "double stigma" of dementia and sexuality".<sup>11</sup> This, supplemented by the enhanced ageism reported in the LGBTQ communities, where age is often synonym of invisibility or stigmatization,<sup>12,13</sup> makes this need for awareness and mobilization efforts even more important for the sexual minorities.

### **Access to Personalized, Coordinated Assessment and Treatment Services for People with AD and Their Family/ Informal Caregivers**

Limited access to assessment, diagnostic, treatment and management services was identified as an issue for the people living with AD and their caregivers. The access to appropriate care could be even more limited for LGBTQ2 individuals as the reports of general fear of accessing healthcare, being denied healthcare or being provided with inferior healthcare due to the perception of their sexual or gender identities still remain a concern in the recent literature from United States and Canada.<sup>5,14-18</sup> To tackle the current distrust and improve access for sexual minorities, experts advocate for the development of up-to-date culturally competent practices with LGBTQ2 older adults living with AD, using research literature with a focus on person-centered care approaches.<sup>5</sup> Another



need often expressed from the field is the training of relevant healthcare professionals and staff.<sup>5,11,15,17,19</sup> More adapted practices, such as improvements in the ways in which professionals collect information, availability of LGBTQ2 educational material or representations<sup>20,21</sup> and ensuring the use of appropriate and unbiased language could help create welcoming, affirming, and supportive environments.<sup>5,15,20</sup> This could be achieved by involving LGBTQ2 health activists in organizations, services, and policy development.<sup>22</sup>

### **Promotion of Quality of Life and Access to Home-Support Services and to a Choice of High-Quality Alternative Living Facilities in the Advanced Stages of AD**

There is often a lack of trust towards the healthcare system from the LGBTQ2 older adults, who report avoiding formal care despite identified needs for services. As a result, when home-support care providers are involved, they are frequently unaware of the lived identities of their LGBTQ2 clients.<sup>15,23</sup> This fear of disclosure is associated with high levels of anxiety, further enhanced by the reduced ability to manage sensitive information about oneself or their partner and to remember ‘who knows what’ due to AD.<sup>24</sup> Additionally, the number of service providers involved in home-support care can be high with AD and the ‘coming out’ process to every professional can be wearying and stressful. When entering the private space of home, special care should be taken to provide safe and supportive interactions where LGBTQ2 older adults may feel comfortable to disclose their identities, if and when they choose.<sup>24</sup>

The fear of having to leave their home is even greater.<sup>25</sup> LGBTQ2 older adults are worried about possible discrimination and mistreatment but also about the more subtle phenomena of invisibility, isolation and barriers to connect with others. This invisibility and isolation stemming from the fear of disclosure can come from small details such as not feeling comfortable to display pictures of their loved ones or not relating to the life stories being discussed by other residents.<sup>26</sup> As sexuality is often set aside for older adults in long-term care facilities (LTCF), sexual diversity is even less addressed.<sup>27,28</sup> If the current situation appears to be better in Canada

than elsewhere (38% of all mistreatment events in LTCF were directed towards LGBTQ2 in the United States),<sup>26</sup> the LTCF experiences are still mixed. Whereas some feel completely welcomed and recognized, others report more negative encounters. This is especially true for trans patients with AD remembering and re-experiencing their past lived under another gender identity or for trans individuals receiving intimate care.<sup>25</sup> Mistreatment in alternate living facilities can include verbal/physical harassment from residents/staff, restriction of visitors, refusal to use the name/pronoun in accordance with their gender identity, refusal to provide basic services or care, denial of medical treatment, and threats to disclose identity.<sup>26,29</sup> In response, some discussed the possibility of developing specific sections in LTCF, dedicated to a LGBTQ2 population.<sup>19,25,30</sup> Others felt this type of project would label them as potential targets and preferred mainstream care facilities, yet with clear inclusive policies and culturally-sensitive healthcare professionals.<sup>15,19,24,30</sup> Some provinces are already planning to adapt their LTCF policies to better answer the needs of LGBTQ2 residents.<sup>31</sup>

### **Promotion of High-Quality, Therapeutically Appropriate End-of-Life Care that Respects People’s Wishes, Dignity, and Comfort**

The end-of-life (EOL) is an understudied aspect of LGBTQ2 individuals’ life and care, except for the specific case of HIV and bereavement in gay men.<sup>32,33</sup> EOL resources and LGBTQ2 resources themselves were found to have very few, if no intersections at all.<sup>34</sup> Throughout the rare interviews available, LGBTQ2 individuals expressed their need for the acknowledgement of their identity. They also reflected on the importance of an open and nonjudgmental environment and of the recognition of their “chosen family” in an inclusive understanding of family-centered care.<sup>32</sup> Specialized support groups were set forth as possible options,<sup>20</sup> as LGBTQ2 patients and caregivers often found their needs and identities not included in the current provision of services. Existing resources could adapt their policies and program to sexual minorities through education and policy changes, as previously described for home-support services and alternative living facilities.



## **Treatment of Family/Informal Caregivers as Partners Who Need Support**

LGBTQ2 older adults are at a greater risk for social isolation than the general population.<sup>5,18,35</sup> They are twice as likely to live alone and four times less likely to have children.<sup>35</sup> Furthermore, many LGBTQ2 older adults are estranged from their families of origin. As a result, informal support for LGBTQ2 older adults is often organized and provided by “chosen family” members. These caregivers might benefit from the same legal privileges if they are married, living in a civil union or a common law couple.<sup>36</sup> Yet, they might not have access to the same resources or feel welcomed to the same spaces.<sup>15,18</sup> LGBTQ2 caregiving is thus still frequently met with challenges, barriers, and lack of understanding on individual, systemic, institutional, and societal levels.<sup>18</sup>

It remains important to affirm chosen families and to recognize their unique significance for LGBTQ2 older adults through institution policies, especially given their historic and continued marginalization.<sup>19</sup> Further, as stated in the 519 report, “service providers need to not only recognize the concerns of LGBTQ older adults, their chosen families, and friends; where possible, allyship, spaces and services should be guided by those they serve”.<sup>37</sup>

## **Developing and Supporting Training Programs**

Education and staff training emerged as a response to many of the encountered difficulties specific to the LGBTQ2 population healthcare. Experts suggested the development of training programs, implemented either through healthcare institutions or embedded in the initial training, possibly targeted to context with the highest needs.<sup>19,20,22,26</sup> A few programs are already developed as training kits for the inclusion of LGBTQ older adults in healthcare services.<sup>19,29</sup> However, no program specifically designed for LGBTQ older adults with AD could be found. Montreal appeared as a special case in Canada, where healthcare providers were highly sensitive to the issue.<sup>19</sup> Its experience could be drawn upon to bridge the gap for LGBTQ older adults with AD.

