GOVERNMENT OF BERMUDA

Ministry of Youth, Social Development and Seniors

2025

DEMENTIA INTEGRATED CARE PATHWAY (ICP) REPORT

Contact us

To learn more about the Dementia Integrated Care Pathway or the Ministry of Youth, Social Development and Seniors, please contact us. For technical questions, contact the Bermuda Health Council. We look forward to hearing from you.

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Bermuda Hospitals Board

- Emergency Room staff
- Geriatric Medicine team
- Hospitalist team
- Nursing and Allied Health teams
- Mid-Atlantic Wellness Institute team

Department of Health team

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Community and Care Organisations

- Bermuda Wellness and Outreach Centre
- Westmeath Residential and Nursing Care Home & Day Activities Program

MINISTERIAL FOREWORD

Dementia touches the lives of individuals and families across our community. As our population ages, the need for coordinated dementia care has become more urgent than ever.

The 2024 National Seniors Strategy highlighted dementia because of its significant impact on individuals, families, and the wider community, as well as the government's commitment to addressing this growing public health issue. Healthy Ageing is the focus of Pillar One in the Seniors Strategy, which emphasizes improving our understanding of dementia in Bermuda and developing initiatives that address gaps and challenges related to the disease Dementia, and its effects on our society.

To help develop sustainable solutions for addressing gaps, in July 2024, the Ministry of Youth, Social Development and Seniors commissioned the Bermuda Health Council to create an Integrated Care Pathway for Dementia. This work was developed in consultation with the Council's dementia health needs assessment and in alignment with the Ministry of Health's Bermuda Health Strategy 2022–2027. This Pathway represents a significant step forward in addressing gaps in our current system. For too many Bermudians, the journey with dementia has meant confusion, isolation, and exhaustion. The Dementia Integrated Care Pathway aims to change that by connecting health, social care, and community supports for people living with dementia and their caregivers.

Every Bermudian family deserves clear answers and coordinated support if dementia touches their lives. We are committed to standing with them, particularly those most vulnerable, including low-income families, non-Bermudian residents, and isolated seniors.

I greatly appreciate the work of the Bermuda Health Council in producing this report, and I thank all stakeholders who contributed to its development. I welcome the Dementia Integrated Care Pathway as a foundation for building a more responsive, person-centred system of dementia care for Bermuda. The work begins now.

The Hon. Tinee Furbert, JP, MP
Minister of Youth, Social Development and Seniors

GOVERNMENT OF BERMUDA
Ministry of Health

MINISTERIAL FOREWORD

Bermuda is entering a demographic transition that will shape our future for decades to come. By 2026, nearly one in four persons will be age 65 or older. With an ageing population comes a rising prevalence of dementia; a syndrome that has profound impacts not only for individuals, but also for families, caregivers, our health system and society at large. Already, dementia is among the most costly conditions for our island, placing a strain on resources while deeply challenging the lives of those affected.

Dementia is more than a clinical diagnosis. It is a lived experience that affects memory, identity, independence and the bonds that bring families and communities together. The progression of dementia can often bring fear, stigma, and uncertainty for an individual. Caregivers may experience exhaustion, financial stress, and isolation. Therefore, it is imperative that our health system is part of a well coordinated response that bridges medical, social, and community services.

This is why the Integrated Care Pathway for dementia is so vital. Grounded in the pillars of the National Seniors Strategy 2024-2030 and the Bermuda Health Strategy 2022-2027, it advances the vision of healthy ageing and person-centered care to preserve dignity, empower families, and strengthen community resilience. The Pathway highlights the importance of early detection through systemic screening, the provision of multidisciplinary medical and social supports, and the integration of formal and informal caregivers into a unified network of care. It also underscores the need for compassionate and well-planned end of life support, ensuring that our seniors are treated with the respect they deserve throughout the final stages of life.

At its core, this Pathway is about closing gaps in our current system by increasing awareness, reducing stigma, expanding dementia-ready services, and ensuring that no family bears this burden alone. It recognizes that seniors are in a vulnerable life stage and that protecting their dignity is both a health and social imperative.

The Ministry of Health, in close collaboration with the Ministry of Youth, Social Development and Seniors, is committed to ensure that healthcare is supplemented by social services, and that accessible solutions are embedded within the community. This Pathway serves as a practical, evidence-based guide to better coordinate services, strengthen partnerships, and build a dementia-friendly Bermuda.

We owe it to our seniors of today and tomorrow to act with urgency, compassion and unity. The Integrated Care Pathway for Dementia is a key step in the commitment, and I encourage all stakeholders, professionals, caregivers, and community members to join us in making this vision a reality.

The Hon. Kim Wilson, JP, MP
Minister of Health

BERMUDA HEALTH COUNCIL FOREWORD

The recently published Joint Strategy Needs Assessment highlights the category of mental, behavioural, and nervous system diseases as the third leading cause of mortality in Bermuda. Within this category, dementia stands out as the most common diagnosis, significantly impacting the health of our population. Additionally, dementia ranks as the second most costly condition in terms of insurance claims during 2020–2021, underscoring its substantial economic and social burden.

Recent media reports and anecdotal evidence indicate that the situation is worsening. Many people, as they age, are facing increasing challenges with dementia and our hospitals are experiencing pressure from a rising number of dementia patients who are unable to be discharged for various reasons. Family members and caregivers often find themselves overwhelmed, struggling to provide adequate care, further hindering healthcare resources.

Without targeted and sustained intervention, this issue will likely intensify as Bermuda's population continues to increase in average age. The rising prevalence of dementia will place additional demands on healthcare services and community support systems, necessitating urgent action.

In response, this Integrated Care Pathway is designed to combine insights from local experts with the best available evidence from around the world. The goal is to develop a tailored, Bermuda-specific approach that effectively addresses current needs while adapting to future challenges. This pathway builds upon previous work, including the comprehensive Dementia Health Needs Assessment, to ensure a cohesive and strategic response that improves outcomes for individuals living with dementia, supports their families, and relieves the pressure on our community and healthcare system.

Dr. Ricky Brathwaite
Chief Executive Officer

GLOSSARY OF TERMS

A

- **Activities of Daily Living (ADLs):** Basic self-care tasks such as eating, bathing, dressing, toileting, and mobility.
- **Ageing and Disability Services (ADS):** The government department that supports older adults and people with disabilities in Bermuda.
- **Adult Day-Care Programmes:** Community-based services that provide supervised care, social activities, and limited health or personal support to adults during daytime hours, offering respite for caregivers and promoting participant well-being.
- **Advance Care Planning (ACP):** The process of discussing and documenting a person's preferences regarding future healthcare, including treatment choices and end-of-life care.
- **Alzheimer's Disease:** A progressive neurological disorder and the most common cause of dementia, characterised by memory loss, cognitive decline, and behavioural changes.
- **Assessment:** The process of evaluating an individual's cognitive, functional, and medical status to determine the presence and progression of a disease (dementia)

B

- **Behavioural and Psychological Symptoms of Dementia (BPSD) / Responsive Behaviours:** A range of non-cognitive symptoms that individuals with dementia may experience, including agitation, depression, anxiety, and hallucinations.
- **Best Practices:** Evidence-based approaches and strategies that have been proven effective in care and management.

C

- **Capacity (Mental Capacity):** The ability of an individual to make decisions for themselves. A person is considered to have capacity if they can understand, retain, weigh, and communicate their decision, using relevant information. Capacity is decision-specific and may change over time. If a person is unable to perform any of these steps, they may be deemed to lack capacity for that particular decision at that time. Capacity assessments should be conducted when necessary and reassessed as needed.
- **Care Coordination:** The organisation of care activities between healthcare providers, caregivers, and social services to ensure seamless, person-centred care.
- **Caregiver:** An individual (formal or informal) who provides care and support to a person living with dementia, or with other care needs, including family members, friends, and professional care staff.
- **Cognitive Stimulation Therapy (CST):** A structured programme of group or individual activities designed to improve cognitive function and quality of life in people with dementia.

- **Community-Based Care:** Care provided outside of institutional settings, including home care, adult day programmes, and community health services, including services for persons with dementia.
- **Comprehensive Geriatric Assessment (CGA):** A multidimensional assessment to evaluate the medical, psychological, and functional capabilities of older adults, including those with dementia.

D

- **Delirium:** A sudden change in mental status, often temporary, marked by confusion, disorientation, and difficulty focusing attention.
- **Dementia:** An umbrella term for a group of cognitive disorders that affect memory, reasoning, communication, and daily functioning.
- **Dementia Care Pathway:** A structured, evidence-based approach to diagnosing, treating, and supporting individuals with dementia and their caregivers throughout the disease.
- **Dementia-Friendly Community:** A community designed to be inclusive and supportive of people living with dementia (PLWD), enhancing accessibility, awareness, and social inclusion.
- **Department of Health (DoH):** The government department responsible for public health programmes, regulation, and services in Bermuda.
- **Diagnosis:** The process of identifying a disease (dementia) through clinical evaluation, cognitive testing, neuroimaging, and other medical assessments.

E

- **Early-Onset Dementia:** Dementia that develops before the age of 65, often presenting unique challenges for diagnosis and care.
- **Electronic Health Record (EHR):** A digital record of a patient's health information designed to be shared across healthcare providers and settings, supporting coordinated and integrated care.
- **Electronic Medical Record (EMR):** A digital version of a patient's chart within a single healthcare provider's practice, containing medical and treatment history.
- **End-of-Life Care:** Support and treatment provided in the final phase of life, focused on comfort, dignity, and quality of life.
- **Enduring Power of Attorney (POA):** A legal document that grants an appointed person the authority to make healthcare and financial decisions on behalf of someone with cognitive impairment, including dementia.
- **Evidence-Based Practice:** Care approaches and interventions that are backed by rigorous research and clinical evidence.

F

- **Frailty:** A clinical syndrome in older adults involving reduced strength, endurance, and physiological function, increasing vulnerability to adverse outcomes.

- **Functional Ability:** The capacity of a person to perform activities of daily living (ADLs) such as bathing, dressing, and eating.

G

- **General Practitioner with a Special Interest (GPwSI):** A General Practitioner who has undertaken additional training and practice in a specific field, such as geriatrics or dementia care
- **Geriatrics:** A branch of medicine focusing on health and care of older adults.
- **Geriatrician:** A medical doctor specialising in the care of older adults, including those with dementia.

H

- **Health Needs Assessment (HNA):** A systematic process used to identify the health and social care needs of a population.
- **Home Care:** Care services provided in an individual's home, including personal care, medical support, and respite services.

I

- **Integrated Care:** A coordinated approach to healthcare that ensures individuals receive seamless services across different sectors, including health, social care, and community support
- **Integrated Care Pathway (ICP):** A structured, evidence-based plan that outlines the key steps in diagnosis, treatment, and support for people with dementia, ensuring care is coordinated and consistent across health and social services.

L

- **Long Term Care (LTC):** A range of services for people with reduced physical or cognitive capacity who need ongoing help with daily living. It includes home care, day care, respite, rehabilitation, palliative, and related support services.

