

25/03/25

Good evening Finance Committee MLAs,

Please see attached the Alzheimer's Society's response to the 2025-26 budget consultation for your information ahead of the Oral briefing on the budget that is due to be presented to you at Committee tomorrow.

I hope you find it interesting, and we are happy to meet with any of you to discuss how improving dementia diagnosis can in turn reduce the devastating economic impact of dementia on the health and social care system.

Many thanks

Martin Reilly (He/Him)

#MyNameIs pronounced Mar-tin Ri-Lee

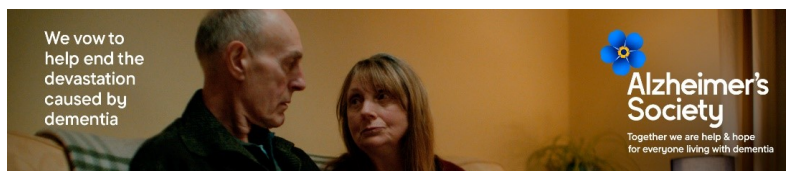
National Influencing Officer

+44 7591 588 293

alzheimers.org.uk/

facebook.com/AlzheimersSocietyNorthernIreland

twitter.com/AlzSoc_Martin



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Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

<https://www.alzheimers.org.uk>

Alzheimer's Society is a registered charity in England and Wales (296645) and the Isle of Man (1128). A company limited by guarantee, registered in England and Wales company number 2115499. Isle of Man company number 5730F. Registered office: 43-44 Crutched Friars, London EC3N 2AE

Northern Ireland draft budget 2025-26 consultation response



30 Skegoneill Street
Belfast
BT15 3JL

Executive Summary

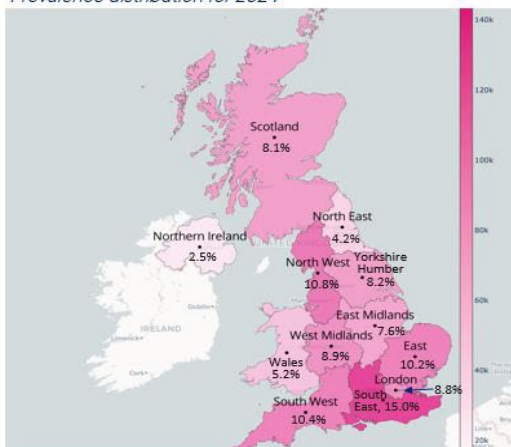
Alzheimer's Society is the largest dementia charity in England, Wales and Northern Ireland. Dementia is a growing issue across these islands, with the largest increase in prevalence expected to occur in Northern Ireland. Dementia costs Northern Ireland approximately £1 billion each year, this will increase to £2 billion by 2040.¹

An ageing population means the number of the UK population with dementia will increase by 43% by 2040, with the biggest increases (51%) in Northern Ireland and London (53%)

UK dementia prevalence by region
Number of people with dementia

	2024	2040	% change 2024-2040
England	825,860	1,183,126	43%
South East	147,211	211,298	44%
North West	106,343	147,899	39%
South West	101,595	147,822	46%
East of England	100,287	142,201	42%
London	87,303	133,956	53%
West Midlands	87,189	121,286	39%
Yorkshire and The Humber	80,574	112,609	40%
East Midlands	74,300	108,687	46%
North East	41,059	57,367	40%
Scotland	79,789	111,493	40%
Wales	51,226	69,982	37%
Northern Ireland	24,700	37,409	51%
UK	981,575	1,402,010	43%

UK dementia prevalence by region
Prevalence distribution for 2024



Module 1: Annual costs of dementia



Urgent action on dementia in this budget, and in future multi-year budgets, is required. Dementia is a profound and growing whole-system challenge. Last year, we commissioned new evidence, including one of the largest UK studies with health agency Carnall Farrar, on healthcare resource utilisation by patients with dementia, using a cohort of over 25,000 patients. This evidence demonstrates how improving access to dementia diagnosis, utilising

¹ Alzheimer's Society and Carnall Farrar (2024). [The economic impact of dementia – Module 1: Annual costs of dementia](#).

evidence-based treatments, and investing in the social care workforce can enhance the lives of people affected by dementia, reduce pressure on the health system, and achieve significant economic benefits.

