

The Alzheimer Society of Ireland submission to the Public Consultation on the Cost of Disability

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The Alzheimer Society of Ireland (ASI) welcomes the opportunity to make a submission to the Public Consultation on the Cost of Disability. The ASI is the leading dementia-specific service provider in Ireland, working across local communities and advocating for the rights and needs of all people with dementia and their carers. The contact details for this submission are as follows: Sarah McDonnell (Policy Officer), sarah.mcdonnell@alzheimer.ie.

Introduction

Over 64,000 people are currently living with dementia in Ireland, a condition that is recognised as a disability under the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and in Irish equality laws. The economic impact of a dementia diagnosis for an individual is significant, with the cost of dementia care ranking higher than stroke, heart disease and cancer. A dementia diagnosis carries significant financial consequences for individuals and families, arising from additional care, healthcare, transport and household costs. This submission outlines the urgent need for financial support for those affected by dementia. The development of a Cost of Disability payment would be a welcome step in responding to this increasingly critical issue.

The Financial Impact of Dementia

Dementia is a syndrome caused by a range of progressive brain diseases, the most common of which is Alzheimer's Disease. It is characterised by a progressive loss of cognitive and functional abilities, often impinging on quality of life and the ability to live independently. Dementia is a life-changing diagnosis and the difficulties faced by people diagnosed with dementia and their families are profound and complex.

However, what is often overlooked is the financial strain that people with dementia and their families face by reason of them having the condition. The estimated total annual cost per person with dementia in Europe is on average €32,506.73 (in 2019).¹ This includes a myriad of expenses such as formal and informal care, transport, mobility, household, medication, healthcare, psychological and mental health support.

The impact of this financial burden on the individual is often very significant. The ASI regularly hears from people living with dementia who report depleting their life savings to cover the costs of dementia care, forgoing medical appointments or medication due to the cost, or planning to sell their home due to financial hardship. In a recent consultation with people living with dementia carried out by The ASI in April 2026, 10 out of 11 respondents felt that the additional costs of living with dementia have a negative impact on their quality of life, with four saying that impact is significant.

Unique Challenges Faced by People with Young-Onset Dementia

People with Young-Onset Dementia (YOD) face unique financial challenges. YOD refers to dementia diagnosed before the age of 65. There are approximately 5,200 people in Ireland with YOD.² At time of diagnosis, many are still employed with significant financial obligations. They often have dependent children who might be at school or university. They may have mortgages, rent payments, car payments, or are the primary earner in their household. As dementia is a progressive disease, people diagnosed with it are invariably required to cease employment. Therefore, a person with YOD often faces a compound financial challenge whereby they suffer a loss of income, which is further exacerbated by additional expenses owing to dementia.³ At an Oireachtas briefing on the issue of YOD on 25 March 2026, a person living with YOD shared that having their employment terminated 8 months after their dementia diagnosis at age 52 was “*worse than getting my diagnosis.*” They described the financial strain as “*mentally and physically crippling.*” They stated: “*It destroyed me. I*

¹ Cantarero-Prieto, D., Lanza Leon, P., Blazquez-Fernandez, C., Sanchez Juan, P., & Sarabia Cobo, C. (2019). The economic cost of dementia: A systematic review. *Dementia*, 19(8), 2637–2657. <https://doi.org/10.1177/1471301219837776>

² Health Service Executive. (2023). Model of care for dementia in Ireland. [Model of Care for Dementia in Ireland](#)

³ Kilty C, Cahill S, Foley T, & Fox S (2023). *Young onset dementia: implications for employment and finances*. *Dementia*, 22(1), 68–84. <https://doi.org/10.1177/14713012221132374>

was so panicked and worried how I could provide for my family. The weight of it was all-consuming.”

Challenges in Accessing Social Protection

Despite dementia being recognised as a disability under the UN CRPD, that recognition is often not experienced by people living with dementia in Ireland, in particular when it comes to the right to social protection. As a State Party to the Convention, Ireland is obliged under Article 28 UN CRPD to take appropriate measures to realise *“the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability.”*

Two key issues arise in this regard.