M

- **Mild Cognitive Impairment (MCI):** A condition that causes minor cognitive decline but does not significantly impact daily life. It may be a precursor to dementia.
- **Ministry of Health (MoH):** The government ministry overseeing health policy, planning, and services, including regulation and administration of healthcare in Bermuda.
- **Mini-Cog/Montreal Cognitive Assessment (MoCA)/Mini-Mental State Examination (MMSE)/Abbreviated Mental Test (AMT): T**hese are standardised tests used in the assessment of early stages of cognitive decline or dementia.
- **Multidisciplinary Approach:** A collaborative approach to care that involves healthcare professionals, caregivers, and social service providers.

- **Multidisciplinary Team:** A team of professionals from different fields (e.g., geriatricians, neurologists, social workers, and therapists) working together to provide comprehensive care.

N

- **National Institute for Health and Care Excellence (NICE):** A United Kingdom (UK)–based organisation that provides clinical guidelines and quality standards for healthcare, including dementia care.
- **Neurodegenerative Disease:** A progressive condition that affects brain function, including Alzheimer's disease and other forms of dementia.
- **Neuropsychological Assessment:** A series of tests used to evaluate cognitive function and detect early signs of dementia.

P

- **Palliative Care (End-of-Life Care):** Support and medical care provided during the final stages of life, focusing on comfort, dignity, and quality of life.
- **Person-Centred Care:** A care approach that prioritises the individual's preferences, values, and needs to enhance their well-being and dignity.
- **Preventive Strategies:** Public health and lifestyle interventions aimed at reducing the risk of developing illnesses and chronic diseases, such as adopting a healthy diet, engaging in physical activity, and maintaining cognitive engagement.
- **Primary Care Provider (PCP):** A licensed healthcare professional such as a physician, nurse practitioner, or physician assistant who serves as the first point of contact for patients, delivering comprehensive, continuous, and coordinated care, including prevention, diagnosis, treatment, and referral to specialty services as needed.
- **Public Guardian:** An appointed official or statutory office responsible for protecting the personal and/or financial interests of individuals who are unable to make or communicate decisions for themselves, ensuring their rights, well-being, and assets are safeguarded in accordance with the law.
- **Psychosocial Interventions:** Non-medical approaches, including therapy, counselling, and social engagement, to improve the well-being of people with diseases, including dementia.
- **People Living with Dementia (PLWD):** Refers to individuals who have received a dementia diagnosis and are living with the condition, whether at home or in care settings.

Q

- **Quality of Life (QoL):** The overall well-being and life satisfaction of individuals, influenced by physical, emotional, and social factors.
- **Quality Standards:** Benchmarks for care that define best practices and ensure consistent, high-quality services.

R

- **Receivership:** A legal arrangement in which a court appoints a guardian (receiver) to make decisions for a person who is no longer capable of making informed choices.
- **Respite Care:** Temporary relief for caregivers by providing professional care services for individuals.
- **Responsible Person:** An individual identified by or for an adult to assist with decision-making, provide consent where authorised, or serve as the main point of contact with care or service providers, ensuring the adult's needs, preferences, and best interests are supported.
- **Risk Factors:** Lifestyle, genetic, and environmental factors that contribute to the likelihood of developing a disease.

S

- **Screening Tools:** Cognitive tests and assessments used to detect early signs of disease, including dementia.
- **Stakeholder Engagement:** The process of involving key individuals and organisations in planning, implementing, and evaluating initiatives.
- **Support Groups:** Community or online groups that provide emotional and practical support to people living with challenges, including dementia, and their caregivers.

T

- **Telehealth:** Remote healthcare services, including virtual consultations and monitoring, that can support care.
- **Treatment Plan (Care plan):** A personalised plan outlining medical, therapeutic, and support interventions for a person.

W

- **Workforce Development:** Training and education programmes designed to equip healthcare providers and caregivers with the necessary skills.
- **Wandering:** A common behaviour in dementia where individuals move around aimlessly or become lost, requiring specialised safety interventions.

EXECUTIVE SUMMARY

"Estimated annual impact of dementia on Bermuda's economy: $94.5 million (1.5% of GDP)."

Dementia poses a growing clinical, social, and economic challenge for Bermuda. With nearly a quarter of the population projected to be 65 or older by 2026—and more seniors likely living with dementia—the island faces mounting pressures on acute care, long-term services, and family caregivers. In 2020–21 dementia ranked as the second highest condition by local insurance claims, and using global dementia costs (1.5 % of GDP) translate to an estimated $94.5 million annual impact on Bermuda's $6.3 billion economy.

The Integrated Care Pathway (ICP) for Dementia is a strategic initiative commissioned by the Ministry of Youth, Social Development and Seniors (MYSDS). It is supported by the pillars and action items outlined in the National Seniors Strategy 2024. It aims to improve dementia care in Bermuda by integrating local and international best practices.

This ICP for Dementia has been developed through a structured methodology combining:

- A comprehensive literature review of global best practices (WHO, NICE, Lancet Commission, Dombrowski et al.)
- Stakeholder engagements with clinicians, allied health, government, third-sector leaders, caregivers, and patient advocates
- A gap analysis of Bermuda's current dementia services and policy frameworks
- Iterative recommendations refined through feedback loops with local authorities and care providers

KEY FINDINGS & SYSTEMIC GAPS

- **Varying Awareness & Knowledge:** The public and providers lack a consistent understanding of dementia's causes, progression, and local support services.
- **Delayed Diagnosis & Stigma:** Fear of losing independence leads to late help-seeking, often only after crises such as wandering or hospital admission.
- **Fragmented Service Delivery:** No standardised screening in primary care; disjointed care pathways; absence of a central access point.
- **Caregiver Strain & Workforce Shortages:** Limited specialist capacity, minimal respite options, and significant family caregiver burnout.
- **Institutional & Home-Care Limitations:** Few dementia-ready long-term care beds; inadequate hospital environments; sparse in-home supports.

- **Financial & Social Inequities:** Wealthier patients fare better; vulnerable groups—low-income, immigrant, or isolated seniors—bear a disproportionate burden.
- **Insufficient End-of-Life Planning:** Late discussions on power of attorney and palliative options result in unnecessary hospitalisations.

PROPOSED INTEGRATED CARE PATHWAY

The ICP is structured across seven interconnected phases, each with defined aims, objectives, actions, key partners, and dependencies:

1. **Awareness & Risk Reduction:** Public education campaigns; targeted caregiver training; formal dementia care certification.
2. **Initial Detection:** Annual cognitive screening for > 65 years in primary care and hospitals; first-responder training; standardised electronic medical record (EMR) prompts and billing codes.
3. **Diagnostic Workup:** Agreed testing protocols; referral pathways to a unified memory clinic; exclusion of reversible causes.
4. **Diagnosis Disclosure:** Multidisciplinary feedback sessions, family inclusion, and immediate linkage to care coordination and education programmes.
5. **Ongoing Medical & Social Care:** Yearly multidisciplinary reviews; brain-health specialists; robust EMR-enabled care plans and a national dementia registry.
6. **Care in the Community:** Expand home-based services, respite beds, day-care, and develop dementia-friendly long-term care.
7. **End of Life Support:** Adapt Standard Health Benefits (SHB) for non-continuous end-of-life coverage

ADDITIONAL SYSTEMWIDE RECOMMENDATIONS

- Establish legislative and regulatory standards for home care and long-term care providers.
- Collect and analyse long-term care financing data to inform sustainable funding models.
- Develop local professional bodies for dementia care and accredited training programmes (Continuing Education Units/Continued Professional Development).
- Deploy enabling technologies: interoperable electronic health record (EHR), remote monitoring tools, online care registers.
- Strengthen inspectorate capabilities and cross-sector partnerships to ensure quality and compliance.

INTRODUCTION

Dementia is not an inevitable or normal part of ageing; it is a disease process impacting the brain. Dementia is an umbrella term used to describe a range of cognitive and behavioural symptoms which can include memory loss, problems with reasoning and communication, changes in personality, and a reduction in a person's ability to carry out daily activities, such as shopping, washing, dressing, and cooking. Dementia causes more disability than the normal memory loss associated with ageing.

The 2020 Lancet Commission on dementia stated that “40% of dementia cases could be prevented or delayed if exposure to 12 known risk factors were eliminated: high blood pressure, smoking, obesity, low education, depression, diabetes, physical inactivity, hearing impairment, social isolation, excessive alcohol consumption, head injury, and air pollution” (Lancet Commission, 2020).

Preventable Dementia Risk Factors
(Adapted from the 2020 and 2024 Lancet Commission on Dementia)

2020 estimate (40%)

- High blood pressure
- Smoking
- Obesity
- Low education
- Depression
- Diabetes
- Physical inactivity
- Hearing impairment
- Social isolation
- Excessive alcohol consumption
- Head injury
- Air pollution

2024 update (45%)

- Untreated vision loss
- High LDL cholesterol

Dementia is a disease that impacts cognition, memory, behaviour, and daily function; however, it tends to be diagnosed later in life, therefore making the risk for older adults higher. Recent headlines of bed crisis in hospital and across care facilities, family stories of stress and burden, and an increase in missing older adult alerts show anecdotally that dementia is one of the pressing public health challenges facing Bermuda today. With an ageing population and increasing life expectancy, the prevalence of dementia is set to rise, further straining health and social care services, long-term care facilities, and family caregivers.

This report outlines the current landscape, identifies gaps, and proposes a structured care model. It aims to provide a roadmap for policymakers, healthcare providers, and community organisations to enhance dementia care outcomes across the island.

Through this review, an Integrated Care Pathway designed to enhance support for individuals living with dementia and their caregivers is defined, ensuring a seamless and effective care experience that is both sustainable and patient-centred. The pathway is built on international best practices, incorporating an approach to early diagnosis, treatment, and multidisciplinary long-term management.

It emphasises the importance of dementia-friendly environments, community-based interventions, and equitable access to services. Furthermore, it highlights the urgent need for workforce development, financial sustainability, navigation support for caregivers and families, and policy integration to ensure Bermuda is prepared to meet the growing demand for dementia care services.

