

Joint Oireachtas Committee on Health

Opening Statement from The Alzheimer Society of Ireland February 7th, 2024

Thank you Chair and thank you for invitation to speak with the committee this morning.

Worldwide, it is estimated that over 55 million people are currently living with dementia¹. According to the World Health Organisation, dementia is now the seventh leading cause of death and one of the major causes of disability and dependency among older people globally. In Ireland it is estimated that 64,000 people are living with dementia, and this figure is predicted to rise to 150,000 by 2045². There are 500,000 Irish people whose families have been affected by dementia³.

Dementia is an umbrella term for a series of symptoms that cause changes to the brain. The most common subtypes are Alzheimer's Disease, Vascular Dementia, Mixed Dementia and Dementia with Lewy Bodies but there are over 400 more. It is a progressive neurological condition, associated with a range of cognitive, behavioural, and psychological symptoms including memory loss, problems with reasoning and communication, and changes in personality that impair day to day living. The difficulties faced by people diagnosed with dementia and those who provide care and support are complex and immense.

Yet despite this stark scenario, The Alzheimer Society of Ireland (The ASI) comes before the Joint Oireachtas Committee on Health today with a message of hope. Our vision is an Ireland where people on the journey of dementia are valued, can realise their rights and exercise choice, and are living well where they choose⁴. We believe this vision can be realised and here is why.

¹ World Health Organisation (2023). <https://www.who.int/news-room/fact-sheets/detail/dementia>

² HSE & National Dementia Office (2023). <https://www.hse.ie/eng/dementia-pathways/files/dementia-prevalence-figures-2020.pdf>

³ <https://www.hse.ie/eng/dementia-pathways/about/understand-together-programme/>

The Department of Health launched Ireland's first National Dementia Strategy⁴ ten years ago. In recent years there has been a considerable increase in funding for services and supports for people affected by dementia from this government, under the leadership of Minister for Older People, Mary Butler TD.

This funding ensures our services continue to grow. In 2023, The Alzheimer Society of Ireland delivered 125,959 Home Care Hours and 78,125 Day Care at Home Hours. We trained 819 family carers to support their loved ones with dementia and in 2023 our team of Dementia Advisers had 4,674 new referrals and 13,067 meetings. Our Day Centres had 63,379 attendances this year and our Social Clubs had 10,522 attendances. In 2023 our Helpline team had 6,526 interactions.

The launch of the landmark Model of Care for Dementia in Ireland⁵ is a gamechanger and its implementation will be a life-changing pathway from diagnosis to end of life. Key targets and pathways set out in the Model of Care, such as a network of Memory Technology Resource Rooms, Memory Assessment Support Services and Specialist Regional Memory Clinics are already underway, building on current services. There is ongoing collaboration with the National Dementia Services team alongside enhanced funding as part of the HSE Enhanced Community Care Programme, positive links with the Integrated Care for Older Persons teams and the introduction of new positions at Assistant Director of Nursing level with a focus on dementia service improvement.

In the last three years alone, we developed innovative new services such as Day Care at Home, rolled out Community Engagement initiatives and continued to destigmatise dementia. We have witnessed significant developments in research such as the funding of Dementia Trials Ireland by the Health Research Board which aims to triple the number of clinical trials available for people with dementia in Ireland by 2026.

⁴ Department of Health (2014). <https://www.gov.ie/en/publication/62d6a5-national-dementia-strategy/>

⁵ E Begley, M Gibb, G Kelly, F Keogh, S Timmons. (2023). Model of Care for Dementia in Ireland. Tullamore: National Dementia Services. <https://www.hse.ie/eng/services/publications/olderpeople/model-of-care-for-dementia-in-ireland.pdf>

Internationally there are new disease-modifying therapies for Alzheimer's disease which are expected to be licensed for use in Europe in the coming months (if deemed safe and effective), there is further insights and understanding regarding brain health and dementia risk reduction strategies⁶ together with potential new diagnostic tools such as blood-based biomarkers.

However, despite myriad reasons for hope, and evidence demonstrating service and funding improvements, we know there are people throughout Ireland, at this moment who are struggling and feel hopeless. And we cannot forget them.

The ASI conducted research involving over 650 people undertaken in May and June 2023⁷. People with dementia and family carers reported significant challenges in accessing services. They reported an administrative burden and a stress in having to 'fight' for services and support.

The research found that 63% of carers had difficulty accessing services, with 25% of those experiencing 'great difficulty'. Of the respondents in receipt of home care, almost two-thirds have experienced a delay or a reduction in the delivery of home support hours due to a shortage of home care workers.

People living with dementia told our research team that they are grappling with low mood, isolation, and loneliness, with a majority categorising their mental health as poor or fair. This echoes what many of our front-line colleagues hear on the ground.

We recommend the following to continue to improve the experience of dementia in Ireland so that those who are struggling and facing multi-faceted challenges which dementia presents, can be better supported.

Livingston et. al (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

⁷ The Alzheimer Society of Ireland (2023). The Experience of Dementia in Ireland: A Snapshot in Time. <https://alzheimer.ie/wp-content/uploads/2023/09/The-Experience-of-Dementia-in-Ireland-2023.pdf>

Firstly, improve access to services and plan for the implementation of the Model of Care for Dementia in Ireland.