We make three priority recommendations for cost effective investment and actions to address the whole-system challenge posed by dementia. These are:

Priority 1 – Increase early diagnosis and treatment.

The Department of Health should tackle low dementia diagnosis rates, improve access to early and accurate diagnosis through dedicated funding and run a targeted awareness campaign to improve recognition of symptoms.

Priority 2 – Maximising the value of social care spending

The Department of Health should introduce a funded statutory duty for all care providers registered with the RQIA to ensure the adult social care staff receive dementia training mapped to the Dementia Training Standards Framework.

Priority 3 – Improving dementia data

The Department of Health should improve the collection of dementia data, including by dementia type, across Northern Ireland to prepare the system for new treatments and allow Health and Social Care Trusts (HSCTs) to plan for the increased prevalence of the disease in the next decade.

The scale and cost of dementia

Priority 1 – Increase early diagnosis and treatment.

We need to see investment to increase the numbers of people with dementia who receive an early diagnosis. An early and accurate diagnosis will be one of the most cost-effective ways to improve quality of life, reduce pressure on the health system, and achieve cost savings for both the HSC system.

Lord Darzi has noted that: *“As society continues to age, there is an important challenge to improve both the quality and quantity of care for people with dementia.”*² Yet the Health and Social Care (HSC) system response to dementia is insufficiently prioritised.

² Lord Darzi (2024). [Independent Investigation of the National Health Service in England](#). p.49

The result of this approach is twofold:

Firstly, the **NI Executive is missing out on significant cost savings** that could be made within our Health and Social Care system through a more joined up, strategic approach. Dementia currently has a huge and costly impact on the healthcare system: one in six hospital beds today are occupied by dementia patients, who also visit the GP up to three times more per year than someone without dementia. A third of dementia healthcare costs are generated by unplanned hospital admissions.

Without action, this impact will grow as prevalence increases. By 2040, there will 6.9 million additional primary care contacts associated with dementia, requiring an estimated 1.7 million more hours of primary care time.

Secondly, **dementia diagnosis, treatment and care are not meeting people's needs**. Currently, more than a third of people with dementia in Northern Ireland are undiagnosed, and the diagnosis process is slow and low-quality. Access to treatment that can reduce cognitive decline, and to care and support following diagnosis, is insufficient and there are high levels of unwarranted variation in access to diagnosis and care.



The potential for health and social care savings associated with an early and accurate diagnosis aligns to the Programme for Government's 2024-2027 ambition to drive effectiveness and improve outcomes across the HSC system. Our research shows how undiagnosed dementia can increase the costs of the disease across the system. A lack of early diagnosis is associated with increased costs through higher rates of admission to hospitals and residential care, resulting in inefficient care management and limiting the quality of care provided.

A lack of diagnosis risks increasing people's need to access healthcare

People with dementia, but without a diagnosis, attend A&E, on average, 1.5 times per year, which is more than people diagnosed with mild, moderate and severe dementia and 3 times as much as people without dementia.

In **Northern Ireland**, people living with undiagnosed dementia account for nearly 15,000 A&E visits each year.



Alzheimer's Society | The economic impact of dementia

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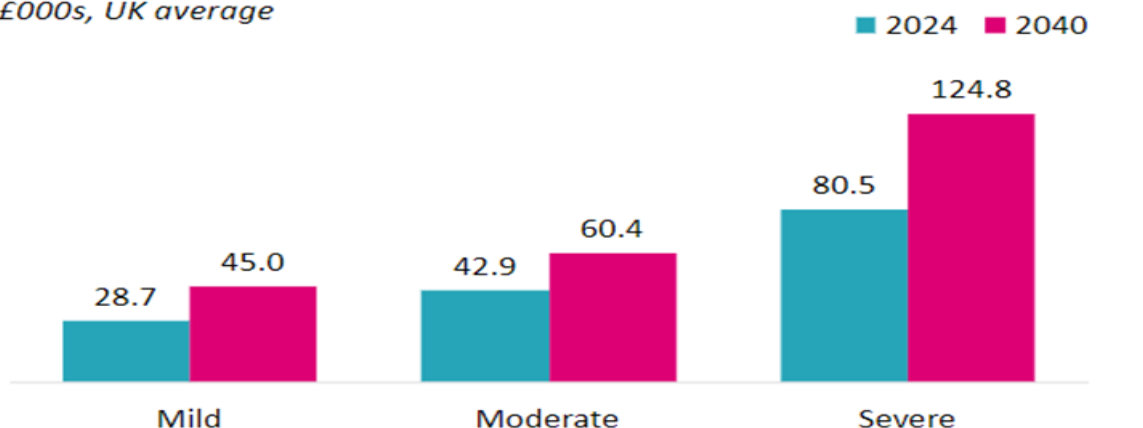
By increasing investment into dementia diagnosis services, the NI Executive will be following the Programme for Government's ambition of *'doing what matters most'* and improving outcomes across the wider HSC system. This investment will also align with the commitment to enhance access to early intervention as part of the work of the Public Sector Transformation Board and £235m Transformation Fund referenced in the Programme for Government.