## **Research Effort of All Members of the University, Public, and Private Sectors**

There is still limited research on LGBTQ2 older adults' health due to difficulties to track and include LGBTQ2 identities in significant ways.<sup>18,32,38</sup> However, we have been witnessing a change on this issue over the past years. If the 2002 blueprint report “Building on Values: The Future of Health Care in Canada” completely ignored LGBTQ2 populations,<sup>39</sup> efforts have since been made to gather more data and include LGBTQ2 communities in health discussions: Statistics Canada started asking about sexual orientation in its official surveys in 2003<sup>40</sup> and Healthy People 2020 asked for nationally representative data on sexual minorities.<sup>41</sup>

Data on subgroups within sexual minorities, such as bisexual, transgender or intersectional subgroups (i.e. Black lesbians; Latina transwomen) still remain scarce.<sup>18,32</sup> Additionally, age-group specific data could help better target interventions, as old age is not a homogeneous group in terms of healthcare needs.<sup>42</sup>

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## APPENDIX G

# Dementia and Adults with Intellectual / Developmental Disabilities

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Adults with intellectual disabilities (ID) are living longer with some individuals reaching ages seen in the general population (Coppus, 2013; Patja, Molsa, & Iivanainen, 2001). Dementia as it affects adults with ID is a growing significant concern for families, services and policy-makers. The World Health Organization and Alzheimer's Disease International (2012) recognize people with intellectual disabilities and their caregivers as having unique needs (p. 54). Additionally, an International Summit on Intellectual Disabilities and Dementia (Glasgow, Scotland – October 13-14, 2016) brought together leading academics and organizational representatives from across Europe and North America. Their work produced a number of summative reports on pressing issues including inclusion in national plans, nomenclature, end-of-life care in advanced dementia, and post diagnostic supports (for a full listing see: National Task Group on Intellectual Disabilities and Dementia Practices, 2018). Various research projects, predominately from other countries, have also focused on dementia related to this often-marginalized group. A sampling of recent studies includes:

- An English study examining diagnosis, survival and risk factors associated with Alzheimer's disease and Down syndrome (DS) utilizing the Aging with Down Syndrome and Intellectual Disabilities (ADSID) research database (Sinai *et al.*, 2018).
- An Irish longitudinal study following adults with DS examined age of onset, dementia features, and co-morbidities (McCarron *et al.*, 2017).

- A United States study investigating aging, dementia and multimorbidity in relation to adults with Down syndrome aged 45 – 89 years (Bayen, *et al.*, 2018, July 22).
- A longitudinal study in the United States follows three dementia-care community-based group homes to observe progression of decline, resident needs, and practice adaptations (Janicki, 2018, June 29).
- The INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) project (National Institutes of Health, 2018).
- Studies by the Alzheimer's Biomarkers Consortium — Down Syndrome (ABC-DS) (2018).

Within a Canadian context, however, few research projects report on dementia as it affects adults with ID. As a result, there is a reliance on international research to inform Canadian policies and practices despite differences in healthcare and social service systems. Additionally, across Canada, the provinces and territories differ in their respective health and social services as well as data collection strategies in relation to this population, making it difficult to compile national evidence on dementia affecting adults with ID and or DS. A cursory review of provincial strategies found no specific actions related to individuals with ID and or DS and their families.

This paper highlights extant evidence pertaining to adults with ID affected by dementia including prevalence of dementia, assessment and diagnosis, and family caregivers. It draws heavily upon international work. The inclusion of adults with ID and their families in national plans developed by other countries is then considered.

## PREVALENCE OF DEMENTIA

Studies examining the prevalence of dementia affecting adults with ID without Down syndrome (DS) report mixed findings. In the United States, Janicki and Dalton (2000) found an overall prevalence of 6.1% for adults aged 60+, similar to rates in the general population. Zigman *et al.*, (2004) also found comparable rates of dementia. Yet other studies suggest higher prevalence. For example, Cooper (1997) found a prevalence of 21.6% in the UK, much higher than expected for a comparable age group in the general population. In Manitoba, Canada, a prevalence of 13.76% was reported for adults with ID aged 55+, again higher than prevalence in the general population (Shooshtari, Martens, Burchill, Dik, & Naghipur, 2011). Methodological differences including criteria used to diagnose dementia likely explain these differences in the research findings (Silverman, Zigman, Krinsky-McHale, Ryan, & Schupf, 2013; Strydom, Livingston, King, & Hassiotis, 2007).

That said, there is longstanding agreement that adults with DS are at high risk of acquiring dementia. Generally, estimates suggest 25% will be affected after age 40 and at least 50 to 70% are affected after age 60 (National Task Group on Intellectual Disabilities and Dementia Practice, 2012). McCarron, *et al.* (2017) confirmed a high risk associated with Down syndrome that ranged from 23% for individuals aged 50 years to 80% for adults aged 65+. Sinai, *et al.* (2018), also reported a younger average age at diagnosis (55.80 years) and a reduced survival time from diagnosis (average 3.78 years) for people with DS. Bayen, *et al.* (2018) also confirmed a high rate of dementia in a California study of people with DS as well as an increased number of comorbid conditions in those adults affected by dementia compared to those without dementia, particularly hypothyroidism, epilepsy, anemia and weight loss.