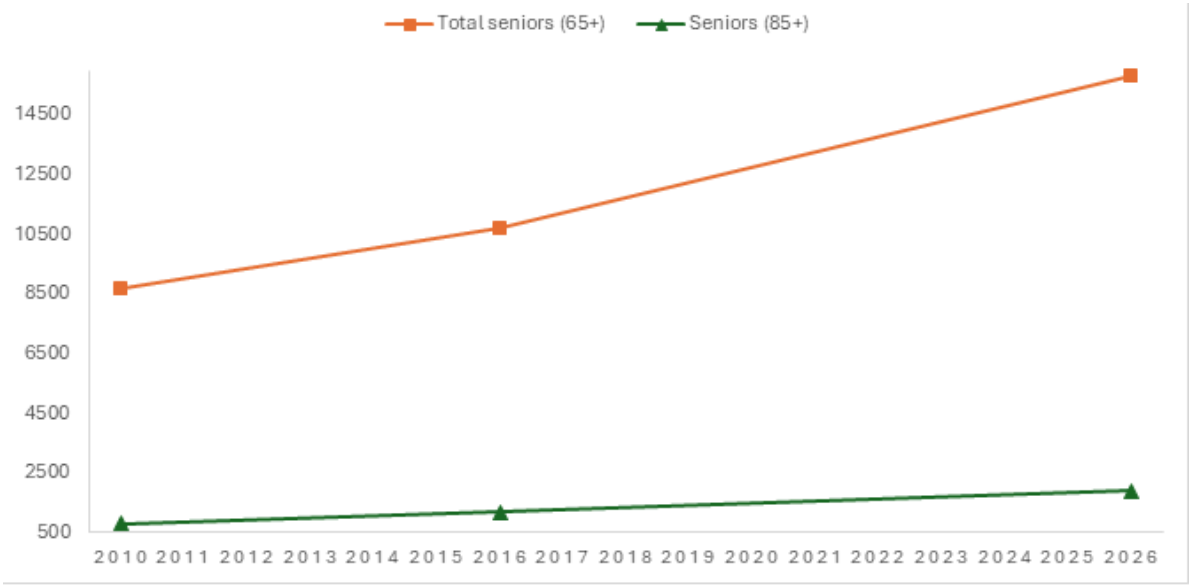
BACKGROUND ON BERMUDA

Bermuda is home to 63,779 people according to the 2016 census (64,185 in the 2010 census). Bermuda is governed by the Westminster model of parliamentary democracy. The Government of Bermuda consists of a governor, a deputy governor, a Cabinet, and a Legislature. The Legislature is made up of the House of Assembly and the Senate.

Projections of Bermuda's population based on the 2016 population and housing census show that by 2026:

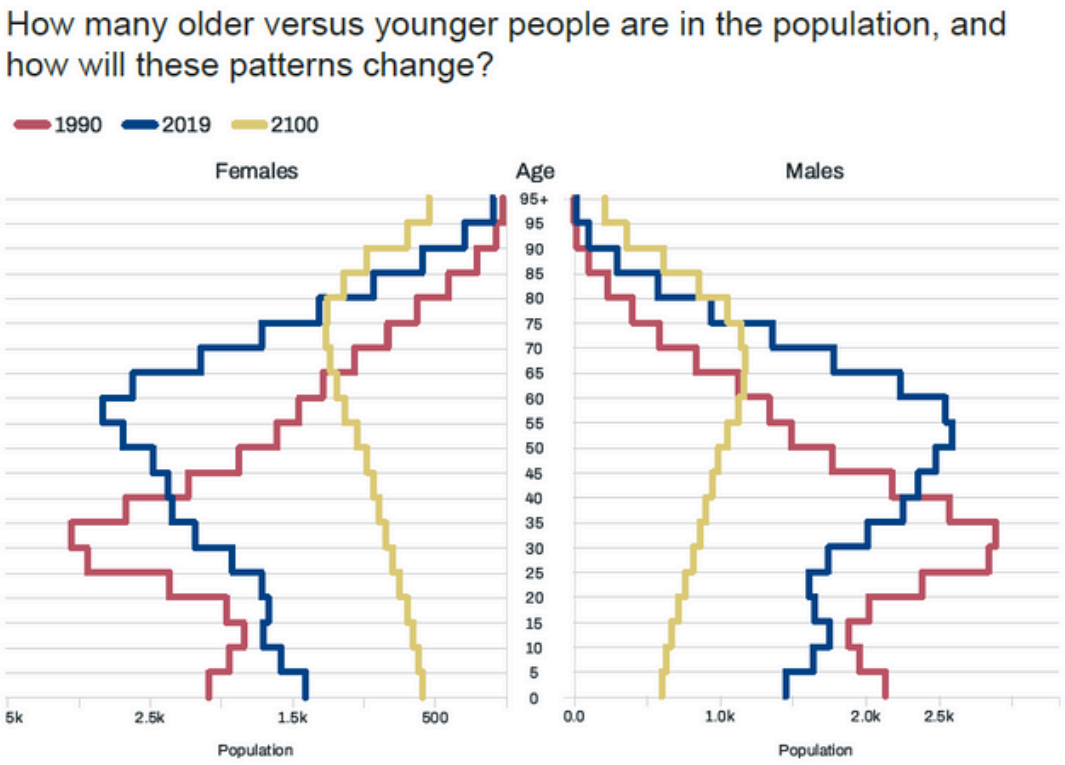
- **24.9% of the population** will be **65 years or older**.
- **10.8% of all residents** will be **75 years or older**.
- If the current percentage of persons over 65 with a disabling **Long-Term Condition** remains the same, the number of people needing more intensive Long-Term Condition services and support will increase from **1,213 to approximately 2,318**.
- **2016 Census: 10,704 seniors aged 65 years or older** (up from 8,683 in 2010). Seniors comprise **17% of Bermuda's population** (up from 13% in 2010). This is projected to be **15,825 in 2026 (24.9%)**.
- **1,194 seniors**, or **11.2% of the senior population**, are **85 years old or older** (up from 825 or 9.5% in 2010). This is projected to be **1,904 in 2026**.

GRAPH 1: GROWTH IN BERMUDA'S AGING POPULATION



Source: Department of Statistics, Bermuda Population Projections 2016-2026

GRAPH 2: CHANGING POPULATION PATTERNS BY AGE



Source: Institute for Health Metrics and Evaluation

BACKGROUND ON DEMENTIA IN BERMUDA

Due to limitations in data collection, Bermuda does not have a defined/confirmed prevalence rate based on verified local data. Current data suggests that a significant number of Bermuda's older adults experience cognitive decline or dementia-related symptoms; however, the exact prevalence of clinically confirmed dementia has not yet been established. Variations in diagnostic practices and data sources mean that existing figures should be interpreted with caution. Ongoing work to standardise diagnostic pathways and strengthen data collection will enable more accurate national estimates in the future.

The model from the Global Burden of Disease, Dementia Forecasting Collaborators, estimates that 57.4 million people were living with dementia in 2019. The prevalence rate of dementia among those 65 and over in the United Kingdom (UK) in 2019 was 7.1%. In the United States of America (USA), it is estimated that 10% of older adults have dementia.

By 2026, it is projected that 25% of Bermuda's population (~15,000) will be aged 65 and over. This would equate to 1,100–1,500 seniors in Bermuda who may be living with dementia at that time. This translates to a country prevalence rate of 1.7-2.3%. This is higher than the estimates for European countries (see Table 2). The figures provided by Alzheimer's Disease International for Dementia in the Americas are similar to those in Europe. Given the projected trends in population ageing, the prevalence of modifiable risk factors for dementia, and global population growth, the number of people with dementia is expected to triple by 2050.

Local providers' estimates suggest higher current numbers of dementia burden that would be closer to the global based 2050 projection (closer to 3,000 cases). The estimates were determined by local memory care specialists that considered international dementia prevalence, local referrals and caseloads, and the high prevalence of dementia risk factors found in Bermuda. As the estimates are significantly higher than would be expected, they require further exploration and review.

Data provided by the Bermuda Hospitals Board (BHB) on unique patients with dementia-related diagnoses in 2024, based on International Classification of Diseases, 9th and 10th Revision codes, were 3,657 indicated persons. King Edward VII Memorial Hospital (KEMH) Geriatric Clinic, which provides formal dementia diagnoses, provided services to only 496 of the 3,657 individuals during the same period. It is unclear if all persons indicated as having dementia had a clinical diagnosis.

Further explanation of Bermuda's current dementia statistics can be found in a published Health Needs Assessment (HNA) on Dementia, conducted in 2025 by the Bermuda Health Council. Summary data from the HNA can be found within subsequent sections.

[1] *Dementia Bermuda (formerly Action on Alzheimers & Dementia) is a registered charity (#929) founded in 2012*

TABLE 1: PREVALENCE OF DEMENTIA IN EUROPE, BY AGE AND SEX, 2018

Age Range	Overall Prevalence	Prevalence in Females	Prevalence in Males
60-64	0.6%	0.9%	0.2%
65-69	1.3%	1.5%	1.1%
70-74	3.3%	3.4%	3.1%
75-79	8.0%	8.9%	7.0%
80-84	12.1%	13.1%	10.7%
85-89	21.9%	24.9%	16.3%
90+	40.8%	44.8%	29.7%

Source: Alzheimer Europe

TABLE 2: PREVALENCE OF DEMENTIA IN EUROPE BY COUNTRY

Country	Men	Women	Total	% of Population in 2018	% of Population in 2050
Austria	46,537	100,263	146,801	1.66	3.18
Belgium	61,173	131,753	192,926	1.69	2.95
Bulgaria	34,290	74,594	108,884	1.54	2.47
Croatia	19,535	46,341	65,876	1.6	3.06
Cyprus	3,744	6,345	10,088	1.17	2.44
Czech Republic	46,338	103,295	149,633	1.41	2.65
Denmark	30,228	57,148	87,377	1.51	2.65
Estonia	5,375	17,567	22,942	1.74	3.06
Finland	29,980	65,856	95,836	1.74	3.13

Country	Men	Women	Total	% of Population in 2018	% of Population in 2050
France	374,260	853,298	1,227,558	1.83	3.31
Germany	511,050	1,074,115	1,585,166	1.91	3.43
Greece	75,538	138,141	213,678	1.99	3.95
Hungary	39,876	105,812	145,688	1.49	2.64
Ireland	18,900	33,836	52,736	1.09	2.49
Italy	402,965	876,402	1,279,366	2.12	4.13
Latvia	7,712	26,035	33,747	1.74	3.17
Lithuania	11,783	37,174	48,957	1.74	3.67
Luxembourg	2,479	5,060	7,539	1.25	2.44
Malta	2,242	4,309	6,552	1.38	3.31
Netherlands	87,292	169,239	256,532	1.49	3.15
Poland	147,733	377,351	525,084	1.38	3.23
Portugal	59,989	133,527	193,516	1.88	3.82
Romania	87,514	192,093	279,607	1.43	2.56
Slovakia	18,101	44,394	62,495	1.15	2.59
Slovenia	10,061	24,076	34,137	1.65	3.40
Spain	271,984	580,758	852,741	1.83	3.99
Sweden	58,222	110,021	168,243	1.66	2.63
United Kingdom	356,741	674,656	1,031,396	1.56	2.67

Source: Alzheimer Europe

ECONOMIC AND SOCIAL IMPACT OF DEMENTIA CARE

Approximately 50% of dementia costs are attributable to care provided by informal caregivers (e.g., family members and close friends), who provide, on average, 5 hours of care and supervision per day. This number is expected to more than double by 2030, reaching US$2.8 trillion, which will further undermine global social and economic development.

"In 2019, dementia cost the global economy $1.3 trillion, equivalent to 1.5% of the global GDP"

Bermuda's GDP in 2021 was $6.3 billion; 1.5% of that GDP if aligned with the current global spend on dementia care, would result in a cost of $94.5 million in Bermuda. Half of this cost would suggest a personal home-care programme associated with more than $40 million annually in reimbursement expenses. Even at half of those costs, the projection doubles our budget for personal home care programmes through the Health Insurance Department.

