Manitoba's Framework for

Alzheimer's Disease and Other Dementias

Focused on what matters most › to families.

Manitoba

Introduction

The prevalence of dementia is projected to increase worldwide over the next generation (25 years) and it is anticipated that Canada will also experience this trend. Presently, over 747,000 Canadians have Alzheimer's disease or another dementia and this number is expected to rise to over 1.1 million, or 2.8% of the population, by 2038 (Alzheimer Society of Canada, 2010).

Currently, nearly 20,000 Manitobans have Alzheimer's disease or another dementia. By 2038, it is expected to reach over 34,000, representing 2.5% of the Manitoba population. Last year, there were more than 4,500 new cases of Alzheimer's disease or other dementias in Manitoba. By 2038, this number is anticipated to rise to over 9,350 a year (Smetanin et al, 2009).

The rising prevalence of dementia is anticipated to create strain on caregiver and economic resources. In Manitoba, the total number of hours of informal care provided to persons with dementia is expected to increase from over 9.0 million hours per year in 2008 to over 22.0 million hours per year by the year 2038 (Smetanin et al, 2009).

In addition, the annual economic cost of dementia in Manitoba for 2014 is estimated at over 984 million dollars and it is expected to grow to more than 4.4 billion annually by the year 2038 (Smetanin et al, 2009).

In recognition of the need to augment care and services for persons with dementia, a *Strategy for Alzheimer Disease and Related Dementias in Manitoba* was released in 2002 and addressed nine strategic areas. Since then, many improvements that enhance and impact the care and support of Manitoban's with dementia and their families and caregivers have been made. Highlights of these advancements include:

- Establishment of the First Link® program in Manitoba,
- Proclamation of the *Caregiver Recognition Act* and establishment of the Caregiver Advisory Committee,
- Development and renewal of published and online caregiver resources and toolkits,
- Implementation of primary care reform and initiatives to improve access to primary care providers throughout Manitoba,
- Expansion of the nurse practitioner primary care model in personal care homes (PCH) and communities,
- Enhancements to community living supports and housing options through the Aging in Place Strategy,
- Establishment of new Winnipeg-based programs and services to support frail, elderly individuals in the community (e.g. PRIME Health Centre, Hospital Home Teams),

- Expansion of Geriatric Mental Health resources such as clinicians and outreach teams,
- Implementation of educational programs for PCH staff to address dementia and behavioural assessment and care (i.e. P.I.E.C.E.S.™ , Enhanced Orientation Program for Nurses New to Long Term Care), and
- Implementation of the PCH Staffing Initiative which provided an increase in hours of nursing care to 3.6 hours/ resident/day.

To strengthen and enhance the body of evidence and knowledge base surrounding dementia care and planning in Manitoba, the Manitoba Centre for Health Policy and the Centre on Aging have engaged in various research projects that address issues such as service/care projections and best practice approaches to dementia care (e.g. medication use).

It is recognized that ongoing work is required to further enhance dementia care in the province. In October of 2011, the province committed to supporting the First Link® program and to a renewal of the 2002 Strategy for Alzheimer's Disease and Related Dementias in Manitoba. Manitoba Health (MH) established a planning committee of stakeholders [Manitoba's Framework for Alzheimer's Disease and Other Dementias Development and Implementation Advisory Committee (DIAC)] to work together to improve the care and services for those individuals with dementia, and to better support their caregivers, families and health care professionals by developing a renewed Framework for Alzheimer's Disease and Other Dementias for Manitoba (the 'Framework').

In light of the anticipated future economic and personal impact of dementia, the Framework, in conjunction with the various other MH initiatives and strategies, will serve as a roadmap over the next five years to guide Manitoba's health system planning and investment to improve care and support for Manitobans with dementia, and their families/caregivers.

The Framework was developed in early 2014 after conducting an inventory of initiatives since the 2002 Manitoba strategy and completing a comprehensive scan and review of other provincial and international dementia strategies and relevant literature. Based on this information, a gap analysis was completed to identify potential areas of strategic opportunities. Current provincial initiatives with potential impact and overlap were also considered. Focused stakeholder consultations were held with caregivers and care/service providers in both Winnipeg and rural Manitoba to validate the strategic themes and directions outlined in the gap analysis.

The Framework outlines recommendations that follow the 'Responses to Dementia' people would experience in their dementia journey. Strategic themes are organized by these Responses and corresponding gaps and opportunities identified. The five Responses include:

1. Raising Awareness and Understanding
2. Early Recognition and Initial Assessment and Diagnosis
3. Management, Care and Support
4. End of Life Care
5. Research and Evaluation

The Framework outlines provincial strategic opportunities to provide a renewed commitment to improve the care and services for persons with dementia and their families/caregivers in Manitoba by building on past successes and working collaboratively with partners, stakeholders and other related initiatives.