## ASSESSMENT AND DIAGNOSIS

Guidelines for the assessment and management of dementia as it affects persons with ID were first published in the mid 1990's, see Janicki, Heller, Seltzer and Hogg (1996). These alongside other reports including community support guidelines (Jokinen *et al.*, 2013) and an assessment framework for physicians (Moran, Rafii, Keller, Singh, & Janicki, 2013) recognize the challenges inherent in assessment and diagnosis of dementia for people with ID. Canadian primary care guidelines also offer recommendations for action in regards to assessment of dementia (Sullivan, *et al.*, 2018).

Assessment requires the use of instruments different from those used with the general population and Table 1 offers examples of commonly used measures for clinical assessment. Best practice guidelines do speak to the need for healthcare professionals to be familiar with the population to avoid diagnostic overshadowing. The assessment process critically compares previous with changed behavior and function. The guidelines all suggest adults with an ID have an established baseline of abilities to facilitate the assessment process if needed. There are a number of options to record such a baseline (e.g., video, pen/paper). The NTG-EDSD (Esralew *et al.*, 2013; National Task Group on Intellectual Disabilities and Dementia Care Practices, 2013) may also be used for this purpose (Jokinen, *et al.*, 2013). This is, an administrative tool specifically designed for family and direct care staff to document change over time and discuss any changes noted with a healthcare professional. Its usefulness has been noted in a German study (See Zeilinger, Gärtner, Janicki, Esralew, & Weber, 2016) and the tool has been adopted in a number of jurisdictions. In North America, a baseline of abilities has been recommended for people with DS commonly beginning at age 30 or 40 or 30 and by age 40 or 50 for individuals with other ID to facilitate assessment should the need arise.

**Table 1: Measures for Clinical Assessment of Dementia in People with Intellectual Disabilities\***

Name of Measure	Instrument characteristic	Strengths/weaknesses
Adaptive Behaviour Dementia Questionnaire (ABDQ) (Prasher, Farooq, & Holder, 2004)	15-item questionnaire used to detect change in adaptive behavior by comparing current functioning to typical functioning.	<p><b>Strengths:</b> Detecting change in everyday functioning, easy to administer and score, family member as informant, length of time must know adult is specified.</p> <p><b>Weaknesses:</b> No differential diagnosis, not useful to track intervention response.</p>
Assessment for Adults with Developmental Disabilities (AADS), (Kalsy, McQuillan, Oliver, & Hall, 2000); (Oliver, Kalsy, McQuillan, & Hall, 2011)	Measure of function with focus on behavior and performance related to cognitive and physical decline; 28 items with respect to 'how often', 'management difficulty', and 'effect'.	<p><b>Strengths:</b> Assesses current everyday functioning/ behavior, and behavior changes. Easy to administer, standardized administration, descriptive, indicates who needs further evaluation/care, many informants.</p> <p><b>Weaknesses:</b> No differential diagnosis. Questions are complex.</p>
Dementia Questionnaire for People with Learning Disabilities (DLD)*, (Evenhuis, 1992); (Evenhuis, 1996); (Eurlings, Evenhuis, & Kengen, 2006)  *Originally named the Dementia Questionnaire for Mentally Retarded Persons (DMR)	Made up of eight sub-scales: short term memory, long term memory, orientation (making up Sum of Cognitive Scores), speech, practical skills, mood, activity and interest and behavioral disturbance (making up a Sum of Social Scores).	<p><b>Strengths:</b> Designed for all levels of functioning as early screening instrument. Easy to administer as informant completion item or interview. Indication of dementia signs at one assessment and over repeated assessments.</p> <p><b>Weaknesses:</b> Level of functioning (e.g., IQ) required for norms. No differential diagnosis. Some concern among clinicians regarding its appropriateness for individuals in the severe and profound ranges of intellectual functioning.</p>
Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID), (Deb, Hare, Prior, & Bhaumik, 2007)	Comprised of 43 questions in three sections. Measures memories, confusion, feelings of insecurity, sleep problems, and behavior problems. Includes information about medical conditions, psychiatric conditions, and medication.	<p><b>Strengths:</b> Current everyday functioning assessed, easy to administer/score, wide range of respondents considered appropriate, length of time informant needs to know adult specified.</p> <p><b>Weaknesses:</b> For differential diagnosis just lists possible other conditions and medications.</p>

\* Adapted from Source Jokinen, *et al.* (2013, p. 7)



## FAMILY CAREGIVERS

Research and the literature point to the varied and unique situations of family caregivers faced with the prospects of dementia care (see as examples the narratives in Jokinen *et al.*, 2018). Many adults with ID continue to live with family in middle and older age. In the United States, for instance, 71% of adults live with family – 24% with parents aged 60+ (Braddock, Hemp, Tanis, Wu, & Haffer, 2017). Other middle-aged and older adults with ID live in varied circumstances (e.g., alone, with unrelated adults in home shares or group homes). Family members living with their relative with ID affected by dementia provide primary support and those living separately often remain involved in supportive roles (Jokinen, *et al.*, 2018). Many families remain committed to provide support despite changes encountered with dementia (Janicki, Zendell, & DeHaven, 2010).

Most adults with ID and their families have different life experiences than people in the general population affected by dementia. They have:

- decades long involvement with various education, health and social services
- long time exposure to stigmatization, discrimination, and exclusion
- and endured changes in philosophy and social support from institutional care to community living (Jokinen, 2016).

These family caregivers are a distinct group often being older-aged parents or siblings versus a spouse or adult offspring and providing care for decades since the birth of their relative with ID compared to assuming responsibilities later in life (Jokinen, *et al.*, 2018). After providing a lifetime of support, families face new challenges when dementia presents and begin to question their abilities to continue as caregivers given the transitions from established routine care to that related to stage-related changes (Heller, Scott, Janicki, & Pre-summit Workgroup on Caregiving and Intellectual/ Developmental Disabilities, 2018). The literature, however, is sparse on how families cope with the various transitions encountered in dementia care (Jokinen, Janicki, Hogan, & Force, 2012).