We need to see investment to increase the numbers of people with dementia who receive an early diagnosis, and access to NICE-recommended treatments and interventions. We know that dementia is a progressive condition, and the cost associated with it grows significantly as severity increases. This would be a cost-effective way to improve quality of life, reduce pressure and achieve cost savings for both the wider HSC system. By early diagnosis, we mean a patient receiving a clinical diagnosis around the time of onset of dementia symptoms, when the disease is still in its mild stages before significant cognitive and functional impairment has occurred.

The average per person annual cost of mild dementia is £29,000: this increases to £81,000 for severe dementia, primarily due to increased need for costly residential care. Interventions that can help with symptoms and support people to maintain independence for longer, therefore have significant potential to be cost effective. Yet there is underinvestment in these interventions, including in early diagnosis, treatment and dementia training for the care workforce.

Per person costs of dementia by severity

£000s, UK average



Source: Alzheimer's Society and Carnall Farrar (2024) *The economic impact of dementia*, Module 1, p.40.

Improving Social care

Priority 2 - Maximising the value of social care spending

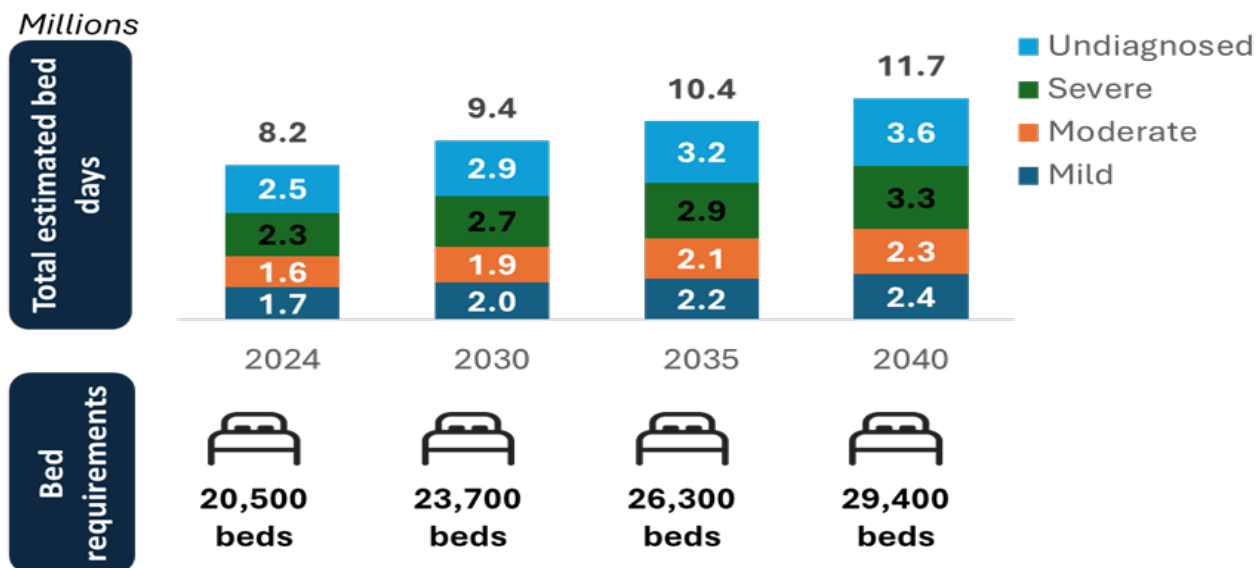
The Department of Health should introduce a funded statutory duty for all care providers registered with the RQIA to ensure the adult social care staff receive dementia training mapped to the Dementia Training Standards Framework.