Contextual Considerations

Manitoba's diversity in geography and culture requires service and care approaches that are flexible and can be tailored to an individual's needs and home community. These distinct needs must be recognized within dementia care and services to ensure capacity to address an individual's needs regardless of background and whether they live in an urban or rural setting.

To align with Manitoba Health's vision for healthy Manitobans though an appropriate balance of prevention and care, it is important to coordinate areas for action that centre around their mission to provide the right care, in the right place, at the right time. There is also a need to ensure coordination and integration between and within various health and social sectors and programs. It is recognized that there are a number of ongoing initiatives within Manitoba that will have a positive impact on the care and support of persons with dementia and their families/caregivers. The possible overlap of action items from these various initiatives were considered as the Framework was developed. It is recognized that collaboration between various health, social and community agencies leading these initiatives will be needed to avoid duplication of effort, promote a collaborative spirit and provide a voice for dementia care. Such Manitoba initiatives include:

- The Continuing Care Blueprint,
- The Mental Health Strategy,
- The Aging in Place Strategy,
- Age Friendly Manitoba,
- Healthy Together Now (Chronic Disease Prevention Initiative),
- Spiritual Health Care Strategic Plan,
- Primary Care Reform, and
- Activities related to the Caregiver Recognition Act.

The voice of the caregivers was also seen to be an important aspect of the development and validation of the renewed Framework. As extensive caregiver consultations have been held with Manitoban and Canadian caregivers in the recent years (Funk, 2012; Greenberg, 2013; Manitoba Alzheimer Strategy Overview Committee, 2011; Statistics Canada, 2013), a focused approach to validate the Framework's proposed strategic directions was taken. Feedback from these focused caregiver consultations aligned with themes from reports of the previous larger consultations and are reflected in the strategic opportunities outlined in the Framework. Feedback from caregivers includes the need for:

- Assistance with system navigation,
- Information about existing programs and services,
- Strengthening and improving access to existing programs and services,
- Further training and education for health and social services staff,
- Increasing awareness of caregiver contributions and support needs, and
- Creation of more flexible workplace and financial policies that support caregiving obligations.

Manitoba's Framework for Alzheimer's Disease and Other Dementias

Goal: To serve as a roadmap over the next five years to guide Manitoba's health system planning and investment to improve care and support for Manitobans with dementia, and their families/caregivers.

Guiding Principles:

- All care and services will be provided through a person-centred approach, with a focus on respect for the person with dementia,
- An ethical approach to decision-making and care and service provision will be promoted,
- An evidence-informed process and information will be used in decision-making, practice, and care and service delivery.

Guiding Principles: In support of the overall goal, the Framework's guiding principles address the concepts of a person-centred, ethical and evidence-based approach to dementia care and services. These principles are key to guiding the development and enhancement of services for people with dementia and will act as the lens in which all futures strategies and specific measures will be considered.

Responses to Dementia and Corresponding Strategic Themes:

1. Raising Awareness and Understanding

In 2011, an on-line survey of Canadians suggested that the general public is unfamiliar with crucial information pertaining to dementia. When asked to identify signs of Alzheimer's disease, 75% per cent recognized memory loss as an early warning sign. However, more than half of the respondents were not able to describe other critical symptoms such as: loss of interest/withdrawal from activities, mood and behaviour changes, language difficulties, placing things in inappropriate places, and poor reasoning and judgment (Alzheimer Society of Canada, 2012).

Increasing public awareness of dementia and its effects is desirable as it has been found to reduce the stigma attached to dementia, build community capacity to enhance the support of persons with dementia within their community, and improve early diagnosis and treatment (ADI, 2012).

Specific to enhancing community capacity, the Age-Friendly Manitoba initiative supports seniors in leading active, socially engaged, independent lives that contribute to healthy aging. The Seniors and Healthy Aging Secretariat works with partners and local communities to create environments that value older adults and all members of the community. Their vision is to create communities that:

- Value and support the contributions of older people;
- Celebrate diversity, refute ageism and reduce inequities; and
- Provide age-friendly environments and opportunities for healthy choices that enhance independence and quality of life.

Currently there are over 100 Age-Friendly communities in Manitoba registered with the program.

Although not specific to the support and care for persons with dementia, there exists an opportunity for collaboration with the Age-Friendly Manitoba initiative to build and foster dementia-friendly communities to support individuals living well with dementia in their home community.

