



PRE-BUDGET SUBMISSION **2025**

Equal Dementia Supports  

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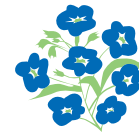
**Building on Momentum in 2025**



THE Alzheimer  
SOCIETY OF IRELAND



Cover image: **Tony McIntyre** of the **Dementia Carers Campaign Network (DCCN)** and the **Dementia Research Advisory Team (DRAT)** and **Mary McIntyre** member of the **Irish Dementia Working Group (IDWG)** which are groups supported by **The Alzheimer Society of Ireland**.



**The Alzheimer Society of Ireland (The ASI) is calling on Government to improve equity of access to dementia supports and services across Ireland. Increased investment is needed in community services, acute services, mental health supports, social protection, dementia research and the dementia workforce.**

The ASI is urging the Government to continue moving the Model of Care for Dementia in Ireland from paper to practice and to honour the Programme for Government and the National Dementia Strategy by **investing €5.5 million in dementia in Budget 2025** alongside critical social protection, policy and workforce planning

## €4.4 million in equal dementia supports

- €1 million Day Care at Home
- €600,000 Day Services
- €300,000 Weekend Activity Clubs
- €608,000 Dementia Advisers
- €1,880,000 Dementia Nurse Specialists
- A Dementia Registry

## €62,000

Address the mental health challenges of people with dementia and those who care and support them by investing €62,000 to develop a dementia specific counselling service

## €1,059,000

Invest €1,059,000 in Dementia Research by expanding investment in Dementia Research Network Ireland and the Team Up for Dementia Research service to support increased participation in quality dementia research

## Social Protection

Increase Social Protection for Family Carers, Carers Allowance to €325.  
Make Carers Allowance a Qualifying payment for the Fuel Allowance

## Sustainable Workforce

Address the unsustainable workforce in Dementia Sector by addressing Pay Parity in Section 39 organisations and standardising rates of pay for Home Care Workers





*"We are good friends, we have a lot of things in common with each other and talk a lot"*  
**Tadhg, living with dementia, chats about Lee who provides his Day Care Home service**

## Submission Context

**The Model of Care for Dementia in Ireland:** The landmark Model of Care for Dementia in Ireland was published in 2023 (1). It sets out 37 targets and a series of practice recommendations to advance the assessment, treatment, care and support of people with dementia and their families.

The model is underpinned by five core principles - citizenship, person-centred approaches, integration, personal outcomes and timeliness.

Building on the National Dementia Strategy (2), The Model of Care for Dementia in Ireland brings together best practice in relation to dementia diagnosis, communicating a diagnosis of dementia and post-diagnostic support.

The model is developed within the context of Sláintecare 2020–2023 (3) and the health reform agenda, in which delivering the right care, in the right place, at the right time, by the right team, is a central principle.

Implementation of this ambitious model is currently underway; however momentum is being lost due to HSE recruitment restrictions. The Alzheimer Society of Ireland (The ASI) believes the publication of a timebound resourcing plan should now be priority. The Asks in this Pre-Budget Submission align with the values and targets of the Model of Care and will support its implementation.



**Programme for Government:** The current Programme for Government (4) states a commitment to implementing the National Dementia Strategy, which was developed to *“improve dementia care so that people with dementia can live well for as long as possible, can ultimately die with comfort and dignity, and can have services and supports delivered in the best way possible”*.

**Rising need:** An estimated 64,000 people are living with dementia in Ireland and this number is expected to rise to 150,000 by 2045 (5).

**Human Rights:** People with dementia face cultural, social and economic barriers to fulfilling their rights. The Charter of Rights for People with Dementia (6) states that people with dementia have the right to:

- Access appropriate levels of care providing protection, rehabilitation and support
- Help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life
- Live as independently as possible with access to recreational, leisure and cultural life in their community.

**Ongoing cost of living challenges:** People with dementia and their carers continue to experience significant financial challenges. Research published by The ASI, in collaboration with Family Carers Ireland, in 2022 and 2023 (7, 8) highlights the disproportionate impact of the cost of living on people with dementia and family carers, with many struggling to make ends meet.



## Submission development

**The ASI is a grassroots organisation operating in the heart of communities across Ireland. As an organisation grounded in evidence and the voice of people affected by dementia, the investment asks outlined in this Pre-Budget Submission are informed by multiple sources including:**

- National research (8), conducted in 2023, with 72 people living with dementia and 594 current family carers.
- Ongoing consultation and discussion with people living with dementia and family carers.
- Ongoing feedback and evaluation from the people who use our services.
- Internal data and consultation with front-line staff providing dementia supports and services.
- A comprehensive review of external reports and research.





# 1 Challenge: There is not equitable access to dementia services and supports across Ireland.

In Ireland, the majority (63%) of people with dementia live at home in their communities (9). As the prevalence of dementia in Ireland continues to rise, the gap between services and need widens. While there has been enhanced investment in dementia supports over the last number of years, we must keep pace with demand.