## INCLUSION OF ADULTS WITH ID AND THEIR FAMILIES IN NATIONAL PLANS

Despite the recognition of adults with ID as a unique population that should be included in national plans (World Health Organization & Alzheimer's Disease International, 2012), a review of national plans indicates a number of them make essentially a descriptive mention of adults with ID and their families and nominal attention is given to the challenges caregivers encounter with dementia. Yet other countries have made some specific mention including the latest iteration of Norway's Dementia 2020 plan, (Watchman *et al.*, 2017). Another example is the USA National plan that has included specific mention of adults with ID, possibly in part because of the work of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and their frequent presentations at meetings of the Federal Advisory Council on Alzheimer's Research, Care, and Services (Janicki & Keller, 2014). The current update on the US Plan (U.S. Department of Health and Human Services, 2017) includes the following specific references in reference to ID / DS:

- Strategy 1.C: Accelerate Efforts to Identify Early and Presymptomatic Stages of Alzheimer's Disease and Related Dementias. Refers to the work of the National Institutes of Health's Alzheimer's Biomarker Consortium-Down Syndrome (p.15).
- Recommendation 1: The 2017 National Plan should continue to provide a robust, comprehensive, and transformative scientific Road Map for achieving the goal of preventing, effectively treating, and providing effective care and services for AD/ADRD by 2025. Speaks to establishing research milestones that "Include and prioritize specific milestones for populations at high risk for AD/ADRD (e.g., people with Down syndrome, African Americans)" (p.62).
- Recommendation 17: Federal agencies, states, national health and aging organizations, and community partners must continue to expand public awareness and training, reduce stigma, and help connect people to information and available resources. Outreach should include children and youth, diverse racial/ ethnic/socioeconomic groups, and people with IDD.

Includes: "Increase engagement of national health-related organizations (e.g., Down syndrome, heart, and diabetes) in providing information and resources addressing dementia" as well as "Beyond research-specific efforts, NIH is also committed to continuing to enhance and provide evidence-based information, resources, and referrals through the ADEAR Center to specific populations of people with AD/ADRD and their caregivers including younger people, non-traditional families, people with IDD, such as Down syndrome, and ..." (p. 75).

## CONCLUSION

Adults aging with ID and their family caregivers affected by dementia have unique experiences and needs compared to people in the general population. A lack of Canadian research and reliance on international research to guide policy and practice negates our healthcare and social context. A Canadian National Dementia Strategy that includes actions to address the needs of adults with ID and their families affected by dementia may provide an impetus for localized dementia strategies to also incorporate similar actions as well as begin to inform policy and practice for all persons affected by dementia.

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## APPENDIX H

# Technology for Dementia

### AGE-WELL

*Prepared by Arlene Astell, PhD, and Dorina Simeonow, MSc*

The advent of smartphones and tablets in the last 10 years has opened up personal computing to many new audiences and created increasing interest in how such devices can be used to empower people. Similarly growing awareness and availability of emerging technologies such as robots, Virtual Reality (VR), smart home systems (e.g. Amazon Alexa, Google Home Hub) and autonomous (i.e. driverless) vehicles are causing an explosion of interest in how they can improve wellbeing, including for those living with dementia. Although it has only recently gained mainstream attention, research applying technology to dementia has been taking place alongside biomedical research for many decades. However, technology development has received comparatively little funding, resulting in much research that is limited to pilot or feasibility studies. Consequently, the amount and range of evidence-based technological interventions for dementia is small but growing.

One particular consequence of limited funding over many years has been limited commercialization of research, with few products arising directly from funded projects. However, various commercial products have been launched that offer a range of functions and services for dementia. These include products specifically targeting dementia, e.g. GPS tracking devices advertised for dementia, DayClock (Designability, UK) and others, such as tablets that contain functions that can benefit people with dementia. Potential customers for technological solutions include people living with dementia, family care providers, health and care organisations, research organisations and pharmaceutical companies.

This paper summarises the main developments in technology research and product development in dementia plus information about where to access these (see Resource Table).

## ASSESSMENT

The most developed and researched use of technology in dementia is for conducting cognitive assessments. These products are aimed primarily at healthcare professionals offering cognitive assessments, and organisations, particularly pharmaceutical companies, conducting research trials. Two of the earliest technology-based cognitive assessment batteries - *CANTAB* (Sahakian *et al.* 1988) and *ECO* (Ritchie *et al.* 1993) - were developed in the late 1980s and early 1990s using touchscreen technology. *CANTAB* is now marketed worldwide through Cambridge Cognition as a tool for running drug and other large-scale trials. The advent of smartphones and tablets has created opportunities for new mobile assessments such as the brief community screening assessment created by Barnes and colleagues (2014) for spotting people at high risk of cognitive impairment, another by Weir and colleagues (2014) for use in hospital settings and a third by Onoda and colleagues for population level screening (2013), among many others. There are also websites such as *Cogniciti* where people concerned about their memory can complete a short online test to see if they should consult their doctor. In addition, the potential of VR for assessing people with dementia is also being explored with projects such as virtual navigation (Cushman, *et al.*, 2008), and *VIRTUALKITCHEN* (1).

## MONITORING AND TRACKING

Technology in various forms has also been used to monitor people with dementia both at home and outside during various activities. Much of this monitoring has arisen in response to concerns from caregivers about the safety and security of people with dementia, for instance during activities such as cooking or when leaving home unaccompanied. This has given rise to one of the most controversial uses of technology in dementia (2), namely the application of electronic tagging and Global Positioning Systems (GPS) as responses to people with dementia going out unaccompanied. Back in 1998 McShane and colleagues examined the feasibility of using specific electronic tracking devices to locate people who have dementia, and Miskelley in 2005 tested a GPS-enabled cell phone. Since then numerous devices have emerged and are commercially available online. These include wearables (e.g. GPS watch), attachables (GPS devices for clothing, belts, etc), insertables (GPS insoles) and portable GPS trackers (to go in bags, pockets). In Japan, the city of Iruma introduced tracking of individuals with dementia across the city using QR codes attached to people's fingers or toes. Multiple companies now exist specializing in these products with prices ranging from approximately \$150CAD for a single device to several hundreds of dollars for a system of several connected devices and services. The majority of these are aimed at family caregivers or care organisations to monitor the people they care for. These technological solutions can be utilized alongside nontechnological responses such as various versions of the Silver Alert Program of community notification when people are reported missing, and programs such as the MedicAlert and Safe Return programs run by the US Alzheimer's Association which includes an ID bracelet and personalized emergency wallet card. The evidence base for these products relate to the efficiency and reliability of the GPS technology and success in locating individuals.