A growing body of evidence indicates that a healthy lifestyle, one that includes healthy eating, physical activity, smoking cessation, control of chronic conditions such as hypertension, and promotion of brain health, can reduce the risk of developing certain types of dementia.

Healthy Together Now, formerly the Chronic Disease Prevention Initiative, is an ongoing program that supports communities across Manitoba in their efforts to prevent chronic diseases such as cancer, diabetes, arthritis, cardiovascular, renal and pulmonary disease. Healthy Together Now projects work to address the three major risk factors that lead to chronic disease: smoking, physical inactivity and unhealthy diets, as well as support efforts to promote mental well-being.

Participating communities develop programs and activities to address the risk factors affecting their community members.

There is a need to increase individual and community awareness and recognition of risk factors and reduction strategies to reduce the likelihood of developing dementia or to delay the onset of dementia. The Healthy Together Now strategy does not address dementia specifically, however, the target risk factors are also relevant to reduction of risk for dementia. An opportunity exists to develop linkages to existing prevention programs, such as Healthy Together Now, as well as expand awareness in relation to other preventative strategies for dementia including head injury protection and mental well-being.

Gaps and Opportunities

Two strategic themes emerged under the Response 'Raising Awareness and Understanding'. The following gaps and opportunities are provided for each theme;

RESPONSE TO DEMENTIA

Raising Awareness and Understanding

Strategic Issues	Gaps/Opportunities
Prevention and Risk Reduction	■ Promote recognition of dementia as a chronic condition that may be amenable to preventative interventions ■ Develop linkages to existing prevention initiatives and mechanisms (e.g. Healthy Together Now, Mental Health Strategy) to include dementia in these prevention activities ■ Expand prevention strategies to include dementia-specific factors, including head injury protection ■ Provide public messaging regarding health promotion and preventable risk factors relating to dementia
Raising Awareness	■ Develop and implement a public and service provider information campaign regarding; ● Symptoms, importance of early intervention, reducing stigma, and recognition and role of caregiver; and ● Available supports and services ■ Build community capacity to create dementia-friendly communities (e.g. linkages to Age Friendly Communities and volunteer recruitment and training initiatives)

2. Early Recognition and Initial Assessment and Diagnosis

Early recognition and diagnosis of dementia is desirable as it facilitates appropriate treatment options and support for the individual and family/caregiver early in the dementia journey. It promotes a proactive approach to dementia care and support by preventing crisis situations that ultimately arise if the disease is recognized late in its progression. Early multi-component support for caregivers is the only intervention that has been shown to reduce or delay admission to a long-term care facility (ADI, 2013).

In Manitoba, primary care physicians are the main practitioners who assess and confirm diagnoses of dementia. Specialist support is available for consultation in atypical presentations and includes geriatric mental health, geriatric medicine and neurology physician specialists and clinicians. At present, a coordinated single-access referral system for specialists in dementia care is not in place and referrals are based on practitioner preference. Access to urban-based specialists from rural settings is sometimes accommodated through Telehealth sessions, but in many cases, specialist access in rural settings for consultation support is limited.

In general, access to medical specialists in dementia care in Manitoba is available but limited due to insufficient numbers of geriatricians, neurologists and psychiatrists specialzing in geriatric and dementia care. When compared to other provinces, Manitoba has the third lowest number of certified geriatric medicine specialists and approximately half the ratio of certified specialists per 10,000 individuals over the age of 65 (Hogan et al, 2012). Due to the lack of new recruits to the specialty in Manitoba, over the next decade this resource will become increasingly sparse unless a targeted training and recruitment strategy is organized and priortized.

As the majority of diagnoses are made by primary care physicians and nurse practitioners, access to primary care providers is crucial to support timely assessment and diagnosis. To increase access to primary care providers, a number of primary care initiatives have been launched in the province including; the Physician for All by 2015 campaign, development of Primary Care Networks, expansion of the Access Centre model in Winnipeg, expansion of the nurse practitioner primary care model in PCH and community, and launch of Mobile Primary Care Clinics to rural and remote communities.

Current Canadian Consensus Guidelines exist to support evidence-informed diagnosis and treatment of dementia. Ongoing primary care physician education on dementia assessment and management has been limited in the province. There is opportunity to collaborate on an existing Ontario-developed certification program promoting the care of the elderly that could potentially be offered to primary care physicians in Manitoba by local specialists, which represents an opportunity to build capacity and local physician experts and mentors in geriatric care.