The government's total spending on all long-term care in Bermuda in 2017/18 was $104 million. This excluded private expenditure and social and voluntary contributions (Ministry of Health, 2018). The average cost of long-term care per resident is $92,000 annually (Bermuda Health Council, 2023). This ranges from $84,000 to $144,000. The cost of care in the hospital is significantly higher (more than $1,000 per day).

Dementia Care Costs: At a Glance

- **~50% of costs** carried by informal caregivers, averaging 5 hours per day.
- Global costs are projected to reach **US$2.8 trillion by 2030**.
- In Bermuda, **1.5% of GDP (2021) = $94.5 million**, if aligned with global spending.
- Average long-term care cost: **$92,000 per resident per year.**

These figures emphasise the urgent need for structured, government-supported funding for dementia-friendly home care services, respite programmes, care homes and infrastructure in Bermuda.

EXCERPTED FINDINGS FROM THE BERMUDA HEALTH COUNCIL'S HEALTH NEEDS ASSESSMENT (HNA) FOR BERMUDA

The Health Needs Assessment provides a system-wide view of dementia in Bermuda, examining demographic patterns, service utilisation, caregiver experiences, long-term care capacity, and policy gaps. As outlined in the Background on Dementia in Bermuda, current prevalence figures require careful interpretation due to variability in diagnostic pathways and coding practices. The HNA therefore does not attempt to redefine prevalence; rather, it focuses on understanding how dementia is experienced across the population and where the health and social care system is struggling to meet emerging needs.

The assessment highlights the practical realities faced by individuals living with dementia (PLWD) and their caregivers: increasing strain on families, inconsistent access to specialised services, limited dementia-ready care settings, and significant socioeconomic vulnerabilities. It also identifies the structural challenges—such as fragmented service delivery, workforce limitations, inadequate transportation options, and gaps in respite and community supports—that must be addressed to build a coordinated, sustainable dementia care system.

Locally, individuals aged 80-85 are the group most affected by dementia. There are significant socioeconomic challenges with 22% of PLWD reporting no income and an additional 35% indicating low- or unknown-income levels. The burden of dementia care falls predominantly on families. While community programmes, 18 care homes, and a dementia services pilot programme exist, service delivery remains fragmented.

Key challenges in dementia care also include limited transportation to services, inadequate respite care, and inconsistent caregiver training. Access to specialists and diagnostic tools remains restricted, and notable policy gaps hinder adequate service provision. Key strategic priorities for action include developing a national dementia plan, formalising care standards and training, integrating dementia care into primary and community health services, providing financial protection for families, and enhancing data collection efforts.

Key Challenges and Priorities

- **Most affected:** ages 80–85
- **Socioeconomic strain:** 22% no income; 35% low/unknown income
- **Family burden:** majority of care; services fragmented
- **System gaps:** transport, respite, training, specialist access, policy
- **Priorities:** national plan, care standards, primary care integration, financial protection, stronger data

METHODOLOGY

Campbell (1998) describes Integrated Care Pathways as "structured multidisciplinary care plans which detail essential steps in the care of patients with a specific clinical problem." They have been proposed as a way to help translate national and international guidelines into local protocols and support their application in clinical practice. They also aim to improve the collection of clinical data for audit and to encourage changes in practice.

The Bermuda Health Council was commissioned to develop an integrated care pathway for dementia care in Bermuda, incorporating local and international best practices. The development process followed a structured methodology consisting of the following components:

1. **Literature Review:** A comprehensive literature search using Google Scholar to document and review global best practices in dementia care and pathway design. This review encompassed published and grey literature[1] on dementia, dementia care, and dementia care pathways. It also incorporated recommendations for published literature by local experts and policymakers. We reviewed abstracts and summaries of the search results. The most relevant articles were downloaded in full and reviewed.
2. **Stakeholder Engagement:** Consulting with Bermuda's health and care providers, government services, and patient advocates. This included representatives of all the providers and professionals who look after people living with dementia (PLWD) in Bermuda. The tool for data collection was a semi-structured questionnaire that was developed and pretested. Data collection was conducted by a semi-structured interview. The interview was recorded, transcribed, and analysed for themes and suggested changes. An additional stakeholder engagement programme was conducted at the end of the review to gather feedback on the findings and to secure agreement on the recommended actions.
3. **Additional Data Collection:** Incorporating findings from the Health Needs Assessments on Dementia conducted by a team within the Bermuda Health Council. This provided a comprehensive assessment of Dementia care in Bermuda.
4. **Gap Analysis:** Identifying existing challenges in Bermuda's dementia care system, based on the identified standards in the literature, best practices, and the practice on the Island.
5. **Recommendations Development**: Outlining actionable solutions for policy, legislation, care delivery, and funding. This was reviewed with the stakeholders and refined following their suggestions and additional recommendations.

[1] *Grey literature refers to research and information published outside of traditional academic journals, such as government reports, policy documents, and conference papers.*

REVIEW OF LITERATURE

Dementia is a leading public health challenge worldwide, requiring integrated, person-centred care models that address the complexities of diagnosis, treatment, and long-term management. The World Health Organisation (WHO), the National Institute for Health and Care Excellence (NICE), and various international studies provide valuable insights into best practices for dementia care.

A comprehensive evidence review was conducted to guide the development of Bermuda's Integrated Care Pathway for Dementia, ensuring alignment with global best practices while addressing local challenges.

KEY EVIDENCE AND REPORTS

Dombroski's Report (2024)	One of the most comprehensive and detailed ecosystem maps and frameworks of best practices in dementia care. This report highlights the critical role of care partners, clinicians, and social services in effectively managing dementia. **In the report, an ideal care ecosystem focused on:** • Care partners (family, friends, and neighbours); care workers (paid providers of services) • People at risk of dementia and people living with dementia (PLWD) before diagnosis • PLWD after diagnosis and their interaction with clinicians • People at risk of dementia, and PLWD, and their interaction with the non-clinical community and with social services • Digital health solutions, data infrastructure and other technologies that enable ideal care • Other non-technology relevant groups and enablers of ideal care. **This paper proposes what should be included in:** • Raising awareness of dementia and risk reduction for dementia • The care pathway for initial diagnosis • The factors to be considered in the initial workup • Disclosure of initial diagnosis • Standards for medical care for PLWD • Considerations for other levels of care for PLWD In addition to these, the paper explores stimulating activities to preserve cognition and the role of community-based organisations, governments, and health systems. It also looks at support and engagement for care partners, care packages for PLWD, and the role of technology, research, and training.
The National Institute for Clinical Excellence (NICE, 2018)	Produced clinical guidance on the assessment, management and support for PLWD and their Caregivers (NG97). This synthesises the available evidence and provides clinical guidance on dementia care.

The National Institute for Clinical Excellence (NICE, 2018) contd.	**The main themes in this guidance include:** **1. Involving PLWD in decisions about their care** • Involving people in decision-making - Encourage and enable PLWD to give their own views and opinions about their care. • Providing information - Provide PLWD and their family members or Caregivers (as appropriate) with information that is relevant to their circumstances and the stage of their condition. • Advance care planning - Offer early and ongoing opportunities for PLWD and people involved in their care to discuss the benefits of planning ahead; ◦ Enduring (lasting) power of attorney - an advance statement about their wishes, preferences, beliefs and values regarding their finances and future care; advance decisions to refuse treatment; their preferences for place of care and place of death. **2. Diagnosis** • Initial assessment in non-specialist settings, assessing cognitive, behavioural and psychological symptoms and excluding reversible causes of symptoms. • Diagnosis in specialist dementia diagnostic services aiming to diagnose a dementia subtype (if possible) • Review after diagnosis disclosure with family and/or caregivers, as well as multidisciplinary team care for the PLWD. **3. Care coordination** • Providing PLWD with a single-name health or social care professional who is responsible for coordinating their care. • Protocol for transferring information between services and care settings. Ensure that data and care plans are shared between providers while maintaining confidentiality. • Making services accessible for PLWD, including financial assistance, affordable and accessible transport and culturally appropriate care services. **4. Interventions to promote cognition, independence, and well-being** • Activities tailored to individual preferences • Group cognitive stimulation, group reminiscence therapy and cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia. • Do not offer non-evidence-based treatments or therapies for dementia care. **5. Pharmacological interventions for dementia** • Appropriate pharmacological management for the various dementia subtypes and for symptom management. **6. Medicines review to avoid medicines that may cause cognitive impairment** • Regular review and titration of medicines to avoid polypharmacy and optimally manage dementia and other co-morbid conditions.

The National Institute for Clinical Excellence (NICE, 2018) contd.	**7. Managing non-cognitive symptoms, such as --** • Agitation, aggression, distress, and psychosis • Depression and anxiety • Sleep problems • Parkinson's disease **8. Assessing and managing other long-term conditions in PLWD** • Pain • Falls • Diabetes • Incontinence • Sensory impairment **9. Risks during hospital admission** • PLWD are at increased risk when admitted to the hospital. They are at increased risk of disorientation, increased length of stay, increased mortality, increased morbidity on discharge, delirium, etc. **10. Palliative care** • Use of the anticipatory care process for end-of-life planning for PLWD, taking into account the unpredictable progression of the disease. **11. Supporting Caregivers** • Offer Caregivers of PLWD psychoeducation and skills training. • Ensure tailored support to Caregivers. • Signpost Caregivers to resources available, including respite care and mental health support. **12. Moving to different care settings** • Manage transition between care settings based on need and the PLWD wishes (including any care and support plans). **13 Staff training and education** • are and support providers should provide all staff with training in person-centred and outcome-focused care for PLWD, including data protection, managing difficult conversations, and challenging behaviours • Consider allowing Caregivers and/or family members to attend and participate in dementia training sessions. NICE (2019) also produced measurable quality standards for dementia to help measure the progress towards high-quality dementia care. **These are covered in the following seven statements:** • **Statement 1:** People accessing behaviour change interventions and programmes in mid-life are advised that the risk of developing dementia can be reduced by making lifestyle changes. • **Statement 2:** People with suspected dementia are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated.