People living with dementia need to be able to easily access affordable, high quality social care that meets their specialist needs, delivered by a well-trained workforce. People with dementia make up a significant proportion of the population who draw on social care. Improving social care for people with dementia would not only improve the quality of life for people with dementia and their paid and unpaid carers but also reduce pressures on the health system and deliver economic benefits.

Our 2024 research with Walnut Unlimited highlighted when asked what would best help to improve the lives of people living with dementia, 65% of people said more care workers who are skilled in caring for those with dementia.³

³ Walnut Unlimited. (2024). [Personal experiences of the dementia journey: The true picture. Alzheimer's Society.](#)

Bed days and bed requirements for people with dementia



Source: Alzheimer's Society and Carnall Farrar (2024). The economic impact of dementia, Module 2, p.22.

High-quality dementia training for care home staff is cost-effective, reducing GP and hospital visits and lowering the need for more expensive residential care. It also reduces staff turnover. In England, only 29% of care workers have received dementia training. In Northern Ireland, there is no comprehensive national data available on levels of dementia training amongst care staff.

Our new report, *'Because we're human too: Why dementia training for care workers matters and how to deliver it'* demonstrates why high-quality mandatory dementia training for the social care workforce is imperative. For people with dementia, well-trained social care staff means improvements in their day-to-day quality of life – and best practice examples of training have been shown to reduce use of antipsychotic medication and physical restraints. For care staff, being trained in dementia can lead to increased confidence and job satisfaction – and could potentially help address an urgent national imperative, namely reducing staff turnover. For care providers, benefits can include increased staff engagement and enhanced reputations with regulators and local commissioners.

Alzheimer's Society's research shows that scaling up dementia training for the social care workforce is economical when using person-centred, evidence-based programmes like 'Wellbeing and Health for People Living with Dementia (WHELD) and 'New Interventions for Independence in Dementia' (NIDUS) Professional.

Investing in evidence-based dementia training for care staff is cost effective - impact from the two programmes was carefully measured and demonstrated savings of approximately £2,000 per care home, per year (primarily due to fewer hospital and GP visits).

The NIDUS- Professional model focused on the training of domiciliary (homecare) staff and showed that the cost to one agency was £1,600, which is less than two weeks of full-time care in a care home.

The NIDUS Professional training could help keep more people with dementia at home for longer, reducing the time they need to spend in costly residential or nursing homes which on average cost £800 per week for residential and £1,078 for nursing, paid by local authority and/or families.

Additionally, we welcome the recent action of Regional Dementia Project Board (RDPB) Education and Training Task and Finish Group, who have included making dementia training mandatory for the social care workforce as their long-term goal.

Better data to ensure population health approach works for dementia

Priority 3 - Improving dementia data

The Department of Health should improve the collection of dementia data across Northern Ireland to prepare the system for new treatments and allow Trusts to plan for the increased prevalence of the disease in the next decade.

Minister Nesbitt has said that *“data is absolutely key to maximising the resources and the capacity of the health and social care system to deliver for patients.”*⁴ The rollout of Encompass gives Northern Ireland an opportunity to comprehensively upgrade our existing dementia data to provide parity with the data on dementia type that’s available in England. Each HSCT retains data on the number of patients in their area living with dementia, but don’t retain or publish the dementia data broken down by type. By improving dementia data, we will be able to identify and implement the levers required to delay system pressure resulting from severe dementia – the pressure we know is there now and will apply with ever-growing intensity over the next 15 years.

Data is a critical foundation for essential transformation in healthcare, increasing understanding of the dementia pathway, improving service planning, and aiding the prioritisation of resources – and crucially preparing the system for new treatments.