Three strategic themes emerged under the Response 'Early Recognition and Initial Assessment and Diagnosis'. The following gaps and opportunities are provided for each theme;

RESPONSE TO DEMENTIA

Early Recognition and Initial Assessment and Diagnosis

Strategic Issues	Gaps/Opportunities
Diagnosis and Treatment	■ Develop and promote linkages to Primary Care Reform initiatives to enhance access to timely assessment and diagnosis ■ Enhance curricula in relation to dementia and cognitive impairment in post-graduate medical programs, nurse practitioner and physician assistant programs ■ Develop and promote primary care physician/provider information, education and resources pertaining to dementia ■ Promote use of diagnostic and treatment guidelines [4th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCTDT4), DSM-V] ■ Review process and access for additional diagnostic support from specialists ■ Enhance rural support and access to specialists
Medical Specialist Resources	■ Develop a health workforce strategy to recruit and retain additional geriatricians, neurologists with an interest in dementia and geriatric psychiatrists to Manitoba ■ Promote the Care of the Elderly Enhanced Skills Program to primary care physicians ■ Investigate the opportunity to offer a care of the elderly certificate course in Manitoba delivered by local specialists
Initial Individual and Caregiver Information/ Support	■ Develop and provide support mechanisms at time of diagnosis (e.g. dementia information package, linkage to support services, caregiver needs assessment – current and future) ■ Implement dementia support and resource centres [e.g. PRISMA (Quebec), MAIA (France) model] or system coordinators/ navigators for post-diagnostic support

3. Management, Care and Support

It is recognized that all people living with dementia will experience each response uniquely and will journey through the responses to dementia at a different pace. Following diagnosis, persons with dementia and their families/caregivers will need ongoing support and person-centred care which can be customized to their changing needs. The contribution and involvement of families/caregivers also needs to be recognized and valued and support provided for their caring role.

Best practice management, care and support of persons with dementia and their families/caregivers entails many aspects such as: access to appropriate care and services at the right time, system navigation and coordination, accessible and affordable community and residential living options, workforce education, and support and resources for caregivers.

Available Programs and Services

Many programs and services currently exist to support the needs of persons with dementia and their caregivers/families. Manitoba has an integrated, coordinated Home Care Program that provides in-home services and support based on an individual assessment, as well as access to respite services including day programs.

Geriatric programs and services include out-patient Geriatric Day Hospitals in Winnipeg that provide assessment and short-term treatment, as well as outreach geriatric assessment and geriatric mental health teams/services in both urban and rural areas. Personal Care Homes provide personal care services to individuals who can no longer manage independently at home with family support and/or community services such as Home Care and where other assisted and supportive housing options are not suitable.

In addition to these well-established services, enhancements to available programs to support frail, complex elderly individuals have been made in recent years. In Winnipeg, two programs have been developed and piloted with the goal to support and maintain these individuals living in the community. PRIME: A Health Centre for Seniors based out of Deer Lodge Centre provides alternatives to entering a PCH by offering an all-inclusive health service including medical care, personal care, socialization and exercises, after hours support, rehabilitation, day program, Home Care coordination and access to a team of health care professionals.

Also, the Hospital Home Team (HHT) initiative is a highly integrated inter-professional team linking Home Care with community-based health and social services. The resulting interdisciplinary care maximizes client functioning (reablement) thereby maximizing independence in the community. The outcome is reduced hospitalization and emergency department visits. The HHT targets individuals with unstable/complicated health conditions, although not specific to, but can include individuals with dementia.

This project was implemented at two hospitals in Winnipeg and will now be expanded to others based on the success of the initial sites. Although these initiatives are currently based in Winnipeg, the opportunity exists to expand these two program models to rural settings.

Community and Residential Living Options

In 2006, the *Aging in Place Long Term Care Strategy* was introduced which focused on home-based services and community living options to support individuals to age in their homes and communities as they grow older.

Through the Aging in Place strategy, there has been an increase in the number of Supportive Housing units made available in Winnipeg and rural communities (528 in Winnipeg and 202 in rural Manitoba as of December 31, 2013). Since 2006, there also have been more than 3,500 units of Supports to Seniors in Group Living (SSGL) and 113 Specialized Supports spaces established for individuals with complex needs (Manitoba Health, 2013).

Although much progress has been made in establishing these spaces and programs, more work is needed to address challenges with the various existing models and to explore alternative housing with service models that will allow older adults, including those with dementia, to remain safely in their communities for as long as possible.

There are currently 125 licensed PCHs (9,715 PCH beds) operating in Manitoba (as of March, 2013). The demand for PCH beds is anticipated to be stable until approximately 2021, and is predicted to grow more dramatically with the aging of the baby boomer demographic. In recent years, Government has committed to funding the development of new PCHs in the province, and efforts have been made to improve the quality of existing PCHs.