## REHABILITATION AND COGNITIVE TRAINING

The possibility of using technology to deliver rehabilitation of cognitive functions has also long been recognised. As early as 1994 McConatha and colleagues tested a commercially available interactive computer programme - Prodigy™ - with older adults in long-term care, to increase their use of computers. In 1999 Schreiber and colleagues trained 10 people with dementia in real - life household tasks using *MultiTask*, another commercially available system. More recently, Garcia-Betances and colleagues (2015) produced a review (3) and guidelines (4) for developing cognitive rehabilitation and training using VR functionality. In a trial of computer-delivered rehabilitation Lee and colleagues (2013) demonstrated that the intervention was as successful for people with mild to moderate dementia as the same intervention delivered by a therapist. In their European project, (5) conducted a pilot study with 21 participants of "Kitchen and cooking", a serious game developed for older adults with cognitive impairment, and demonstrated that a four-week training using the game improved concentration but there was no investigation of transference to actual cooking tasks (5). The finding that practice improves performance on the practiced tasks but does not transfer to other tasks or improvement in cognition, has been confirmed through fMRI.

Although there are some promising results for rehabilitation, the evidence currently available is at odds with the appetite among people with dementia and caregivers for apps or devices that can provide 'brain training.' Luminosity for example is a very popular product despite being fined \$50million (settled at \$2m) in 2016 by the US Federal Trade Commission (FTC) for "deceptive advertising" regarding its claims to "delay cognitive impairment". Another popular app, MindMate has the strapline "Get fitter, improve your brain health and stay independent for as long as possible". Some of the contents of this app (games, physical activity, nutrition) have been developed to reflect evidence from research studies, particularly the FINGER study which explored the impact of a multidomain intervention on the cognitive function



of older adults are risk of dementia. However, the app is independent of the FINGER researchers and there has been no research conducted into the app itself, which may not be immediately obvious to visitors to the website.

## SMART HOMES

Delivering interventions to people with dementia directly where they live in response to changes detected in the surroundings has been another popular focus of technology research and product development. Emphasising the potential for maintaining people with dementia at home and delivering care remotely, numerous products and systems utilising sensors and instrumented devices have been developed. For example, the COACH system (Mihailidis *et al.*, 2004) uses computer vision to prompt people through the sequence of hand washing. Research integrating a number of devices include SmartCondo™ and smart apartment (Canada), the Gloucester Smart Home (Orpwood, *et al.*, 2004) and Deptford smart flat (Orpwood, *et al.*, 2008; UK), and Dem@Care and DOMUS smart apartment (France). Since 2006 researchers at the Oregon Centre for Aging and Technology (ORCATECH) have equipped almost 500 homes with the Life Lab smart system, an in-home monitoring system for sleep, gait, mobility, activity patterns, medication adherence and computer use (6). They are developing algorithms to detect changes in ability and performance that may indicate significant decline and initiate intervention.

In the UK the 2016-18 technology Integrated Health Management (TIHM) project is a joint healthcare/academic/industry Internet of Things project utilising existing devices to monitor the health of people with dementia at home.

Commercially available smart home systems include CareLink Advantage (Canada), CareSensus a partnership between Philips and Cordaan a Dutch care provider, Just Checking and Canary Care (UK), and Abilia (Europe). Additionally, individual items such as bed occupancy sensors, floor mat sensors, door opening alerts, motion detection, activity monitors can be purchased online for individuals and organisations to establish their own monitoring systems. In addition to custom and off-the-shelf technologies, a number of websites offer advice on creating a 'dementia-friendly home'. As with the GPS

devices, these products are largely purchased by care providers (formal and informal) although some, such as the Miihome project (UK) are now being co-created with people who have dementia to provide ambient support to maintain their activities of daily living.

## COMMUNICATION

Technology-based support for communication and social interaction has also long been a focus of investigation. For example, Alm *et al* (2014) developed Computer Interactive Reminiscing and Conversation Aid [CIRCA], a touchscreen-based interactive, multimedia conversation support containing generic contents, developed in partnership with people with dementia and caregivers. A web-based version of CIRCA that can be populated and labelled with contents from different countries and cultures is just being launched. In 2015, Ekström, Ferm & Samuelsson (7) created a personalized version of CIRCA for a lady with young onset dementia and reported a positive impact on her communication. In terms of mainstream technology people with dementia can continue to use email, cell phones, texts and apps such as FaceTime and WhatsApp if they used them before. Skype is popular in long-term care as a means of connecting residents with family. In terms of dementia specific commercial products, there are various simple cell phones such as Memory Picture Phone and Dial-Less Phone (Canada), Doro (UK), and the KISA phone (Australia).

## FUN AND GAMES

Another important application of technology is to support people with dementia to engage with and enjoy leisure activities. Just like the rest of the population, people with dementia seek meaningful and enjoyable activities. Games can provide this satisfaction but despite the millions of games in online stores, very few are dementia-friendly, i.e. accessible for people with dementia. To address this the AcToDementia website is a resource containing reviews of games in different categories (e.g. card games, art games), that have been identified for their dementia-friendly features (<https://www.actodementia.com>). In addition to apps, games systems, particularly motion-based devices such as Xbox Kinect, are popular mainstream devices that can be enjoyed by people with dementia as a group activity or something to play with

the grandkids. Dove and Astell (2017) set up an Xbox Kinect bowling group while Neubauer and colleagues (2018) tested virtual Tai Chi in participant's homes and Schikhof and Wauben (2016) found a positive effect of virtual cycling using a commercially available product. Based on their experience Astell, *et al* (2018) produced system development guidelines for other developers and researchers interested in utilising motion-based technologies for dementia. Other activities developed specifically for people with dementia include viewing art on a tablet (Tyack, *et al.*, 2017), creating art on touchscreen devices (Leuty, *et al.*, 2013), digital storytelling delivered on an app (Critten & Kucirkova, 2017), music-making on a custom-made device (Riley, *et al.*, 2009) and House of Memories (UK), a museum-led dementia awareness programme using an app to explore historical artefacts.