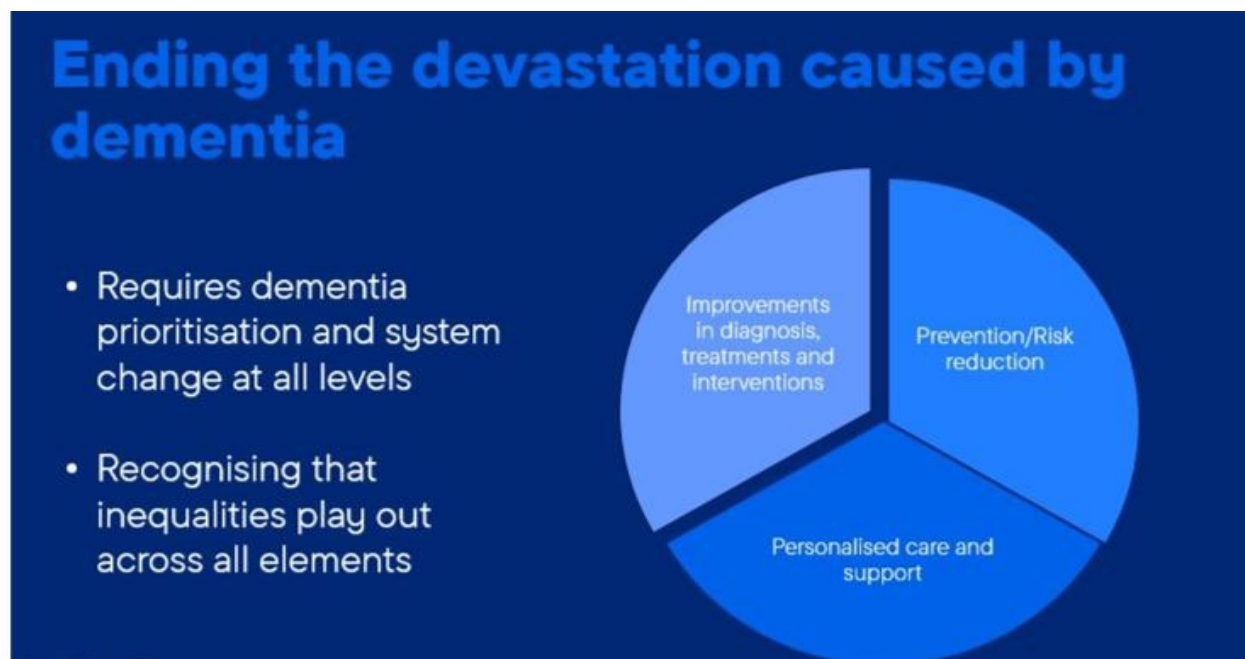
⁴ NI Assembly Health Question Time

<http://aims.niassembly.gov.uk/questions/oralsearchresults.aspx?&qf=0&qfv=1&ref=AQT%20371/22-27>

Diagnosing the specific type of dementia is crucial because it allows for targeted treatment plans, as different types of dementia may respond differently to medications and therapies. This can lead to better management of symptoms and improved quality of life for the person living with dementia. The absence of publication of comprehensive, up-to-date dementia type data hinders effective service planning and performance measurement for the HSCTs – leading to increased costs.

Conclusion

We recognise the current challenging fiscal environment. Our recommendations provide solutions to challenges to enable the NI Executive to both plan for the increased prevalence of dementia across Northern Ireland and reduce the financial impact that this disease has on our public finances. During our recent meeting with Health Minister Mike Nesbitt MLA, he indicated his plans to make dementia a priority in a future multi-year budget settlement. This would be a welcome step, and we encourage the Minister to make this commitment public.



We have over 1,200 online campaigners who support our work, and we are inspired every day by the people living with dementia who shape our campaigns on what matters most to them. We ask that dementia is made a priority in 2025-26 budget allocations – and are committed to supporting the Regional Dementia Project Board and its Task and Finish groups in addressing key priorities for dementia care.

Alzheimer's Society stands ready to work with the NI Executive and to provide our evidence, insight, convening power and understanding of the lived experience of people with dementia to ensure their voices and experiences are heard and reflected in future budget policies – including delivering on the Health Minister's commitment to prioritise dementia in any future multiyear budget cycle.

For more information or to engage further with us on this consultation response, please reach out to Ruth Barry, National Influencing Manager at Ruth.Barry@alzheimers.org.uk

ENDS

13th March 2025