Improvements and committed expansions to residential and long-term stay programs for complex cognitive (behavioural) care have been made. These include: the past redevelopment of the Selkirk Mental Health Centre geriatric mental health and acquired brain injury programs; the establishment of new special care unit beds in rural Manitoba and Winnipeg; and commitments to the expansion of behaviour care beds in Winnipeg.

Workforce Dementia Education

The development, maintenance and recognition of a skilled workforce are crucial to support best practice dementia care. Multi-level dementia training that includes all individuals who provide aspects of care and services to persons with dementia and their families/caregivers has been shown to promote skill development, enhance communication and approach, provide recognition of valued work contributions and promote staff retention (ADI, 2013).

In Manitoba, funding to offer the P.I.E.C.E.S.™ education program to staff in PCHs has been provided for the past 5 years. As of March 31, 2013, nearly 1,600 licensed PCH staff members (such as nurses, social workers, recreational and rehabilitation professionals, etc.) attended the P.I.E.C.E.S.™ education program. Additionally, modules for non-licensed staff (such as care aides, environmental services staff, recreation assistants, etc.) have been developed and delivered by various educators. Currently, an evaluation of the P.I.E.C.E.S.™ education program is underway to inform future planning as to the best approach to dementia education in the province.

In 2012-2013, the Enhanced Orientation Program for Nurses New to Long-Term Care was implemented provincially based on a successful pilot project in Winnipeg. Through mentorship and education, this program aims to attract and retain nurses to the long-term care area of practice by enhancing confidence, leadership ability, and knowledge in geriatric care. The education portion of the program includes foundational information on the assessment and care of residents with dementia and complex cognitive (behavioural) care needs. Provincial funding is provided to allow the new nurses to be paid to attend the workshop sessions.

Although much work and commitment has been made in the area of dementia education in Manitoba, most of these energies have been focused on the long-term care area. Expansion of dementia education programs into other areas of health care (e.g. community and acute care), social services (e.g. community/housing support staff) and public sectors (e.g. financial/banking, police, etc.) is needed.

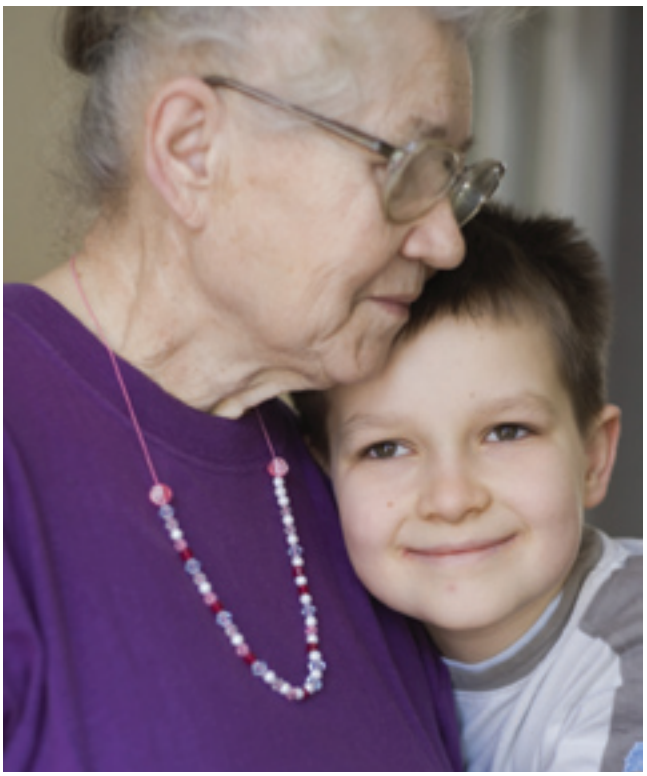
Caregiver Support

Early multi-component, professionally-led interventions for caregivers, including education, training, support and respite, help maintain caregiver mood and morale and reduce strain. It is the only intervention that has been proven to reduce or delay transition from home to a long-term care facility (ADI, 2013).

In 2011, the Manitoba government proclaimed the *Caregiver Recognition Act*. This legislation made a long-term commitment to increase support and recognition of the valued role and contribution of caregivers in Manitoba. The *Act* outlines general principles relating to caregivers and also includes a provision for the appointment of a Caregiver Advisory Committee to provide information, advice and recommendations pertaining to caregiver supports, programs/services and recognition to the Minister responsible for Healthy Living and Seniors.

In 2012, consultations were held with 400 Manitoba caregivers to identify issues and concerns and the Caregiver Advisory Committee has met to discuss the findings and identify potential solutions. Caregiver recognition events and education sessions have been held and caregiver resources have been developed or updated, such as *"A Guide for the Caregiver: Information and Resources for Caregivers of Older Adults"*.