## CAREGIVER EDUCATION AND TRAINING

For formal caregivers, a range of web-based training interventions have been developed. The CARES program developed for nursing assistants was shown to improve new information and skills and reduce stress relating to caregiving (8). Technology has also been applied to creating integrated care packages for people with dementia, such as the intervention-management-system developed by Eichler and colleagues to suggest recommendations to GPs (Eichler *et al.*, 2014). A recent review (9) found that Interacting with an online coach or other caregivers could benefit informal caregivers and support their own mental health and wellbeing but systematic evaluation of Internet-based training and support is lacking. A 2017 review of mobile apps targeting caregivers found only 46 apps out of approximately 165,000 healthcare apps in Google Play and iTunes. Analysis of these apps found they focused on five main areas: information and resources, practical problem-solving, family communication, interaction with care-recipient and caregiver support.

## ROBOTS

Research into robotics generally has gathered pace over recent years. In healthcare for older adults, efforts fall into several areas including robots as direct caregivers, robots as assistants, robots as companions and robots

as facilitators of social interaction. Coughlin (2015) suggested that robots could provide a solution to the predicted 'caregiver crisis' and potentially reduce the sky rocketing costs of long-term care (approximately \$219.9 billion in the US in 2012) and \$522 billion per annum of informal, unpaid caregiving provided by family or friends of the care recipient. The possibility of robot carers goes back to NurseBot (1993), a project to create an assistant or companion to replace a human caregiver (Pineau, *et al.*, 2003). More recently Nejat and colleagues (McColl, *et al.*, 2012) created Brian (a humanoid robot developed to support people living with dementia in long-term care facilities at mealtimes. Brian's creators have also developed Casper (Bovbel & Nejat, 2014), a prototype robot to prompt people through the steps of meal preparation, and Tangy (Louise, *et al.*, 2015) a non-humanoid robot to support bingo in care homes. Other developments have utilised telepresence robots which are basically a video conferencing system controlled by a remote user, i.e. rather than appearing on a fixed desktop monitor or screen, the person speaking can move the robot around the environment from their own location. Currently a range of telepresence robots are available to purchase including Giraff, Anybots® (QB), Beampro™, VGO, Double Robotics, and MantaroBot (10). Of these, Giraff has been developed and used in a number of European research projects such as Giraffplus (11), focused on supporting older adults at home by combining the robot with a network of sensors. At this time the bulk of robot research and testing is on combatting loneliness, social isolation and prompting people with daily tasks, but there is still work to do before these can be deployed at scale.

## CAREGIVING

Regarding the use of technology to assist with caregiving, a survey of 72 family caregiver's identified that devices they perceived as having high usefulness were familiar, intuitive, easy to use, simplified activities and prevented accidents, with safety often given priority over the privacy and autonomy of their relatives with dementia (Mao, *et al.*, 2015). In care services the use of technology is expanding rapidly to encompass a wide range of activities, which demand a technology-enabled workforce. An example is Hammond Care in Australia, an organisation embracing technology to deliver care and support to its residents. The organisation uses technology to facilitate

the organisational goals and values through enabling connecting and communicating through a web-based sharing platform (SharePoint), cloud-based video conferencing, customer relationship management, training, learning and continued professional development (CPD). Hammond Care is a partner in developing the Virtual Reality-Empathy Platform (VR-EP), cutting edge software that enables architects, designers and builders to explore potential environments as if they were a person with dementia. Hammond Care also uses technology to support delivery of care through smart systems in the cottages where their residents live, that includes sensors for monitoring routines, addressing issues (e.g. falls), silent nurse call system, and environmental monitoring. They also utilise PainChek™, an app to assess pain in people with dementia, which uses artificial intelligence and Smartphone technology to visually analyse facial expressions, assess pain levels in real time and update cloud based medical records. As a model of technology-enabled care for people with dementia, Hammond Care is an example for the world.

## SUMMARY

As there are currently no disease-modifying drug therapies for any dementia subtypes and little drug discovery research into the less common ones, there is huge potential for technology, in the forms of devices, applications and services, to assess and optimize functioning of people to live with dementia (13). In addition, technology can benefit families caring for a relative with dementia through dedicated devices and services, plus support through online forums and education about dementia. Technology can also support service providers through a digitally-enabled workforce, assessment and monitoring functions and provision of interventions. To date a wide range of technologies has been applied to an equally wide range of challenges created by dementia (see also (Jodrell & Astell 2016), (15), (Meiland, *et al.*, 2017) for recent literature reviews) and Resource Table).

While research into technology for dementia has been underway for almost 40 years and in some areas has made great progress, there are still gaps. Most notable is the small number of products aimed at supporting individuals who have dementia to address their cognitive challenges and maintain their daily and leisure activities.

By far the bulk of research and commercial products has targeted family and organisational care providers plus research and pharmaceutical organisations conducting cognitive assessments. This may reflect perceptions of who the intended or likely consumers of the research and products are. There is also a real issue about who should pay for and support the purchase, deployment and maintenance of technology for people with dementia. For example a smart phone provides telephone calling, text, email and video access to family and services to combat social isolation, calendars for scheduling and reminding which can be shared with caregivers, GPS, maps, and a compass to support navigation, games for cognitive stimulation and fun, but it is unlikely at the present time that a healthcare provider or insurance company would pay for a phone and the data package for a person with dementia. Going forward we need increased awareness among healthcare providers of available technologies and functionality, engagement by companies with people with dementia or care providers (such as the exciting examples from Hammond Care) and realistic proposals for funding the solutions to keep people with dementia well at home for as long as possible.

## About AGE-WELL

AGE-WELL is Canada's Technology and Aging Network. The pan-Canadian network brings together researchers, non-profits, industry, government, care providers, older adults and caregivers to develop solutions to support healthy aging. AGE-WELL includes more than 150 funded and affiliated researchers from 37 universities and research centres across Canada. Over 225 industry, government and non-profit partners have joined the network. We work closely with older adults and caregivers to help current and future generations of Canadians enjoy the best quality of life possible. We do this by developing technologies and services that increase their safety and security, support their independent living, and enhance their social participation. AGE-WELL was launched in 2015 through the federally funded Networks of Centres of Excellence program.