The National Institute for Clinical Excellence (NICE, 2018) contd.	• **Statement 3:** People with dementia are given the opportunity to discuss advance care planning at diagnosis and at each health and social care review. • **Statement 4:** People with dementia have a single named practitioner to coordinate their care. • **Statement 5:** People with dementia are supported to choose from a range of activities tailored to their preferences to promote well-being. • **Statement 6:** People with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress. • **Statement 7:** Caregivers of people with dementia are offered education and skills training.
National Institutes of Health	The National Institute of Health cites Shaji et al. in producing comprehensive clinical practice guidelines for the management of dementia. These guidelines for health professionals provide evidence-based guidelines on diagnosing and managing dementia.
Schmachtenberg	There are varying models of dementia care worldwide. These reflect the different health and care systems, available resources, and cultural attitudes. In Europe, many countries have developed comprehensive dementia care strategies. For instance, countries like the UK, Sweden, and the Netherlands have nationwide structures for dementia care, including specialised outpatient and inpatient services. However, regional disparities persist in the availability and quality of these services. (Schmachtenberg 2022)
OECD	A report by OECD highlights the importance of integrating social and healthcare interventions. Countries like Japan and Germany emphasise group-living arrangements and support for family caregivers, which have shown positive health benefits for patients and their families.
The State of American Dementia Care in Four Maps	In the United States, dementia care models vary widely depending on available healthcare infrastructure, funding, and local policies. There are significant regional disparities in dementia care. Rural areas often face challenges such as a shortage of specialists and limited access to diagnostic services. The State of American Dementia Care in Four Maps describes the variation in dementia care across the US. For instance, only 21% of patients in rural locations who need a neurologist will get to see one.
Various Other United States Reports	Some states have developed comprehensive dementia care programmes integrating medical, social, and community services. The US Department of Health and Human Services highlights some examples of good practices. California's Alzheimer's Disease Program provides a range of services, including diagnostic centres, caregiver support, and public education. States like Minnesota and New York have implemented innovative models of care. Minnesota's ACT on Alzheimer's initiative focuses on community-based support and early diagnosis, while New York's Alzheimer's Disease Caregiver Support Initiative provides extensive resources for caregivers.

Various Other United States Reports contd.	Johns Hopkins University's Maximising Independence (MIND) at Home program, features "memory care coordinators" who help families navigate their medical care, build skills to manage dementia, and connect with social services. The University of San Fransico's Care Ecosystem is a model of dementia care designed to provide personalised, cost-efficient care for PLWD and their Caregivergivers. It is a telephone and web-based intervention for providing education and care plans.
Dementia Education	Dementia is a progressive, organic, brain disease. The progression of this disease is not linear; there are periods where PLWD can be symptom-free, and the disease progression can be slowed. One of the most important characteristics of dementia is the cognitive decline over the years of the development of the condition. Research and practical experience make it clear that depending on the degree and type of decline, people with dementia can continue to function in society for quite a long time. Particularly if they receive support to manage their condition and to adapt at work. This is achievable when there is good education about the disease, no stigma associated with it, and a supportive care plan. (Department of Health and Social Care) Little is known about Dementia by the public, limiting available support. There is a need for information and education to fill this gap. The Alzheimer's Society's Dementia Friends programme is the biggest ever initiative to change people's perceptions of dementia. It aims to transform the way the nation thinks, acts, and talks about conditions. This programme has been shown to improve knowledge and confidence in engaging with PLWD. This can be adapted for use in Bermuda to create a population that is aware and supportive of PLWD.
Dementia Bermuda	NorthStar, (now part of Dementia Bermuda) has a programme of education for the families and Caregivers of PLWD, "The Compass Guide to Dementia Care" in 2023, with grant funding provided through the Centennial Foundation. It consists of 12 modules of educational material, along with several supporting interviews with local leaders in Dementia Care services. It also includes all relevant resources, application forms, community agencies, etc., relating to that specific topic area to make things easier for those navigating a diagnosis of Dementia in Bermuda.
Bermuda's Long-Term Care Action Plan (2017) and the 2025 draft Long-Term Care Action Plan (2025)	This was a comprehensive review of projections and unmet needs for services to support persons with a reduced degree of functional capacity (physical or cognitive). This provided recommendations that are also relevant for the care of PLWD. **These recommendations include:** • Ensure collaboration with all relevant stakeholders and partners to uphold the principles of aging well and ensure work in the long-term care sector aligns with the Bermuda Health Strategy and Universal Health Coverage Programme Goals. • Establish legislative frameworks and standards for both formal and informal homecare providers.

Bermuda's Long-Term Care Action Plan (2017) and the 2025 draft Long-Term Care Action Plan (2025) contd.	• Gather data on Long Term Care (LTC) financing:
	  ◦ To advocate for data-driven LTC financing reform and provide solutions and recommendations for an affordable and sustainable system, including dementia care coverage.
	  ◦ Support the development of local LTC professional bodies (licensing, statutory boards, associations, etc.).
	  ◦ Support the development of local LTC education, training, and professional development programmes (including CEUS).
	• Introduce technology to aid oversight, support, and enhancements in the LTC sector, particularly for dementia care needs:
	  ◦ Electronic health records and databases
	  ◦ Scheduling software
	  ◦ Monitoring software for individuals living alone with cognitive impairments prone to wandering (walking with purpose)
	  ◦ Online registers and user-friendly databases to improve public awareness and access to information, enabling informed care decisions for persons with cognitive impairments, especially when presenting at the ER.
	  ◦ Online registration and payment systems for improved access, efficiency, and accountability, while maintaining an age-friendly society with appointment-based services to assist those facing challenges.
	• Clarify and enhance the role of the inspectorate and its members to ensure proper support for enforcement actions needed to support and improve the LTC sector.
	• Strengthen existing partnerships within the inspectorate to ensure timely and effective responses to oversight and regulatory matters

World Health Organization (WHO)	World Health Organization (WHO) Dementia Action Plan (2017–2025) – WHO's framework highlights the need for improved workforce training, community-based support, and innovative technology solutions in dementia care. **It stresses the importance of:** • The development of national dementia strategies with clear performance indicators. • Community-based care models to reduce reliance on institutional settings. • Expansion of workforce training and dementia-specialised care teams. • Financial sustainability through government-supported long-term care funding. Bermuda's proposed pathway aligns with these global directives, aiming to enhance workforce capacity, community involvement, and structured funding mechanisms.

BERMUDA'S DEMENTIA LANDSCAPE

EXAMPLES OF EXEMPLARY PRACTICE

Consultations with stakeholders highlighted several areas of excellent practice. These practices are found in all aspects of dementia care. However, these are not universal and are not industry-wide standards. These practices need to be recognised and scaled up.

In the hospital, the geriatrics service has been able to:

- Include drugs for moderate and mild dementia in the hospital formulary.
- Implement screening tests for frailty and dementia in the emergency department.
- Develop guidelines for treating delirium and dementia in the hospital.

The Emergency Room at the hospital utilises a system of wristbands to help identify patients with cognitive decline. This enables staff to identify patients who may need additional support, especially when they inadvertently wander around the hospital.

In primary care, examples of good practice were highlighted during our interviews with Primary Care Providers. Some of these are:

- Advocating for:
  - quality of life over prolongation of life,
  - preferring minimally invasive treatments, and
  - supporting patients' wishes to die at home, including discussing end-of-life preferences early in the disease progression.
- Providing home visits, even though insurance companies poorly remunerate this service.

There are a few Primary Care Providers who act as General Practitioners with a Special Interest (GPwSI) in Geriatrics and Dementia Care. They take referrals from other Primary Care Providers. They ensure that they:

- Participate in and complete yearly training to keep up to date with geriatric and dementia care, at a teaching hospital.

There are examples of PLWD, who remain at home with their families and are supported with care in the home. These are typically PLWD diagnosed early in their disease, and with great family support.

A small number of care home providers allow patients to stay in the facility and ensure increased services, rather than being transferred to hospitals due to advancing dementia-related care and support needs. They work closely with families during this time. Most of the facilities which embody these practices employ a nurse practitioner, or follow the guidance of their clinical director, who is a well-experienced RN, who helps to coordinate care for PLWD.

STRENGTHS IN BERMUDA'S DEMENTIA CARE SERVICE PROVISION

Home care since 2015 has been funded through the Health Insurance Department (HID) and some private insurers, thus increasing the ability for PLWD to remain at home longer, provided they can secure a caregiver and cover the associated co-payments.

The Government of Bermuda has committed to the creation of a day care centre that focuses on providing care to persons with dementia and work is underway.

Dementia Bermuda is the largest third-sector provider for dementia care in Bermuda. Some of their services are:

- **Awareness & Risk Reduction:** Dementia Bermuda is the leading local effort in dementia education and stigma reduction, utilising Bermuda College, community presentations, media outreach, and social media campaigns to help build public understanding and awareness across Bermuda.
- **Caregiver Education & Support:** Monthly Caregiver Education & Support classes equip family members with essential knowledge and strategies, grounded in best practices for dementia care.
- **Daily Activities:** Dementia Bermuda provides structured, meaningful activities throughout the week that promote routine, engagement and well-being for people living with dementia, while also offering caregivers the opportunity for connection and shared participation in a supportive environment.
- **Cognitive Stimulation Therapy (CST):** This evidence-based group therapy, endorsed by the UK's NICE guidelines, promotes cognitive function, communication, and well-being for individuals with mild to moderate dementia.
- **Dementia Navigation and Support Services:** This began as a pilot programme funded by the MYSDS, which have transitioned to an annual grant to continue supporting these services. The navigation and support services include In-Home Occupational Therapy (OT) services, delivering personalised care planning, cognitive and functional assessments, environmental risk reduction, caregiver training and ongoing case management. Crucially, these services help prevent avoidable hospitalisations, reduce caregiver burnout and delay the need for long-term care, allowing PLWD to remain safely at home for as long as possible.

GAP ANALYSIS

Our stakeholder analysis suggests that our current system has many gaps and challenges, which include:

- **Varying Levels of Knowledge**
  The public and health professionals have varying levels of knowledge about causes, disease progression and management of dementia. There is also varied knowledge of support services and PLWD, and limited educational opportunities related to dementia. An intentional, comprehensive, and funded education and awareness campaign within public health or the third sector would better support PLWD and their families.

- **Late Presentation and Stigma**
  Many PLWD still fear receiving a diagnosis because of stigma and, at times, denial. Additionally, loss of independence and job security (especially in younger patients) are major barriers to early detection. Delayed help-seeking is common; most patients do not seek help early, usually leading to family members or friends bringing them in for assessment at the General Practitioner's (GP) office after significant deterioration or crisis (e.g. wandering, or acute presentation at the emergency room). Delayed help-seeking also drives up the cost of care, as interventions for dementia care tend to increase in cost as the disease progresses, often resulting in avoidable hospitalisations.

- **Limited and Variable Diagnostic Infrastructure**
  The lack of standardised early screening protocols contributes to the high numbers of late diagnoses that we see. Care providers also lack standard diagnostic criteria, which affects the quality of diagnosis data obtained and limits the ability to provide specified subtypes of dementia in the diagnosis.

- **Fragmented Service Delivery**
  PLWD and their Caregivers feel uncertain of where to go for help and assistance (until connected with help, in most cases from Dementia Bermuda).
  - **Disjointed System:** There is no clear, integrated care pathway. Services are siloed, and coordination between community, primary care, and hospital-based services is limited.
  - **Lack of Central Access Point:** There is no "one-stop shop" for dementia care; each professional handles only part of the journey, often without complete visibility of others' contributions.
  - **Variable Practices:** Some Primary Care Providers actively screen older patients for cognitive decline, while others do not, leading to inconsistent early detection.
  - **Need for Standardisation:** There is a call for dementia screening (e.g., Mini-Cog, MoCA) to become routine in primary care, especially for patients aged 65+.

- **Caregiver Burden & Workforce Shortages**

  The recent HNA on dementia in Bermuda shows that we have insufficient numbers of trained dementia care specialists and formal respite care options on the island. Caregiver burden is also mentioned in the HNA and came out as a primary and important topic in the focus group sessions for this report. Family Caregivers, often women, experience significant burnout. Few respite care options exist, and there is a lack of Caregiver education and support.