In national research, with over 650 people, published by The ASI last year, 63% of carers and 57% of respondents with dementia reported difficulty in accessing dementia services. Just 12% of carers and 20% of people with dementia noted that they had access to all the services they need. Navigating services and supports was cited as a key challenge, while more access to information and advice was one of the greatest needs highlighted by participants (8).

The ASI is unable to meet current demand for Day Care, Day Care at Home and Dementia Adviser services. Furthermore, there are approximately 4,500 people with Young Onset Dementia in Ireland who often have young families, financial responsibilities and vibrant social lives, which poses unique and complex challenges.

This cohort have difficulty fitting into existing service provision which is generally tailored to the needs of older people. In fact, research shows





that this is a significant barrier to attending dementia-specific groups and activities (9-12).

Unlike many other countries, Ireland does not have a dementia registry which means there is no national systematic approach to the collection and analysis of dementia data. The lack of hard data on the number of people living with dementia in Ireland and where they live makes our estimations just that, estimations on prevalence rather than evidence-based facts. This creates a significant challenge for planning equitable service provision. The HSE Corporate Plan 2021–2024 (13) outlines the need for robust data and information to support planning and decision making. The development of a national dementia registry has been delayed by HSE recruitment restrictions.

People living with dementia have poor outcomes in hospital including increased falls risk, poor nutritional status, increased dehydration and risk of delirium (14). The cognitive deficits experienced by people living with dementia can put them at risk of rights violations and a fast-paced acute environment may not offer the time for meaningful support to uphold their rights. The availability of a Clinical Nurse Specialist in Dementia can mitigate this risk, however, there is inequity of access to this specialist role across Ireland (15).

## Solutions

### (a) Increase funding for Dementia Specific Day Care at Home Services by €1,000,000

Day Care at Home meets an urgent unmet need for people with dementia and their families by providing variety, stimulation, and personalised enjoyable activities. It delivers quality psycho-social support by providing person-centred activities in block hours.

The allocation of €480,500 made available in Budget 2024 has enabled The ASI to introduce Day Care at Home to new areas which had the most urgent need. This, in addition to €1.7m already in place, will be spent in 2024. The demand for this service continues to rise and there is need to increase service provision and introduce it to new areas.



## Impact:

The delivery of an additional 645 hours of Day Care at Home per week, equating to 32,250 hours of care annually (based on 50 weeks of provision). This will enable The ASI to provide Day Care at Home to 230 more people with dementia per week across the country.

An independent evaluation of The Day Care at Home Service highlights that the service *enhances well-being* and *improves the everyday lived experience* of both people with dementia and their carers. It provides a unique level of *flexibility and continuity of care*, and can *help to delay/avoid admission to long-term care* by creating a more sustainable family care situation (12). Not only is this important from an economic perspective, it aligns with the wishes of most people living with dementia and many family carers - which is to care for their loved one at home for as long as possible.

**Target 30 of The Model of Care for Dementia in Ireland** (1) states that Every person with dementia assessed as requiring home-based care should be provided with personalised and flexible supports that meet both their personal and psychosocial care needs in their home.

## (b) Invest €600,000 in the expansion of Day Centres outside major cities

The ASI's Day Centres provide dementia-specific, person-centred care to meet the needs of the person with dementia in a warm, welcoming, safe environment while providing support and cognitive stimulation. The centres offer the opportunity to interact and socialise with others, fun and entertainment and give much-needed respite to family carers.

Further investment in dementia-specific Day Centres is essential to support people with dementia, at different stages of their journey, to remain at home in their communities and to provide respite to family carers.

There are currently 53 Day Centres in operation across the Republic of Ireland and in 2023 The ASI had just over 63,000 attendances which equates to 1,939 people.



The ASI has identified 11 locations across the country where there is no access or highly limited access to Day Centres and other dementia services. The organisation is aware of several buildings in each area which would facilitate the provision of this service.

### Impact:

## Increased access to Day Centres for people with dementia in across Ireland

This investment will enable The ASI to expand Day Care services, providing much-needed support, to people affected by dementia in the 11 locations where we have identified an immediate need.

An independent evaluation (17) of the role and contribution of dementia-specific day centres states the service is *highly valued by people with dementia and their families*. Those who took part in the evaluation identified a *range of benefits* including the opportunity to socialise, *develop friendships*, partake in physical activity, *retain abilities and skills*, *enjoy a nutritious meal with others*, and *respite* for family carers. The evaluation, published in 2020, highlighted the unmet demand for day care places and the *need for ensuring sustainability for existing service provision*.