For more information visit [agewell-nce.ca](http://agewell-nce.ca)

**Resource Table: Online Resources for Dementia**

Name	Address	Products/services	Target
Cambridge Cognition	<a href="http://www.cambridgecognition.com">http://www.cambridgecognition.com</a>	Cognitive assessment battery	Pharmaceutical companies, research organisations
Hammond Care	<a href="http://www.hammond.com.au">http://www.hammond.com.au</a>	Technology-enabled care	People with dementia Caregivers
US Alzheimer's Association	<a href="https://www.alz.org/help-support/caregiving/safety/medical-alert-safe-return">https://www.alz.org/help-support/caregiving/safety/medical-alert-safe-return</a>	Medic Alert + Safe Return	Caregivers, people with dementia
SafeTracks GPS Canada	<a href="https://www.safetracksgps.com">https://www.safetracksgps.com</a>	GPS devices	Caregivers
GPS Trackershop	<a href="https://www.trackershop-uk.com">https://www.trackershop-uk.com</a>	GPS devices	Caregivers
Techsilver	<a href="https://www.techsilver.co.uk">https://www.techsilver.co.uk</a>	GPS devices	Caregivers
Orcatech	<a href="https://www.ohsu.edu/xd/research/centers-institutes/orcatech/">https://www.ohsu.edu/xd/research/centers-institutes/orcatech/</a>	Life Lab (smart home)	People with dementia Caregivers, research organisations, pharmaceutical companies
Smart Condo	<a href="https://www.ualberta.ca/health-sciences-education-research/simulation-experiences/hserc-spaces/smart-condo">https://www.ualberta.ca/health-sciences-education-research/simulation-experiences/hserc-spaces/smart-condo</a>	Smart home	Researchers, caregivers
Smart apartment	<a href="https://carleton.ca/engineering-design/2008/carleton-researchers-design-products-for-smart-apartment-at-elisabeth-bruyere-centre/">https://carleton.ca/engineering-design/2008/carleton-researchers-design-products-for-smart-apartment-at-elisabeth-bruyere-centre/</a>	Smart home	Researchers, caregivers
Abilia	<a href="https://www.abilia.com/uk/our-products">https://www.abilia.com/uk/our-products</a>	Monitoring	Caregivers, people with dementia
Canary Care	<a href="https://www.canarycare.co.uk">https://www.canarycare.co.uk</a>	Monitoring	Caregivers, people with dementia
Just Checking	<a href="https://justchecking.co.uk">https://justchecking.co.uk</a>	Monitoring	Caregivers, people with dementia
GiraffPlus	<a href="http://www.giraffplus.eu">http://www.giraffplus.eu</a>	Monitoring + robot	Caregivers, people with dementia
COACH	<a href="http://www.iatsl.org/projects/intell_env.htm">http://www.iatsl.org/projects/intell_env.htm</a>	Prompting for hand washing	Caregivers
Bikearound	<a href="https://www.cbc.ca/news/canada/toronto/bikearound-oshawa-1.4625642">https://www.cbc.ca/news/canada/toronto/bikearound-oshawa-1.4625642</a>	Virtual cycling	People with dementia, caregivers
Dementia Circle	<a href="http://dementiacircle.org">http://dementiacircle.org</a>	Crowd-sourced reviews of products	People with dementia, Caregivers
ATDementia	<a href="https://www.atdementia.org.uk/productSearch.asp?page_id=16">https://www.atdementia.org.uk/productSearch.asp?page_id=16</a>	Age-appropriate dementia products	People with dementia, Caregivers
Alzheimer's Australia	<a href="https://www.agedcareguide.com.au/talking-aged-care/new-app-to-dementia-friendly-home">https://www.agedcareguide.com.au/talking-aged-care/new-app-to-dementia-friendly-home</a>	App for creating a dementia-friendly home	Caregivers

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## APPENDIX I

# Implementing a Dementia Plan

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While many countries and most Canadian provinces have published strategic reports related to addressing the growing prevalence of dementia (1, 2), there remains a relative dearth of evidence-informed best practices of implementing dementia-care strategies in primary, home and hospital care environments.

In this document, we first present implementation strategies from existing national dementia plans. Given the paucity of information included in existing dementia plans, in the second part of the document, we provide evidence from studies conducted within or outside a national dementia plan.

## IMPLEMENTATION STRATEGIES FROM EXISTING NATIONAL DEMENTIA PLANS

32 countries or jurisdictions<sup>1</sup> have developed national dementia plans (2). One half are written in either English or French. Of these, eight plans contain sections that explicitly address implementation strategies or programs. While dementia plans vary in both scope and duration, the most comprehensive documents are roughly 100 pages in length. Generally, the implementation strategies in these plans take two forms:

1. The dementia plan is organized thematically, and the implementation strategy is included at the end, roughly four pages;<sup>2</sup>
2. The dementia plan is organized according to objectives, and implementation strategies are linked to specific measures.<sup>3</sup>

## Implementation Strategies

Despite the fact that many dementia plans include sections on implementation strategies, very few plans actually articulate strategies for the diffusion or implementation of dementia care reform. These sections tend to discuss objectives (e.g. “educating more people earlier about the risks of developing dementia”), but not how such objectives will be achieved. The small number of implementation strategies that have been articulated include:

1. Investing in research to increase understanding of how Alzheimer disease progresses, and how to reduce risk for dementia (3-5);
2. Diversifying pedagogical approaches (5);
3. Involving individuals living with dementia and their caregivers in the diffusion of expertise in training (4, 6);
4. Strengthening undergraduate and medical curricula to reflect a multidisciplinary approach to chronic disease management, especially in dementia care (4);
5. Focusing workforce training on therapeutic (non-pharmacological) strategies and on management tactics (4, 6, 7);
6. Developing gender-specific dissemination plans, since women are most affected by dementia in both prevalence and burden of caregiving (4);
7. Creating both qualitative and quantitative measures to assess progress and achievements in dementia care reforms (3, 4).