We need a timebound implementation plan for the Model of Care and ring-fenced multi-annual funding for that implementation. Unfortunately, the plans for 2024 are being impacted by the recruitment embargo within the HSE.

We must continue to grow ASI services to tackle service gaps and geographical inequity. We know that access to dementia specific services can be sporadic, particularly in rural areas and we want to see targeted investment in areas of greatest need.

We must address homecare staffing issues. It is well established that homecare delivery is extremely challenging here in Ireland and internationally. We welcome the WRC agreement last year to move towards pay parity for Section 39 workers and await its application. There is a need to address travel issues for Homecare workers as well as introduce meaningful career progression opportunities.

Secondly, we must open up local communities to address loneliness and isolation

Loneliness is an internationally recognised public health risk and Ireland has the highest rates of loneliness in the EU^{8 9}, and people living with dementia and carers are even more vulnerable to loneliness. Dementia requires a societal response.

We believe continued support for the work of the HSE Understand Together Campaign¹⁰ and our own Community Engagement initiatives including highly successful intergenerational initiatives, in addition to developing an action plan to address loneliness and isolation in line with the asks set out by the Loneliness Task Force¹¹, is

⁸ Institute of Public Health (nd). <https://www.publichealth.ie/loneliness>

⁹ Hawkey, L.C. Loneliness and health. *Nat Rev Dis Primers* 8, 22 (2022). <https://doi.org/10.1038/s41572-022-00355-9>

¹⁰ <https://www.understandtogether.ie/>

¹¹ <https://alone.ie/loneliness-taskforce-calls-for-e5m-funding-to-address-loneliness-in-budget-2024-as-action-plan-remains-on-the-shelf/>

necessary.

Thirdly, we must fund the provision of psychotherapeutic support and education to people with dementia and carers

It is long established that people with dementia and family carers struggle with their mental health. Research tells us that counselling is highly effective in reducing depressive symptoms and anxiety in carers of people with dementia^{12 13}. Education better equips families to cope and support the person with dementia.

Fourthly, we must provide sustainable financial supports to carers

Research by The ASI and Family Carers Ireland has consistently shown that family carers of people with dementia are struggling to make ends meet, which creates stress and anxiety^{14 15}. As inflationary pressures continue, there remains an urgent need to enhance social protection for this cohort.

Finally, we must ensure comprehensive preparation for the application of current and future innovations in dementia care for the benefit of all those impacted by the condition.

The dementia landscape is on the cusp of significant change, with landmark innovations in disease modifying therapies and diagnostics. It is critical to engage with clinicians to plan for the likelihood of at least some of these innovations reaching Ireland.

There is a rapidly growing body of evidence on dementia risk reduction and prevention which must become part of the public discourse. Brain health is everyone's business.

¹² Kishita N. et al (2018). Which interventions work for dementia family carers? An updated systematic review of randomized controlled trials of carer interventions. <https://pubmed.ncbi.nlm.nih.gov/30017008/>

¹³ Lins S et al. (2014). Efficacy and experiences of telephone counselling for informal carers of people with dementia. <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009126.pub2/full>

¹⁴ The Alzheimer Society of Ireland & Family Carers Ireland (2023). <https://alzheimer.ie/wp-content/uploads/2023/03/The-Cost-of-Living-while-Caring-FINAL.docx.pdf>

¹⁵ The Alzheimer Society of Ireland (2023). The Experience of Dementia in Ireland: A Snapshot in Time. <https://alzheimer.ie/wp-content/uploads/2023/09/The-Experience-of-Dementia-in-Ireland-2023.pdf>

There is excellent translational research happening in institutions across Ireland and we must support research professionals and clinicians to ensure this research is embedded into practice.

The ASI views and understands dementia through a human rights lens and is led by principles of personhood and dignity. Dementia care in Ireland has taken huge strides in recent years but we are still not upholding the rights and personhood of every person affected by the condition. However, the tools are there, and with continued funding and political will, we believe life can improve for people living with dementia, their families, and communities.

Appendix.

Overview of The Alzheimer Society of Ireland

The ASI was founded in 1982 by family carers who found that not only were they unable to access even the most basic information about Alzheimer's disease or dementia, but that information, support, and services were non-existent. Their work changed the landscape of dementia forever and The ASI is now the largest dementia service provider in Ireland and employs a team of 712 people.

The ASI operates a National Helpline, open six days a week, offering information and support to anyone affected by dementia on 1800 341 341.

The ASI provide several supports and services to people with dementia and their carers across Ireland, including Day Care Centres, Day Care at Home, Home Care, Family Carer Training, Dementia Advisers, Alzheimer Cafes, Social Clubs and Social Clubs.

We believe that the lived experience of dementia must influence policy and service development. We undertake regular public consultation, research on lived experience, and support and listen to the *Irish Dementia Working Group*, the *Dementia Carers*

Campaign Network, and the *Dementia Research Advisory Team*. We listen closely to our Helpline, Dementia Advisor and Operations teams who speak daily with people impacted by dementia.

Our work is evidence based and we have a strong research and evaluation focus and emphasis on practice development and have excellent links with the Irish and international research community.