1. The challenge faced by people living with YOD to access adequate social protection.
2. The lack of disability-related social protection available to people with dementia over the age of 65.

Barriers to Access Facing People with Young-Onset Dementia

The ASI regularly hears from people with YOD who report experiencing significant difficulties in accessing adequate social protection. While there are a range of supports available to people with disabilities under the age of 65 (i.e. Disability Allowance, Invalidity Pension, Medical Card), anecdotal feedback tells us that many people with YOD cannot access them. Eligibility and access often appear to be contingent on whether that individual happens to receive the correct guidance from public and health services, whether it is their GP, a public health nurse, or a Department of Social Protection official. While supports are available in principle, many people with YOD are not able to access them in practice.

The ASI carried out a recent consultation and survey with 12 family carers of people with YOD in April 2026. A common issue faced by respondents concerned the lack of support in navigating the complex social protection system. Many respondents reported difficulty accessing support to identify which social welfare payments were appropriate for their family member with YOD. One respondent described supporting her spouse with YOD through the social welfare application process, explaining that after submitting three applications for Disability Allowance and waiting 18 months, they were finally informed that he should instead have applied for Invalidity Pension. The

reason given for rejection from Disability Allowance was that dementia is not considered a disability. This is both in contravention of the UN CRPD as well as being inconsistent with other people with dementia's experiences who have been granted Disability Allowance

Another difficulty faced by a great many respondents is a serious lack of understanding of YOD as a condition when navigating social welfare applications. One respondent, who was the agent for her spouse with dementia in his social welfare application, reported him being granted the payment and subsequently being asked for an update on her spouse's condition and whether he would be in a position to return to work. As dementia is a progressive disease, returning to work is virtually not a possibility. Another respondent reported that her spouse with YOD's application for Invalidity Pension was rejected on the grounds that he was deemed capable of manual labour, despite him having had a career in an executive position. It is clear from this anecdotal evidence that those assessing social welfare applications by people with dementia, in particular YOD, require a greater understanding of the condition that applicants are living with.

Where a person living with YOD does have access to social protection, the rate of payment that they receive can be far lower than what they would have been earning before their diagnosis. In Q4 of 2025, the average weekly salary in Ireland was €1,011.88.⁴ The baseline Disability Allowance weekly payment is €254 for 2026, while for Invalidity Pension the maximum weekly payment is €259.50. For many people with YOD, this is a devastating reduction in income. A Cost of Disability payment would help recognise and mitigate the significant income shock experienced by many people with YOD.

Inadequate Supports for Older People with Dementia

As people with dementia face significant additional financial challenges by reason of their disability, the lack of disability-related social protection available to those over the age of 65 is inadequate. Article 28 UN CRPD explicitly requires State Parties to take appropriate steps and measures *"to ensure access by persons with disabilities, in*

⁴ Central Statistics Office. *Earnings and labour costs*.
<https://www.cso.ie/en/statistics/earnings/earningsandlabourcosts/>

particular ... older persons with disabilities, to social protection programmes.” Dementia primarily affects people over the age of 65. Many disability-related supports such as Disability Allowance and Invalidity Pension are tied to one’s ability to work. Therefore, the majority of people living with dementia can only rely on supports that are already available to them due to their age, such as the State Pension. However, while dementia mainly affects older people, it is not a typical part of ageing. A Cost of Disability payment would be an effective way of recognising and alleviating the cost of disability on non-working age groups, such as people over the age of 65.