Other online provincial and national caregiver resources are also available and include resources from the Seniors and Healthy Aging Secretariat, the Manitoba Caregiver Coalition, Manitoba Hospice and Palliative Care, Canadian Virtual Hospice, and Canada Cares.



In 2012, funding to establish the First Link® program in Manitoba through the Alzheimer Society of Manitoba was initiated. First Link® is a referral program for health-care professionals to link individuals and families/ caregivers affected by dementia with support as soon as possible after diagnosis. Available supports include information, support groups, supportive counselling, education sessions and referral to other health resources as needed.

And lastly, a new Home Care initiative is in the early stages of development that aims to support caregivers on two fronts by;

- Providing an information package to caregivers upon admission to the Home Care Program, and
- Offering education to Home Care staff on how to communicate with caregivers and involve them in the care planning process.

Five strategic themes emerged under the Response 'Management, Care and Support'. The following gaps and opportunities are provided for each theme;

RESPONSE TO DEMENTIA

Management, Care and Support

Strategic Issues	Gaps/Opportunities
Best Practice Dementia Care	■ Support and educate staff regarding person-centred culture change across all programs/services ■ Promote best practice complex cognitive (behavioural) care approaches [i.e. psychosocial (non-pharmacological) interventions, guidelines for psychotropic drug use and monitoring, clear definition of chemical restraint] ■ Develop an organized, formalized provincial dementia network with a mandate to determine, disseminate and educate re: best-practice dementia care

RESPONSE TO DEMENTIA

Management, Care and Support

Strategic Issues	Gaps/Opportunities
Education and Training of a Skilled Workforce	■ Review and enhance curricula in relation to dementia and cognitive impairment in formal health provider education programs (e.g. post-graduate medicine, nursing/nurse practitioner, physician assistant, rehabilitation, social work, health care aide, etc.) ■ Develop a standardized multi-level education program with varying degrees of training/content based on area of work and type of involvement/interaction with persons with dementia ■ Expand dementia education to other health and service sectors beyond PCH ■ Partner with the Manitoba Provincial Health Ethics Network to raise awareness regarding ethical issues arising with dementia
Care Coordination/ System Navigation	■ Develop and implement a system navigation/case coordination model (e.g. case managers or dementia support centres) ■ Develop and implement dementia care pathways ■ Promote and educate teams on Interprofessional Collaboration/ Practice and models of care
Available/Accessible Programs and Services	■ Continue to explore and expand community housing options/ models and affordability/funding models ■ Expand model and settings for respite services (e.g. outside of PCH setting) ■ Develop/enhance intermediate care alternatives to acute hospital care (e.g. rehabilitation programs or sub-acute units to promote return to community after hospitalization) ■ Enhance the PCH care experience (e.g. design, approach to care, programming, rehabilitation services funding)

RESPONSE TO DEMENTIA

Management, Care and Support

Strategic Issues	Gaps/Opportunities
Available/Accessible Programs and Services	■ Develop a dementia mobile community crisis outreach teams/ services ■ Develop an emergency/crisis response strategy and plan for the safe care of individuals whose complex behavioural situation poses an emergent risk to self and others (e.g. mobile community response, and/or temporary assessment and treatment program(s), etc.) ■ Develop and implement a plan for diverse needs groups (e.g. young-onset dementia, learning disabilities, etc.) ■ Review age restrictions for Geriatric Mental Health (GMH) services (i.e. individuals with dementia under age 65)
Family/Caregiver Support	■ Increase availability and flexibility of respite resources/services, adult day programs, Home Care services ■ Enhance and provide ongoing caregiver training and education programs ■ Facilitate one-stop information access (e.g. e-portals, helpline, virtual dementia care resources) ■ Promote family/caregiver involvement in care planning discussions and decisions; empower and support their advocacy role ■ Adopt and implement a caregiver needs assessment tool and facilitate development of plans to support caregiver needs ■ Enhance and provide alternative models for peer support (e.g. online, social media, etc.) ■ Investigate and develop flexible community support models for persons with dementia and their families/caregivers (e.g. Dementia café, Tea Houses, etc.) ■ Develop financial assistance/programs ■ Develop flexible workplace policies

4. End of Life

In the absence of a cure, dementia is considered a terminal illness and persons with dementia and their families/caregivers require appropriate care and support tailored to their needs, from the beginning to the end of their dementia journey. Planning for end of life care begins following a diagnosis of dementia, so the person living with dementia can choose to take part in planning their own health care and defining their future care wishes. These early discussions can also facilitate financial and legal planning with families/caregivers. Defining end of life care for persons with dementia and determining when to initiate these discussions presents an unique challenge in dementia due to the progressive nature of the disease over time, in some cases, representing a span of multiple years.