- **Access to Care Barriers**

  There is an extremely limited number of dementia services in long-term care settings on island. Some of the services are not dementia-friendly and their purpose is not structured to provide the care required especially as the disease progresses. However, due to a lack of access and availability of appropriate care settings, they are catering to their needs as best they can.

  - **Long-term Care Facilities:** The majority are not prepared to manage dementia-specific needs, particularly Behavioural and Psychological Symptoms of Dementia (BPSD). This gap also includes end-of-life care for PLWD.
  - **In-Home Services:** Many PLWD do not have sufficient in-home support. This is due to several factors including: limited family support, a lack of funds, high service costs or co-payments; an inability to coordinate their own care; and ineligibility for government benefits
  - **Respite Care:** respite beds are extremely limited due to demand for long-term placement within care homes.
  - **Adult Day-Care Programmes:** The few adult day-care programmes in operation have little to no availability, and access is impeded due to cost (if ineligible for benefits), co-payments, transportation, and eligibility criteria regarding persons with BPSD.
  - **Hospital Long-Term Stay Wards:** These wards provide an inadequate environment for care and lack stimulating activity and supports for PLWD. They are not dementia-friendly, nor were they built or staffed with dementia care in mind. Patients with BPSD are often underserved, due to demand on the Geriatric Clinic at the hospital, and dementia not falling under the remit of the mental health psychiatrists at Mid-Atlantic Wellness Institute (MWI), creating a care gap.

- **Financial and Social Inequities**

  The findings from the HNA and stakeholder sessions for this report show better outcomes occur for those with resources. PLWD who have strong family support or financial means to obtain required support (e.g., private Caregivers, good nutrition, structured and supportive routines) show better long-term outcomes. This data highlights the worrisome gap that exists for our vulnerable populations that are at high risk. (e.g. patients without financial means, limited family support, or immigrant populations facing cultural/language barriers) and suggests that they may be experiencing worse outcomes.

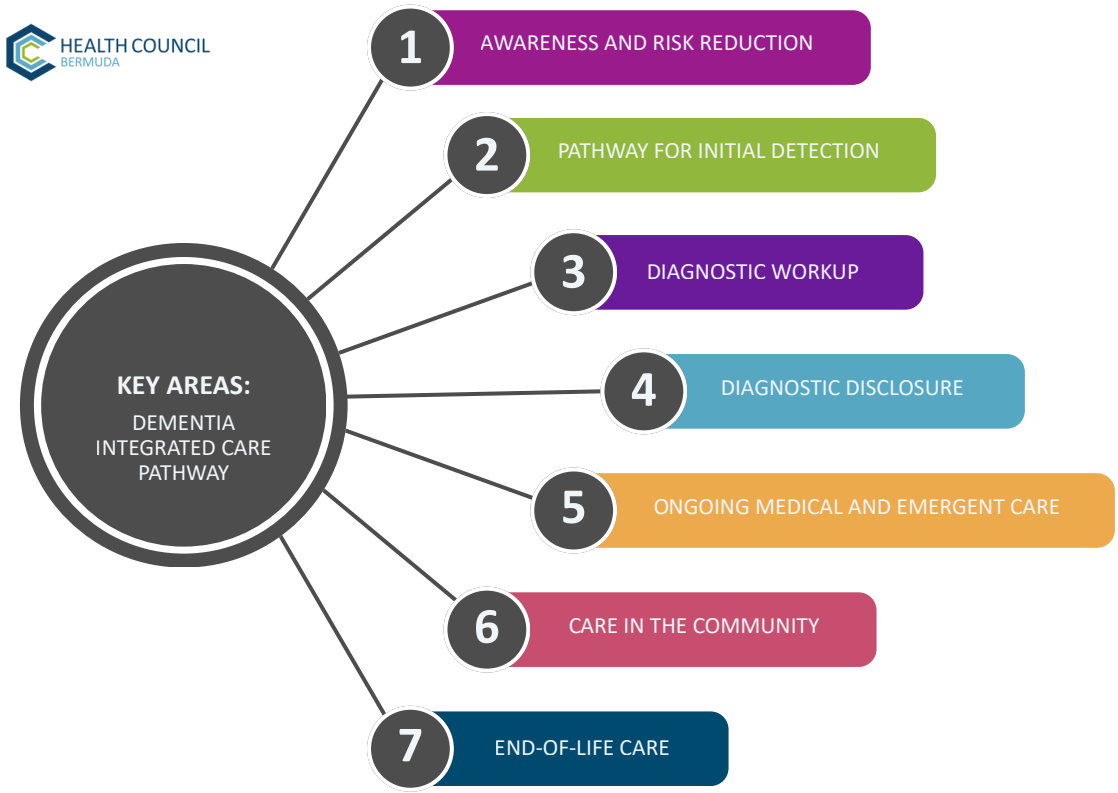
- **Financial and Social Inequities (cont'd)**

  Limited care coordination is another major hindrance to improved dementia care outcomes. Care coordination, including clinical care coordination, service navigation, crisis intervention and ongoing Caregiver support, is critical but limited on the island; and is only provided as a public or charitable service. Third-sector providers (e.g. Dementia Bermuda) are limited as they are largely dependent on grant funding and fundraising. Government social workers in their respective departments are unable to provide intensive, specialised case management when required, due to caseloads and multiple roles under their mandates. Private health professionals do not provide care navigation due to the lack of financing or insurance coverage available for such care, and people typically do not have the funds to pay out-of-pocket costs.

- **Lack of End-of-Life Planning & Options**

  Some PLWD are unnecessarily admitted to hospital near the end-of-life, due to a lack of community-based end-of-life care options, insufficient funding for end-of-life care services, and a lack of knowledge around end-of-life care in the community. Many conversations around one's care and support choices after a formal dementia diagnosis are delayed. As decision-making capacity decreases as dementia progresses, delays can impede the ability for a person to appoint substitute decision-makers and share their care preferences.

PROPOSED INTEGRATED CARE PATHWAY



PERSONAS

INTRODUCTION

The following personas illustrate the diverse challenges individuals with dementia face at various stages of the disease. These narratives highlight the personal, social, and financial complexities that must be considered in developing an effective Integrated Care Pathway (ICP) for dementia care in Bermuda.

MS. CANN (EARLY-STAGE DEMENTIA, EMPLOYMENT CONCERNS)

Ms. Cann is a 50-year-old who is looking forward to retirement but is not yet financially ready to stop working. She has recently noticed some changes in her cognitive functioning and wants to get screened for a formal diagnosis so she can plan and prepare for what she fears is ahead. However, she is afraid of what the implications of a diagnosis of dementia might mean for her job security.

MR. BUTTERFIELD (MIDDLE-STAGE DEMENTIA, RELUCTANT TO SEEK SUPPORT, CHALLENGING BEHAVIOURS)

Mr. Butterfield, a 76-year-old retired tradesman, spent most of his years in public service. He has always led an independent life but now finds himself “suddenly” needing support with basic daily tasks. His children argue that this has been the case for the past four years, ever since he “slowed down” after retirement. However, he remains reluctant to ask for help, insisting that he has always “done things for himself.”

Mr. Butterfield deeply values his independence and enjoys his daily routine of driving to the eastern end of the island to visit his boat. He fears that acknowledging the changes in his abilities will lead to a loss of autonomy. When his children offer assistance, he becomes increasingly agitated, at times lashing out physically or verbally, even cursing at the Caregivers they hire to support him.

He recently suffered a fall while trying to get into the car on his own and is now in the hospital. His family is reluctant to take him home due to the challenges they face in managing his care.

MRS. SOUSA (LATE-STAGE DEMENTIA, FINANCIAL AND SOCIAL CHALLENGES)

Mrs. Sousa, 72, has lived and worked in Bermuda for most of her adult life. Now, as her dementia progresses, she finds herself grappling with the difficult decision of having to leave what she considers home due to a lack of financial means and support. As a non-Bermudian, she does not qualify for financial assistance.

She knows that moving back to her country of birth would provide her access to more benefits than remaining in Bermuda. However, she fears the isolation and loneliness that await her on the other side of that decision. She delays making a choice until she begins to lose full cognitive function, impacting her ability to manage daily life.

One day, she is found wandering in a grocery store, unable to find her way back to her apartment. The police are contacted as she cannot clearly communicate and has no identifiable next of kin locally. She is placed in a local care facility at the taxpayers' expense, with limited support and no advance directives in place. The facility staff are unaware of her wishes for her care as she nears the end of her disease.

MR. & MRS. BAISDEN (COUPLES CAREGIVING, LANGUAGE BARRIERS)

Mrs. Baisden, originally from the Philippines, has been married to Mr. Baisden for 40 years. In recent years, her health has deteriorated, with her cognitive function worsening over time. Due to the progression of her dementia, she has lost the ability to communicate clearly with her husband, as she is no longer able to retain her secondary language.

Both Mr. and Mrs. Baisden now face the immense challenge of navigating ageing, dementia progression, and the strain of a language barrier, which only increases the Caregiver burden on Mr. Baisden and the confusion experienced by Mrs. Baisden.

INTEGRATED CARE PATHWAY RECOMMENDATIONS

Summary of Opportunities and Recommendations Identified During Stakeholder Engagement

- **Integrated Dementia Pathway:** There is strong consensus on the need for a formal, integrated dementia care pathway across all settings (community, hospital, and long-term care). This pathway should incorporate strategies for early diagnosis, a centralised database, and care coordination. The pathway needs to be adequately funded, strengthening care coordination and funding the third sector to provide the services needed.
- **Education and Training:** More professional training in dementia care, better community awareness, and culturally appropriate education are needed.
- **Policy and Infrastructure Support:** Development of dementia-friendly infrastructure, consistent screening policies, funding arrangements, and community-based supports, including support for Caregivers, were highlighted as key strategic needs.

1 AWARENESS AND RISK REDUCTION

AIM

To increase the community's knowledge of what dementia is, how to reduce risk factors, disease progression, management, and resources to support PLWD and their families in Bermuda.

OBJECTIVES

- Provide health education and promotion to increase the public's knowledge of dementia and encourage behaviour change in the development of healthy habits to reduce dementia risk.
- Increase the public's knowledge and encourage cognitive stimulation through brain-training games, regular eye checks, and vision correction, as well as hearing tests and correction.
- Promote regular dental checks to reduce periodontal disease associated with dementia and reduce the risk of serious dental issues that are more difficult to correct in later stages of dementia.

- Ensure PLWD are treated with respect and dignity and supported to remain part of the community.
- Increase formal and informal Caregivers' knowledge of dementia and how to support PLWD to help ensure their own and the PLWD's quality of life.