Families Filling the Gap

A dementia diagnosis poses a significant financial challenge not only for the person living with the condition but also to their loved ones, who often take up informal caring roles. The Irish health and social care system is dependent on family carers who provide the majority of care to people with dementia. 48% of the overall cost of dementia in Ireland is attributable to family care. Therefore, the value of this work to the State is estimated to be in the region of €804m per annum.⁵

The ASI carried out national research in 2023, with responses from 597 informal carers of people living with dementia.⁶ The Experience of Dementia Report outlined that many carers have reduced their working hours or left work entirely to provide support and care to the person with dementia. A clear pattern of financial hardship was evident, with 50% of respondents reporting difficulty in their household making ends meet. In spite of the substantial public good that informal carers provide, 67% of respondents reported that they receive no social benefits (i.e. Carer’s Allowance, Carer’s Benefit, Annual Carer’s Support Grant, or Fuel Allowance). The ASI hears from many family carers who exceed the income threshold for Carer’s Allowance. One respondent stated: *“I can’t work full-time as my Mam and aunts need so much attention with constant phone calls etc., however, I’m over the thresholds for government support so I am the working poor living pay check to pay check.”* Compounding this financial

⁵ Connolly, S., Gillespie, P., O’Shea, E., Cahill, S., & Pierce, M. (2014). *Estimating the economic and social costs of dementia in Ireland*. *Dementia*, 13(1), 5–22. <https://doi.org/10.1177/1471301212442453>

⁶ 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>

hardship is the escalating cost of living which exposes an already financially vulnerable cohort to more difficulty.

These figures demonstrate the significant and unacceptable financial burden which is being shifted onto the families of people living with dementia. The State must adequately fund dementia care to alleviate the financial burden absorbed by families. Introducing a Cost of Disability payment for people with dementia would be an important step in addressing this imbalance.

The ASI's Views on the Design of a Cost of Disability Payment

The ASI would like to highlight several key considerations for people living with dementia in relation to how a Cost of Disability payment should be developed.

Eligibility for a Cost of Disability Payment

The ASI believe that people living with dementia should qualify for a Cost of Disability payment, as dementia is a disability under the UN CRPD and Irish equality legislation. The payment should not be restricted to those already receiving a social welfare payment, as many people with dementia do not receive social welfare, in particular people with YOD, as outlined above. Additionally, a Cost of Disability should not be means-tested as it should compensate for additional costs faced by people with disabilities, regardless of income. Anecdotal feedback received by The ASI in relation to Carer's Allowance indicates that means testing can create poverty traps and work disincentives, as individuals are effectively penalised for supporting themselves through paid employment.

Costs that should be addressed by existing, new or expanded services

Social Welfare: As outlined above, many people living with dementia experience difficulties in accessing social welfare payments, such as Disability Allowance and Invalidity Pension. People living with dementia should receive additional supports and reasonable accommodation to realise their right to access social welfare.

Homecare Support: Accessing home care is a particular struggle for people with dementia. The ASI's Experience of Dementia Report highlights a large discrepancy between the number of hours needed, the number of hours granted and the number

of hours received.⁷ Of the 236 respondents in receipt of home care, almost two-thirds (63%) have experienced a delay or a reduction in the delivery of home support hours or a home support package due to a shortage of home care workers. This leads people living with dementia to having to opt for private home care, the cost of which is often absorbed by themselves and their families.

Medical card: People with dementia should automatically qualify for the medical card. At present, dementia is not considered a “long-term illness” in the context of the medical card.

Blue Badge (Disabled Person’s Parking Card): People with dementia should also qualify for the Blue Badge, as this would assist with transport issues.

Carer’s Allowance: As outlined above, The ASI regularly hears from family carers who are not eligible to receive Carer’s Allowance due to the means test. The ASI urges the Government to remove the means test without delay, as per its commitment in the Programme for Government (2025).

Addressing the Increasing Needs of a Progressive Condition

The costs of living with dementia rise as the condition progresses, driven by increasing need for more complex health, social and informal care. Therefore, a Cost of Disability payment for people living with dementia should be reviewed periodically.

Conclusion

Dementia places a significant and often overwhelming financial burden on individuals and their families. Despite being recognised as a disability, many people with dementia cannot access adequate social protection, particularly those with Young-Onset Dementia. Families continue to absorb much of the cost, providing essential care with limited support. A Cost of Disability payment would help address these inequities and recognise the extra costs associated with dementia. Ensuring access to social protection for people with dementia is both an obligation on the State under the UN CRPD and a matter of fairness and dignity.

⁷ The Alzheimer Society of Ireland. (2023).