

# Government of Bermuda Ministry of Social Development and Seniors MINISTERIAL STATEMENT

by

# Senator Lauren Bell, JP Junior Minister for Health, Economy & Labour, and Housing & Municipalities

### **Dementia Care Services Pilot Programme Update**

Wednesday, April 2<sup>nd</sup> 2025

### **Madam President,**

This morning I rise to share with my Senate colleagues, observations, findings and data, stemming from the operation of the Dementia Care Services Pilot Programme which was first launched by the Ministry of Youth, Social Development and Seniors in October 2023 through its Office of Ageing and Disability Services. The purpose of this programme is to ensure those persons living with dementia who are uninsured or underinsured have access to dementia navigation and support services.

# **Madam President,**

As a backdrop, dementia is an umbrella term for degenerative diseases that impact the brain. This results in memory loss and changes to one's behavior and one's thinking, which impacts our ability to perform everyday activities.

According to the World Health Organization, global numbers for dementia are expected to triple by 2050, due to ageing populations and chronic diseases that are risk factors for this disease. It is estimated that up to 45% of dementia cases could be reduced through addressing modifiable risk factors for dementia. Prevention is always preferable; however, for people

already with the disease, we must support not only them but also their carers through its challenging progression.

## Madam President,

In Bermuda, based on current processes, there are over 3,600 patients inputted into the Bermuda Hospital Board's system as having dementia. Work continues to better define prevalence data and the potential future impact on the Bermuda system. However, to date, as dementia is a progressive disease, people's needs for care and support increase, placing greater demand on our long-term care services and supports over time. A lack of knowledge of the disease and support for those caring for persons with dementia can result in unnecessary and costly hospital admissions or care home placement. It also increases the risk for abuse and neglect, as cognitive impairment is a significant risk factor for such.

### Madam President,

It is within this context that the Government is committed to addressing the social, clinical and economic challenges of dementia. As such, the Ministry of Youth, Social Development and Seniors has undertaken the following related initiatives:

- In 2022, provided several education series on dementia;
- In October 2023, introduced the Dementia Navigation and Care Pilot programme;
- In June 2024, extended the Pilot Programme based on the data obtained;
- In November 2024, developed a detailed project inception plan for the design of a seniors day care facility with a dementia care focus;
- In December 2024, completed the first National Seniors Strategy for Bermuda, inclusive of a focus on dementia;
- In January 2025, contracted the expertise of the Bermuda Health Council to commence developing an integrated care pathway for Dementia; and,
- In February 2025, engaged in meetings to start assessing the designated site for the dementia focused senior day care facility.

Of these initiatives, it is the pilot programme I will provide an update on this morning. In October 2023, NorthStar Dementia Ltd., was contracted to provide a 6-month pilot programme for dementia navigation and support services for persons experiencing dementia who were either underinsured or uninsured. These services included comprehensive dementia assessments, personalized care planning, cognitive compensatory strategies, case management, caregiver education and support, crisis intervention and prevention.

This program was developed based on evidence-based research that recognizes the vital importance and role of dementia care management to not only improve quality of life for persons with dementia, but also their carers, which in turn decreases more costly care caused by hospitalization or crisis management. Northstar Dementia was selected not only because they specialised in this area but also because their service model supplements the pilot programme to expand its reach and depth of support.

### Madam President,

Between October 2023 and December 2024, the Ministry provided a total of \$96,000 to fund the pilot program, which contributed to serving 111 persons with dementia of which:

- o 58% or roughly 63 clients were female
- o 55% or 61 clients were between 75-84 years of age
- o 67% or 74 clients were black Bermudian

For the caregivers who were clients and received services:

- o 56% were the adult children of the client
- 70% were female caregivers

There was a total of 260 client contacts during this period. The intensity and type of contact was tailored to the needs of the family and the stage of the dementia progression.

The question is, what have we learned to date about the need for a dementia care services programme, based on client feedback and data findings? The answer is three key observations:

- 1. There is a funding gap for dementia navigation and support services;
- 2. Persons are not getting formally diagnosed; and,
- 3. Caregivers are stressed and not getting enough support

### Madam President,

Let me briefly speak to each of these three observations.

- 1. There is a funding gap for dementia navigation and support services:
  - Nearly 95% of the clients in the pilot programme were insured.
  - However, 84% of all referrals could not contribute to the full cost inclusive of co-pay of the services.
- 2. Persons are not getting formally diagnosed:
  - At the start of the programme 46% of clients stated they did not have a formal diagnosis;
  - However, after participating in the pilot programme, 77% had obtained a diagnosis.
- 3. Caregivers are stressed and not getting enough support:
  - At the start of the pilot programme16% of the caregivers rated their stress levels as severe, and 52% said theirs was moderate.
  - At the 12-month evaluation mark, for those clients evaluated:
    - 46% felt somewhat less stressed
    - 27% were significantly less stressed
    - 62% felt much more knowledgeable about dementia
    - 77% were more confident in implementing care strategies for their loved one; and
    - 73% were more aware of local resources available.

The Pilot Programme highlighted to its clients the importance of being diagnosed to determine if one is experiencing dementia or not. This allows persons to prepare ahead and put their affairs in order, determine what supports will be needed and get critical legal documents and financial resources in place. After starting the pilot 65% of the clients obtained a power of attorney, and 46% obtained an advance directive.

### Madam President,

The Pilot Programme outlined how persons can start interventions and finding supports sooner rather than later. For example, there are available medications or programs that help decrease the impact of the cognitive decline early in dementia progression.

Additionally, there are non-medical interventions to help manage behaviours or concerns that can reduce the need for costly hospital admission. Roughly 81% of the clients in the pilot programme had no hospital admission, and 46% had an increase in social support for their loved one.

### Madam President,

It is important that family carers have the support they need to continue the care of their loved ones. Access to support groups, respite, day care, activity programs, and care home placement is needed.

The pilot programme demonstrated the critical role of system navigation and care management for family carers and persons living with dementia to provide support and guidance with direct care and available support services.

This is evident by 100% of clients evaluated stating the dementia care services pilot programme should continue.

The pilot findings are only from a small sample of persons diagnosed with dementia. This is why the Ministry's systemic work in collaboration with the Ministry of Health is critical for long term solutions.

Under the framework of the National Seniors' Strategy, the Ministry of Youth, Social Development and Seniors contracted the Bermuda Health Council to develop an integrated care pathway for dementia, in collaboration and alignment with the Ministry of Health's, health system reform work and the Health Council's Dementia Health Needs Assessment. This initiative underway, is mapping current patient journeys and identifying system and service gaps and needs. A preferred care pathway will be established, in consultation with stakeholders, and an action plan will be developed.

This pathway will cover prevention to end of life as the entire spectrum must be addressed to not only reduce the prevalence of dementia in Bermuda but also its negative impact on those living with the disease, their support persons and the sustainability of our health and long-term care systems. Fundamental to this work is establishing a standardized formal diagnosis process to ensure we obtain the most accurate data as possible on dementia and its varying types.

### Madam President,

In closing, we acknowledge and thank all those persons living with dementia, their carers and the service providers who have shared and continue to share their experiences, knowledge, expertise and very limited time as part of this pilot programme work for improving Bermuda's dementia care system for current and future generations.

We look forward to updating the Senate and the community on the continuing progress of these initiatives. During the interim, we encourage our community to increase their awareness of dementia prevention and how to lend support to persons and carers as well as the organizations in place that support persons living with dementia and their families.

### Thank you, Madam President.