<sup>1</sup> Despite combining to form the United Kingdom, England, Scotland and Wales each have independent dementia plans

<sup>2</sup> For example, France's *Plan Maladies Neuro-Dégénératives 2014-2019*

<sup>3</sup> For example, Malta's *Empowering Change 2015-2023*



Overall, most plans recommend the appointment of an individual, committee or board to ensure that many of the above strategies are coordinated in timely fashion, with direct involvement of key stakeholders, at reasonable costs (3-6).

## EVIDENCE FROM STUDIES CONDUCTED WITHIN OR OUTSIDE A NATIONAL DEMENTIA PLAN

The number of studies looking at the impact of implementation strategies to improve dementia care is sparse. Nevertheless, several recently published studies have advanced certain barriers to and enablers of the implementation of optimal primary dementia care. We provide hereafter a synthesis of this current evidence.

The literature on the implementation of dementia care plans states that implementation strategies should be developed to target both individuals and organizations.

At the individual level, four factors may influence the success with which a dementia plan is implemented: (1) Disseminating pragmatic guidelines and provide training in active ways; (2) Targeting the confidence and expertise of healthcare professionals; (3) Addressing concerns of potential adopters (managers, healthcare professionals, community organizations, etc.); and (4) Encouraging adopters to engage with the intervention over an extended period of time.

At the organizational level, four factors may influence the adoption of any dementia plan: (1) Integrating changes that are compatible with current care practices; (2) Identifying and valorizing a “champion” of dementia reform; (3) Adapting the intervention to the organizational context; and (4) Combining quality measurement with quality improvement programs.

It is important to note that many of these implementation strategies are not mutually exclusive. Evidence suggests that different strategies at both levels results in the best chance of successfully changing dementia care (8-11). The strategies are described below.

## Successful Implementation Strategies at the Individual Level: Putting People First

### *Disseminating pragmatic guidelines and training through active, concise and varied formats*

Traditional didactic and passive strategies (lecture-style meetings, printed materials and guidelines, and passive materials) are ineffective strategies for increasing healthcare professional knowledge of, and confidence in, dementia management strategies (11-13). Healthcare professionals benefit most from problem-based and solution-focused dementia training (14). Whatever the intervention, strategies that focus on its pragmatic benefit and usability should be developed (13). Healthcare professionals and informal caregivers alike benefit from practice opportunities, personalized feedback, and collaboration with practitioners (9, 15, 16). Finally, guidelines should be communicated to healthcare professionals and informal caregivers in succinct and synchronized trainings to minimize “guideline fatigue” (12).

### *Promoting confidence and expertise*

It is important that, in addition to generating expertise, implementation strategies target the *confidence* of healthcare professionals (17). Confident individuals are more likely to take a keen interest in dementia and dementia reform (17). Conversely, practitioners who are not well informed about dementia services or guidelines show little interest in acquiring information about them (14). Confidence and expertise may be organic, but governments can also furnish this capacity through additional support staff, like geriatricians (12, 17).

### *Addressing concerns of potential adopters*

Similarly, numerous studies show that when adopters maintain negative attitudes towards dementia interventions, the interventions are less likely to be adopted (18). Specifically, doubts surrounding the value of the intervention, or the capacity for the intervention to improve care for elderly persons, are associated with reduced uptake of the intervention (19-21). Another unique barrier remains the reluctance of some primary care physicians to be trained in dementia care by non-physicians (22). Like with confidence, implementation strategies should be designed to embrace the concerns of adopters, and to target any negative stigma surrounding dementia.

### ***Encouraging adopters to engage with the intervention over an extended period of time***

Interventions take time to implement, and habits take time to change. When practitioners and healthcare professionals engage with new programs for longer durations, their adherence to, and confidence in, the interventions increases (20, 23-26). Eventually, as outcomes become perceivable, members feel increased self-worth and accomplishment (27). Accordingly, interventions should be implemented in ways that encourage practitioners and healthcare professionals to continually engage with the initiative. Positive feedback is important.

## **Successful Implementation Strategies at the Organizational Level: Taking into Account Existing Work Environment and Resources**

### ***Integration with current care practices***

Dementia interventions that are implemented in ways that are compatible with the current healthcare structure are more likely to be well-received by healthcare professionals (18). Accordingly, strategies for implementation should be tailored to the environment and audience for which the intervention is intended. Factors to consider include the current practices of the adopters, the time available (and time required) to learn and enact the intervention, and the capacity for adopters to alter practices (18).

### ***Identifying and valorizing a “champion” of dementia reform***

A critical predictor for the successful implementation of a strategy is the presence of a physician or nurse who serves as a “clear champion” for dementia reform (11, 17). This champion, who recognizes the potential benefits of new recommendations, takes an active role in convincing other colleagues to use the guidelines (17). If the champion is knowledgeable in dementia management, they may also provide support and guidance to peers. Champions may actively participate in knowledge dissemination by organizing training sessions, or may simply motivate staff (11, 17). Championing dementia reform can be individual or team-based (17).

### ***Adapt the intervention to the organizational context***

Governments should consider structural factors (institutions may require adequate resources and staff to adopt the intervention), personal incentives (like remuneration and other motivations) and cultural differences (unique perceptions of dementia and caregiving, especially in rural or Northern communities) when developing strategies for implementation (17, 18, 28).

### ***Quality indicators and quality improvement***

Coupling dementia care quality indicators with quality improvement initiatives can improve dementia care (29). Quality assessment tools may be The Assessing Care of Vulnerable Elders (ACOVE) indicators (30), the International Resident Assessment Instrument (InterRAI) (31), or others. These measures should be coupled with action plans to address specific quality domains that are identified as being weak. Examples of actions in primary care that have proven to improve quality of care include case finding, electronic medical record (EMR) prompts, structured visit notes, physician education, and nurse care management (29). Co-management of dementia care between nurse practitioners, physicians and community organizations has been advanced as a particularly impactful quality improvement endeavour (29).

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