Advanced care planning is a series of steps people take to help them consider and plan for future medical care, so that in the event they are unable to speak or act on their own behalf, their wishes are known and respected. The advanced care planning process has been promoted throughout Manitoba over the past number of years. Within health care sectors, the Advanced Care Plan/Goals of Care process and documentation of conversations with individuals and their families is well established. In the community sector, use of tools such as the Emergency Response Information Kit (ERIK) is encouraged.

Despite the effort to raise awareness about the importance of advanced care planning, there still appears to be some knowledge gaps in this area; both in the importance of initiating these discussions early in the journey of chronic disease, and in relation to the legal and financial options available to individuals and their families/caregivers.

Spirituality is an important aspect of a person's life and is a journey that continues throughout the lifespan into end of life. It has been defined as the beliefs and practices that develop a person's personal values and concept of meaning relating to the purpose of life. There are three components to an individual's spiritual dimension: making personal meaning (which may or may not include connection to a higher life source), coming to an understanding of self, and appreciating the need and value of connections with others (Manitoba Health, 2012).

Manitoba's Spiritual Health Care Strategic Plan was developed to advance and implement spiritual health care as an integral component of holistic health care in Manitoba through: raising awareness, maximizing opportunities for education and knowledge-sharing, building spiritual health care service in health care, and assessing spiritual health needs and enhancing the scope and availability of spiritual health care services (Manitoba Health, 2012). To align with this strategy, there exists an opportunity to ensure these concepts are prominent in end of life approaches and programs for dementia care.

End of life care, or palliative care, refers to the care provided to people of all ages who have a life-limiting illness, including dementia, with little or no prospect of cure. The primary goal of palliative care is quality of life. This type of care involves managing symptoms associated with the illness, while also addressing the physical, emotional, spiritual, social and cultural needs of the person and his/her family/caregivers. End of life care for persons with dementia requires a person-centred approach which is flexible and reflects ongoing assessment, attention to distressing symptoms and an emphasis on promoting quality of life and respect. End of life care supports are available within the province, through health care-based services such as the Home Care program and Palliative Care outreach teams and clinicians, and in-patient Palliative Care units/beds to assist with symptom management. Staff in PCHs also provide end of life care to residents and support to family members.

Annual educational offerings on end of life care are available to staff working in the health care field. In addition, Manitoba Hospice and Palliative Care is an organization that promotes compassionate, effective care for all Manitobans touched by any life-threatening condition or bereavement and provides services and education complementary to the formal health care system.

Traditionally, the need for end of life, or palliative care, has been largely associated with terminal conditions such as progressive cancers or organ/system failure. Further work is needed to ensure that end of life care education available to staff, families and caregivers recognizes dementia as a terminal condition, but distinct from traditional palliative care programs and approaches, and addresses the individual's end of life care needs and approaches that are unique to dementia.

One strategic theme emerged under the Response 'End of Life'. The following gaps and opportunities are provided;

RESPONSE TO DEMENTIA

End of Life

Strategic Issues	Gaps/Opportunities
Best Practice End of Life Care	■ Promote earlier recognition of dementia to facilitate earlier discussions and education surrounding future care wishes ■ Provide public information campaign regarding the importance of legal and financial planning for future scenarios, e.g. Advanced Health Care Directives (AHCD), the Emergency Response Information Kit (ERIK), Health Proxy, Power of Attorney (POA), etc. ■ Promote an ethical decision-making process through utilization of ethical frameworks and provision of ethics education to all care/service providers ■ Provide care/services provider education on end of life care specific to dementia (as part of dementia care education program) ● Incorporate information specific to educating/informing families and caregivers about end of life care in the PCH setting/context ■ Facilitate family/caregiver education and information needs at end of life and bereavement care/support ■ Embed spiritual health care principles in all aspects of end of life programming and services

5. Research and Evaluation

Research is paramount to promoting best practice dementia care and ultimately, a future cure. Additional funding and focus on dementia research is needed in numerous domains including bio-physical (discovery of a cure; prevention and reducing risk of dementia), pharmacological (medical treatments), psychosocial (symptom management; social-emotional aspects of living with dementia), knowledge translation (research into practice), evaluation of the effectiveness of dementia programs/services, and population health measures. Some sources call for a transformation of priorities in health research and the need for a ten-fold increase in investment for dementia research to bring funding in line with other health conditions (ADI, 2013).