ACTIONS

- Develop and expand existing public health dementia awareness and risk reduction campaigns. This includes understanding what dementia is, signs and symptoms, and disease progression; as well as promoting primary prevention actions (e.g. healthy diet; physical exercise; cognitive training; childhood education; social stimulation; addressing hearing loss; reducing vascular risks (diabetes, blood pressure, and obesity); preventing head injury; limiting alcohol and smoking; reducing air pollution; addressing vision loss; and high cholesterol).
- Establish programmes that promote inclusive, dementia-friendly communities for the public, targeting key service and support sectors such as the Dementia Friends programme.
- Facilitate access to specific training for informal Caregiver's (responsible parties) of newly diagnosed patients with dementia, including:
  - Disease progression
  - What to expect at various stages
  - How to address challenging behaviours
  - Available resources
- Certification of registered formal and informal Caregivers should include evidence of training in dementia care. This should be an industry standard with agreed periods of refresher training. (Set at NVQ Level 2/3)
- Build dementia awareness into the ongoing health promotion programmes of the Department of Health.

KEY PARTNERS

- Dementia Bermuda
- Department of Health
- Ministry of Youth, Social Development and Seniors (MYSDS)
- Bermuda College

DEPENDENCIES/LIMITATIONS

- There are no specified government budgetary allocations for dementia education and promotion. Having specific government allocations through direct commissioning of health education and promotion will help address this.

- An increased focus on dementia and its impact on the community will help increase the visibility of this condition and attract funding.
- Existing providers have limited education offerings because of resource constraints. The Department of Health and Dementia Bermuda are committed to leading these efforts; however, resource constraints limit the scale and time frame by which the programmes are implemented.
- Professional training programmes being offered at Bermuda College require additional dementia-specific information and additional certification programmes for relevant health professionals.
- The various regulatory and statutory bodies need to collaborate to amend the current registration requirements.

2 PATHWAY FOR INITIAL DETECTION

AIM

- To ensure that all patients with dementia are diagnosed early in their disease process through a preventive screening process. This should include the subtypes of dementia to the fullest extent possible.

OBJECTIVES

- Encourage and facilitate all patients aged 65 and over and those with high-risk factors to be aware of their cognitive function and obtain an assessment as part of their annual medical examination.
- Establish standardised cognitive decline screening tools for use across all providers.
- Promote early diagnosis through partnerships, awareness campaigns, and education, which highlight the benefits of early diagnosis.

ACTIONS

- Empower families with PLWD who may have symptoms of dementia they are unaware of, to request cognitive assessments, including digital cognitive assessments, through third-sector providers or other healthcare providers. Providers can take into consideration the PLWD medical history.
- Create and implement screening standards for dementia across settings, including subtypes as much as possible.
- Encourage yearly cognitive assessments in primary care settings for all patients aged 65 years and over, or with an established family history, and/or risk factors.
    - In all cases of cognitive decline in older patients, delirium and other reversible causes are to be ruled out.

  - Additional consideration can be given by Primary Care Providers to lower the screening age to 40, due to the increasing incidence of early-onset dementia. This can be done with a simpler screening test, such as the Mini-Cog test, and has the advantage of increasing screening coverage at a minimal extra cost for many residents in Bermuda.
- Require a cognitive assessment for all driving licence renewals for those aged 70+ years. This can be explored with the Transport Control Department.
- Ensure that the hospital maintains its policy of performing a cognitive assessment for all patients aged 65+ years who have no known diagnosis of dementia.
  - In all cases of cognitive decline in senior patients, delirium and other reversible causes are to be ruled out in the emergency room and on admission.
- Expand and standardise training of and screening by first responders and other health professionals. All first responders should receive training to recognise symptoms of dementia and know how to report this to the patient's Primary Care Provider or the hospital.
- Ensure health promotion entities, healthcare providers and support agencies promote benefits of early diagnosis such as the ability to participate in one's own care when capacity is reduced, as well as financial and legal provisions, including Power of Attorney.
- Consider financial relief initiatives such as:
  - a duty-free exemption for equipment for home care,
  - tax benefits for Caregivers (e.g., property and payroll tax relief)

KEY PARTNERS

- Bermuda Hospital Board – *Clinicians, Emergency Department Staff, Geriatricians, Hospitalists, Nursing, and Allied Health Staff, training team*
- Primary Care Provider Offices
- First responders - *Emergency Medical Technicians, Police, and Fire personnel*
- Dementia Bermuda
- Department of Health

DEPENDENCIES/LIMITATIONS

- Screening standards should be developed by practitioners with clinical expertise and interest in dementia (e.g. Geriatricians and GPs with specialisations or interest in dementia).
- Education on and the adoption of the identified standardised screening tools across providers will be necessary and must consider the settings and training required for such.
- Identify and address gaps in organisations' capacity (including first responders) to provide training to providers. Where appropriate, commission or refer training to Dementia Bermuda/ Bermuda College.

- Create a new billing code for screening patients aged 65 years and over. This is required to facilitate implementation and would be developed by the Bermuda Health Council, working in collaboration with insurance companies.
  - The Mini-Cog examination prompt will need to be included in individual practices' EMR systems.
  - Remuneration to account for extra time spent assessing eligible patients for cognitive deficits, should be developed by the Bermuda Health Council, working in collaboration with insurance companies and should be based on the new billing codes for 65+ screenings.

3 DIAGNOSTIC WORKUP

AIM

- To have a standardised method of diagnosing dementia in Bermuda, supported and used by all health professionals.

OBJECTIVES

- Develop a diagnostic pathway that includes screening, referral thresholds, and a referral system for the diagnosis and management of dementia.
- Develop a minimum set of diagnostic tests for suspected dementia/cognitive impairment.
- Introduce and integrate diagnostic standards and the pathway into relevant care settings and regulatory bodies.

ACTIONS

- Create a standardised diagnostic pathway, inclusive of dementia subtypes, in collaboration with a Primary Care Provider with a Special Interest and geriatricians, that:
  - Aims to diagnose the dementia subtype, as this influences treatment
  - Includes a complete history and physical examination, including a neurological examination
  - Excludes reversible causes, such as fluid/electrolyte imbalance, infections, organ failure, hypoglycaemia, and constipation
  - Reviews the medications to exclude drug toxicity and withdrawal syndromes
  - Reviews and considers other comorbidities
  - Ensures tests are completed or arranged for diagnosis, inclusive of:
    - CT or MRI of the brain (without contrast) unless one was performed within the last year
    - Blood tests for Complete Blood Count, Comprehensive Metabolic Panel, B12, Folate, thyroid functions, and Vitamin D
    - 12-lead ECG
    - HIV and syphilis testing if not already known

  - Refer to the geriatric clinic at the hospital, or a Primary Care Provider with a Special Interest in dementia.
- Implement the standardised diagnostic pathway with the support of the Bermuda Medical Council and Primary Care Providers.
- Consider the expansion of the existing services provided at KEMH by the geriatric clinic, to provide a comprehensive geriatric service that incorporates hospital and service providers from the community.

KEY PARTNERS

- BHB Geriatric Clinic
- Primary Care Providers and Special Interest Primary Care Providers
- District nurses and nurse practitioners

DEPENDENCIES/ LIMITATIONS

- The impact of dementia diagnosis standards will be limited if they are not adopted under the standards of practice by the relevant professional authorities and reflected in funding arrangements.
- Diagnostic standards adopted must be realistic in relation to the available resources in Bermuda.
- Diagnostic standards should be developed by practitioners with clinical expertise and interest in dementia (e.g. Geriatricians and GPs with specialisations or interest in dementia).
- The geriatric service at the hospital is not currently set up to provide a seamless and comprehensive national service. The advantage of this approach is that it leverages economies of scale, providing a better experience for both patients and health professionals.

4 DIAGNOSIS DISCLOSURE

AIM

All patients diagnosed with dementia, along with their families and caregivers, are provided with comprehensive support to understand the progression of the disease and to access all necessary resources to maintain a good quality of life with dignity.

OBJECTIVES

- All newly diagnosed patients and their caregivers have access to high-quality information about dementia.
- All newly diagnosed patients and their caregivers have access to support services through a care coordinator.

- All patients should be reviewed in a multidisciplinary team, and a suitable care plan should be developed for their management.

ACTIONS

- Collaborate on health education and promotion campaigns for the community, providers, and families to ensure the diagnosis of dementia is always disclosed in the presence of a responsible party (e.g. trusted family members, friends, or main caregivers) .
- Update relevant standards of practice to reflect diagnostic disclosure requirements.
- Provide access to education for informal Caregivers, which provides information and support, as described in the section on "Awareness and Risk Reduction".
- Require all PLWD, as part of the diagnosis disclosure, to be referred to a care coordinator who has knowledge of dementia care needs.

KEY PARTNERS

- Primary Care Providers
- Advanced nurse practitioners and registered nurses (RNs)
- BHB Geriatric Clinic
- Dementia Bermuda
- Social care workers/care coordinators

DEPENDENCIES/LIMITATIONS

- Health education and promotion campaigns need to include the importance of earlier diagnosis, stigma reduction, and inclusion of PLWD in the community.
- Informal caregivers (families) need training and support. This education can be supported by the programme already developed by Dementia Bermuda and should be offered to all family caregivers for PLWD.
- Funding will be required to enable the expansion of care coordination services, to ensure all diagnosed PLWD have access to a dementia-specific care coordinator. The existing services, via Dementia Bermuda, are only able to support a limited number of PLWD with the existing funding allocated from Government and the third sector.
- Care coordination by government social workers is very limited due to broad service scopes and high caseloads. An expanded service to provide care coordination should be introduced. This could be made up of social care workers who will:
    - help PLWD and their caregivers navigate the available dementia services,
    - be the first point of contact for PLWD and their caregivers,
    - ensure that PLWD are involved in their care and that their wishes are met as much as is practicable.

5 ONGOING MEDICAL AND EMERGENT CARE

AIM

To ensure that PLWD have the appropriate and coordinated clinical care to live with dignity throughout the disease progression.

OBJECTIVES

- To support PLWD in slowing the progression of their cognitive decline by obtaining the appropriate diagnosis, including subtypes, and receiving targeted treatment for their specific disease subtype.
- To improve data collection on dementia prevalence for dementia care monitoring, evaluation, and research.
- Support the development of a dementia registry to assess how the community manages dementia, to obtain the true prevalence of dementia, and to enable the evaluation of interventions and research.

ACTIONS

- Ensure hospital care for PLWD is for acute care needs only and focuses on returning the PLWD as close to their pre-admission state as possible. This should include rehabilitative services and returning them to their usual residence as promptly as possible, as prolonged hospital stays are rarely in the interests of the PLWD.
- Support the establishment of Multidisciplinary Teams (MDT) which coordinate health plans for PLWD, involving Primary Care Providers, community organisations, and social services, to develop and refine care plans. This will improve outcomes for the PLWD and break down care silos.
- Ensure access to brain health specialists for PLWD at least once a year, or more frequently, if needed. This would help with reassessment, disease and medication management, and allow for updated care plans and referrals. This should be within an MDT setting and take into consideration the PLWD comorbidities, if present.
- Ensure access to short-term hospitalisation as required when there is a medical or surgical morbidity, which cannot be managed in the community. Short-term hospitalisations can be an opportunity to identify unmet care needs, as well as the needs of caregivers.
- Identify who will create and host a national dementia registry.