Canadian efforts to enhance research related to dementia include the recently established Canadian Consortium of Neurodegeneration in Aging (CCNA), in which Manitoba is a stakeholder. Also, Phase 1 of the Alberta-based Translating Research into Elder Care (TREC) project is complete and the project (TREC2) has received 1.2 M in funding for the next six years to continue this important work on knowledge translation in elder care approaches.

In Manitoba, the Manitoba Centre for Health Policy and the Centre on Aging are research and academic-affiliated organizations that have supported or engaged in research relating to dementia and/or older adults.

There are also a number of Manitoba-based independent researchers currently engaged in dementia research. However, currently a coordinated or collaborative approach to dementia research in Manitoba does not exist. Funding sources for dementia research are available through the Manitoba Health Research Council and the Alzheimer Society of Canada.

Access to best practice information on gerontological issues and literature is available through a specialized library resource, the J.W. Crane Memorial Library of Gerontology and Geriatrics located at Deer Lodge Centre. The Crane Library is Canada's largest and best-known special library on aging and long-term care. The resource is available to individuals with University of Manitoba Libraries access.

Ongoing evaluation of programs' and services' quality measures is also an important contributor in striving for excellence in dementia programming and support. To be the most effective, it is recommended that quality related to dementia care and service evaluation be measured by three dimensions (ADI, 2013);

- Structures (available resources),
- Process (care that is delivered), and
- Outcomes (excellence in care and quality of life).

Historically, program evaluation has tended to focus on the former two dimensions; structures and resources. More attention is needed to examine the outcomes of care and services provided to determine if they have impact on improving the quality of life of persons with dementia and their families/ caregivers.

In the Home Care Program and PCH sector, efforts have been made to standardize collection of assessment data and quality indicators relating to clients/residents in care. In Winnipeg, the Resident Assessment Instrument-Minimum Data Set (RAI-MDS) tool was implemented to support this consistent approach to quality measurement and improvement. The information collected and reported from the RAI-MDS tool allows for quality monitoring and benchmarking internally within areas of the program or site, and externally with other sites in the health region, across Canada and internationally. Implementation of the RAI-MDS tool in rural Manitoba PCHs and Home Care is pending.

Every two years, PCHs in Manitoba are assessed against the Manitoba Personal Care Home Standards established in the *Personal Care Homes Standards Regulation under the Health Services Insurance Act*. This assessment includes the ability to meet standards relating to: protecting and ensuring residents' rights, the provision of resident-specific care and education for staff in areas of elder care.

Also, in relation to the long-term care sector, the PCH Quality Care Measures survey and initiative conducted by the Manitoba Centre for Health Policy, is in process. This project aims to determine select suitable measures of PCH quality care that would be reported publically to promote transparency and assist in the informed decision-making about long-term care placement of a person with dementia.

Some standardized quality measurement efforts are evident in the Home Care Program and long-term care sector in Manitoba, but require further enhancements and expansion. Inclusion of outcome indicators demonstrating excellence of care/ service and improved quality of life is needed in all areas of evaluation.

One strategic theme emerged under the Response 'Research and Evaluation'. The following gaps and opportunities are provided;

RESPONSE TO DEMENTIA

Research and Evaluation

Strategic Issues	Gaps/Opportunities
Capacity for and Utilization of Evidence-Informed Decision-Making and Processes	■ Promote awareness of current clinical research/knowledge translation supports (e.g. U of M/WRHA Centre for Health Care Innovation) ■ Develop a strategy to attract students and researchers to this area (e.g. partnerships to increase local grant monies, funding for a dedicated Dementia Research Chair position) ■ Develop a coordinated approach to dementia research in Manitoba ■ Clarify and strengthen MB role/visibility in the Canadian Consortium of Neurodegeneration in Aging (CCNA) ■ Integrate CCNA activities with Canadian Longitudinal Study on Aging (CLSA) for recruitment, intake for trials, etc. ■ Expand RAI/MDS across the continuum of care throughout Manitoba ■ Enhance evaluation of dementia programs by including; structures (available resources), process (care that is delivered) and outcomes (excellence in care – quality of care/life) ■ Develop an evaluation plan for the renewed Framework

Conclusion

Much has been achieved and implemented since the 2002 Strategy for Alzheimer's Disease and Related Dementias in Manitoba, but there is still much more work to be done. This renewed Framework provides a roadmap that outlines gaps and strategic opportunities with the goal to further enhance the care and services for persons with dementia and their families/caregivers in Manitoba.

To achieve this goal, we will need to build on past successes, learn from the collective experiences and work of other provincial and international pioneers in dementia care and service, and incorporate new innovations into Manitoba's strategic plan to enhance dementia care and services throughout the province. Through a collaborative approach that includes government departments, health regions, social service sectors and community-based partners, we will be successful.

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