KEY PARTNERS

- Primary Care Providers
- Nurse practitioners
- Geriatricians and hospitalist services
- Allied Health Professionals – physiotherapists, occupational therapists, speech and language therapists
- Social workers

DEPENDENCIES/LIMITATIONS

- Brain health specialists in Bermuda need to be defined. Ideally, this should be the geriatrician service. However, there is not enough capacity to meet the demand. Additional capacity can come from PCPs with a Specialist Interest in dementia or care of the elderly, geriatric psychiatrists, neurologists, and other internists with a Special Interest in care of the elderly.
- The existing remuneration model for brain health specialists needs to be reviewed to account for the increased skill required and complexity of the caseloads.
- EMRs that can communicate seamlessly are required to facilitate coordinated clinical care. The existing systems in the community do not communicate well with the hospital and other providers, although this is being addressed as part of the digital strategy of the Universal Health Coverage plan, we still need to strongly encourage its implementation.
- The development of a dementia registry requires improved data collection to ensure quality data for population monitoring and system planning.
- The present Personal Information Protection Act (PIPA) 2016 does not permit the type of information exchange required in healthcare without explicit consent, which is not always possible with PLWD. Therefore, exemptions are needed for sharing information in the best interests of the patient and the public when consent cannot be obtained.

6 CARE IN THE COMMUNITY

AIM

To ensure that PLWD are cared for in settings best suited to their needs and stated preferences, upholding their dignity and supporting caregivers to meet these needs.

OBJECTIVES

- Ensure affordable care and support so that PLWD are cared for in their own homes, for as long as possible and appropriate.

- Ensure access to institutional care when home-based care is not feasible or unavailable throughout the disease progression. This could be in nursing homes, rest homes, or assisted living facilities.
- Ensure dementia-friendly care settings are available across the range of levels of care required during the disease's progression (e.g. from assisted living to complex care).
- Ensure access to care coordination and crisis intervention services, respite care, enhanced coverage for in-home care support, and adult day-care facilities to offer relief for caregivers and enable working families to provide care while maintaining employment.
- Ensure residential, day-care and activity programmes are founded on evidence-practice that ensures stimulating activities and person-centred approaches to care (e.g. creative engagement, music and art therapy, reminiscence, meaningful activities, cognitive stimulation).

ACTIONS

- Increase the capacity for respite and long-term care beds by supporting existing care facilities and new developments through training, staff availability, and financing. This could be achieved by:
  - An enhanced fee structure to incentivise homes to care for complex dementia needs
  - Providing training through Bermuda College
  - Offering immigration incentives such as:
    - expedited work permit applications and,
    - shorter paths to permanent residence status for registered nurses
  - Support PLWD in the community by expanding services provided by the Department of Health. Additional resources to provide community services should be inclusive of nursing, speech and language therapy, occupational therapy and physiotherapy.
  - Facilitate access to caregiver support groups by ensuring health providers are aware of the available support groups and information is shared.
  - Facilitate access to caregiver support groups by increasing the number of available services.
  - Facilitate or provide access to 24/7 crisis intervention support.
  - Establish and promote standards for dementia programming for the various settings to align with best practice.
  - Expand financial support for existing day care providers and activity programmes and encourage new providers to offer high-quality programming to enable family caregivers to continue working and providing care at home.
  - Support care workers to manage responsive behaviours through increased access to educational opportunities and specific intervention supports and training. These can be provided by MWI staff and by third-sector providers, such as Dementia Bermuda, with additional resources.
  - Consider financial incentives such as reduced or waived land taxes for PLWD who are cared for at home.

- Continue the existing financing programme that allows people to adapt their residence to meet future care needs.

KEY PARTNERS

- Mid-Atlantic Wellness Institute – *psychiatrists, mental health nurses, mental health social workers*
- Care Homes – *residential and nursing homes*
- Senior Day-Care Centres
- Dementia Bermuda
- Department of Health
- Ministry of Youth, Social Development and Seniors
- Ministry of Health
- Social care workers

DEPENDENCIES/LIMITATIONS

- Increasing the availability of dementia-friendly care settings falls under the larger work on improving Bermuda's long-term care system which includes long-term care financing and ensuring accessible, high-quality care at home and in facilities, for all persons living in Bermuda.
- The availability of additional dementia-friendly care settings should take into account the complexities of individual cases, allowing for the recruitment and retention of the right staff.
- Health workforce development initiatives, especially for Registered Nurses, are critical to advance care home capacity to admit and appropriately support persons with dementia as their needs progress. One model could utilise nurse practitioners with training and experience in caring for the elderly to supervise non-nursing staff across many care homes.
- Day-care facilities are limited in number with limited availability. In addition, barriers to accessing day-care exist outside of availability as PLWD may require access to transport and other support services to facilitate attendance.
- There is currently no 24/7 crisis intervention service available for PLWD and their caregivers.

7 END-OF-LIFE CARE

AIM

To help PLWD receive safe and dignified end-of-life care that considers their preferences.

OBJECTIVES

- To help PLWD understand the progression of the disease and make informed choices, including their preferences for end-of-life care.

- Services should be accessible and available to assist PLWD in achieving their end-of-life preferences.
- Ensure financing options exist to facilitate end-of-life care in accordance with people's preferences.

ACTIONS

- Enable access to the SHB palliative/end-of-life care benefits for 3 months in total (or 6 months in exceptional circumstances) without requiring them to be a continuous period. This is important in dementia care, as the progression of the disease is not linear, unlike other conditions, for example, cancer.
- Establish dedicated and accessible services to facilitate and coordinate end-of-life care at home for PLWD.
- Provide support and access to education to care homes to facilitate end-of-life care within their facilities and avoid unnecessary hospitalisations.

KEY PARTNERS

- Dementia Bermuda
- P.A.L.S. (Progressive Alliance of Living with Support) Bermuda
- Ministry of Health
- Bermuda Health Council
- Care homes
- Palliative care specialists

DEPENDENCIES/LIMITATIONS

- Consideration to amend the SHB is required to enable non-continuous use of the palliative/end-of-life care benefit.
- An assessment is required to determine the additional human and financial resources required (outside of SHB changes) to implement an end-of-life service, similar to P.A.L.S. for PLWD.
- Support for care homes to provide end of life services requires LTC strategic actions around financing, professional development, and health workforce development.

NEXT STEPS

The integrated care pathway provides a blueprint for quality dementia care and identifies key actions necessary to achieve such, based on our current services, health and long-term care system. How and when these actions can be achieved requires further engagement and planning.

Accordingly, to advance this initiative, actions will be strategically prioritised through working groups consisting of key stakeholders. This will require:

- Identifying available or required resources,
- Identifying lead agencies
- Setting realistic timelines
- Ensuring coordination with relevant initiatives under the National Seniors' Strategy and Health Strategy
- The prioritisation of required actions

As required, selected interventions (e.g. diagnostic standards and pathways) will be piloted to ensure utility and operational efficiency prior to commencing national implementation and appropriate monitoring and outcome measures are established.

SUMMARY OF REQUIRED ACTIONS AND KEY ORGANISATIONS:

Required Actions	Key stakeholders
Awareness/Risk Reduction	
Expand health education and promotion on dementia risk reduction actions for the general public	• Dementia Bermuda • Department of Health (DoH)/Ministry of Health (MoH) • Ministry of Youth, Social Development and Seniors (MYSDS)
Introduce dementia friendly community training and engagement for the general public	• Dementia Bermuda • MYSDS • MoH
Expand disease awareness, progression, management, and support training and education for PLWD, family caregivers, and other caregivers	• Dementia Bermuda • DoH • MYSDS • MoH

Required Actions	Key stakeholders
Introduce dementia certification training requirements for registered caregivers	• Bermuda Health Council • Bermuda College • Dementia Bermuda
Initial Detection	
Establish screening standards across settings (Primary Care, hospital, first responders)	• Geriatricians • Primary Care Providers (PCP) with specialisation or interest in Dementia • United Health Care (UHC) Clinical Standards Committee
Implement screening standards across settings (GPs, hospital, first responders) • **Training on standards/assessments** • **Integrate screening tools/prompts into existing EMR systems** • **Establish a new billing code for screening**	• Geriatricians with a PCP specialisation or interest in Dementia • Bermuda Medical Council/ UHC Clinical Standards Committee • Emergency medical technicians • Bermuda Fire & Rescue Service • Bermuda Police Service • Social workers (DoH, Ageing and Disability Services (ADS), King Edward VII Memorial Hospital (KEMH)) • Health professional associations • Private care providers • Bermuda Health Council • Private insurers
Promotion of the benefits of early diagnosis to patients, including support for families to request screening or assessments if these are not offered	• Dept of Health • Dementia Bermuda • PCPs
Diagnostic Workup	
Create a standardised diagnostic pathway for dementia **Identify and address resource needs to achieve the preferred pathway** **Adopt as national practice standards**	• Geriatricians • PCPs with specialisation or interest in dementia • Bermuda Medical Council • UHC Clinical Standards Committee

Required Actions	Key stakeholders
Diagnostic Disclosure	
Establish and implement standards for diagnostic disclosure	• Geriatricians • PCPs with specialisation or interest in dementia
Expand care coordination services	• MYSDS • MoH • Dementia Bermuda • DoH
Ongoing Medical and Emergent Care	
Establish MDT review system to develop and monitor care plans • **Ensure Personal Information Protection Act legislation enables such**	• PCPs • Geriatricians • Dementia Bermuda • Allied health services • Social workers • MoH
Define and expand access to brain health specialists across settings (human resources and financing)	• MoH • Bermuda Hospitals Board (BHB) • Bermuda Health Council
Establish a dementia registry	• Bermuda Health Council • ADS • BHB • MoH
Care in the Community	
Increase LTC bed capacity, day centres and respite for PLWD and home care benefit coverage	• LTC Action Planning Committee • LTC financing • ADS/MYSDS
Enhance existing community-based services and access to technology to support in home care for PLWD	• LTC Action Planning Committee • ADS/MYSDS

Required Actions	Key stakeholders
Increase education and support to home care and care home providers for managing BPSD	• Dementia Bermuda • Bermuda Health Council • Bermuda (LTC) Peer Learning Network • MWI • Care homes • Home care providers
Establish community-based dementia care standards	• ADS/MYSDS • Bermuda Health Council • Dementia Bermuda
Implementation of community-based dementia care standards	• Bermuda Health Council • Dementia Bermuda • Care homes • Day Care Providers
Enhance regulatory oversight capacity for care standards	• Bermuda Health Council • MoH
Identify financial incentives to promote and facilitate ageing in place for PLWD	• ADS/MYSDS • MoH • BHC • Cabinet • Finance
Create a 24/7 crisis support line for Caregivers of PLWD	• MWI • MoH • MYSDS • Dementia Bermuda
End-of-Life Care	
Amend SHB palliative/end-of-life care benefit requirements.	• Bermuda Health Council • MoH
Increase access to end-of-life care coordination services for PLWD	• LTC Action Planning Committee • Dementia Bermuda • P.A.L.S.
Address financial and staffing barriers to providing end-of-life support in care homes	• LTC Action Planning Committee • ADS/MYSDS

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