The Model of Care for Dementia in Ireland outlines the importance of day care services to people affected by dementia. However, it highlights the significant disparities and inequity in access to day care services across Ireland. *This investment will make dementia-specific day centres more widely available and reduce some of the disparities to access.*

**Target 28 of The Model of Care for Dementia in Ireland** (1) states that *100% of people with dementia, irrespective of age, dementia subtype and geographical location, are supported to choose from a range of activities and supports that are tailored to their preferences.*



## c) Invest €608,000 in eight new Dementia Adviser Roles and three Regional Leads

The role of Dementia Adviser is to provide a locally based, individualised information, signposting, and emotional support service to people who are concerned about their cognitive health and/or have a diagnosis of dementia.

The Dementia Adviser supports people living with dementia and their families at all stages of the dementia journey, from diagnosis through to end-of-life. In addition, the service plays an important role in providing early intervention to prevent crisis situations.

The Dementia Adviser service is integrated with other ASI services and has achieved strong links with relevant health and social care professionals working in the diagnostic and post-diagnostic services. Dementia Advisers also support local communities to become more dementia inclusive.

Over 51% of referrals to the Dementia Adviser Service are from health and social care professionals within diagnostic and community-based services, reflecting the development of a standardised and integrated referral pathway and the commencement of the implementation of the Model of Care for Dementia in Ireland.

In 2024, the Dementia Adviser referral pathway will be integrated in the HSE Healthlink system, which will enhance referrals from General Practitioners nationwide. These welcome developments combined with the operationalisation of more Memory Assessment Support Services and Regional Specialist Memory Clinics are increasing demand for the Dementia Adviser Service.

There are currently 29 Dementia Advisers working across Ireland who are consistently in demand. For example, in 2023, the service worked with 4,607 new clients, a 12% increase on 2022. In 2024, demand for the first four months of year the service is already 6% ahead of 2023.

### **Impact:**

**Increased Access to Dementia Advisers and enhanced service management**



*The number of Dementia Adviser roles will grow from 29 to 37, expanding the service in 14 counties* (Cavan, Meath, Monaghan, Dublin, Offaly, Westmeath, Wicklow, Wexford, Waterford, Tipperary, Cork, Kerry, Limerick, and Clare). The introduction of three regional leads will support the *enhanced provision and management* of the service.

Providing greater access to the Dementia Adviser Service will support more people living with dementia and their families to *navigate services and supports* and receive *personalised and timely information* about dementia, which has been identified as a significant challenge.

An independent evaluation of this service (18) in 2018 highlighted the high levels of satisfaction with Dementia Adviser Service, and its value to both people living with dementia and family carers. The authors recommended ongoing development and resourcing of this service to meet demand as a post-diagnostic support.

**Target 24 of the Model of Care for Dementia in Ireland** (1) states that 100% of people diagnosed with dementia should be offered contact details for their local Dementia Adviser (DA) and, where required, referral to the service should be facilitated by the diagnosing service.

Practice recommendations outline that further development of the DA service should adopt a population-based approach to ensure the equitable distribution of services and supports.

#### **(d) Continue investment of €300,000 year on year for the provision of Weekend and Activity Clubs for people with Young Onset Dementia**

Tailored weekend and activity clubs support people with Young Onset Dementia to remain active, connected and supported in their communities by providing opportunities for social engagement with the support of trained staff.

This has a dual benefit of supporting family carers by providing respite outside of the typical Monday-to-Friday structure. The focus of these interventions is to get out in the community and the schedule is led by people with dementia.



An investment of €300,000 was provided in Budget 2024 to develop a model and open ten weekend and activity clubs with a special focus on Young Onset Dementia. Now, The ASI request that this funding becomes recurring to sustain and further develop this valuable service. Community-based social interventions provide a much-needed tailored and responsive service to those who are early in their dementia journey and specifically those diagnosed with Young Onset Dementia.

Research highlights the importance of social approaches and active participation for people with Young Onset Dementia post-diagnosis (10, 11, 19). In 2024, the most requested new service among those affected by Young Onset Dementia and those in the earlier stages of dementia was support groups and opportunities to socialise with people in similar situations (8).

The National Dementia Strategy (2) seeks to address “the needs of all people with dementia, including those with younger-onset dementia” and states that the challenges and needs of those with Young Onset Dementia can be vastly different from older people.

### **Impact:**

**Access to age and stage appropriate interventions for people with Young Onset Dementia and those in the early stages of dementia.**

The ASI will *sustain and develop the provision of ten responsive and individualised weekend and activity clubs* across the country to people with Young Onset Dementia and people in the earlier stages of dementia. This will *fill a critical post-diagnosis support gap* for people impacted by Young Onset Dementia and those in the early stages.

This service will support people with Young Onset Dementia to *remain socially active and connected* with their local communities while accessing support from The ASI.

**The Model of Care for Dementia in Ireland (1) states that *age-appropriate dementia-specific activities for people with young onset dementia should be provided.***





*“My experience in hospital was very frightening until I met the Clinical Nurse Specialist in Dementia, she reassured me and understood my unique symptoms of dementia”*  
**Kevin, living with dementia**



## (e) Invest €1,879,320 in Clinical Nurse Specialist in Dementia Roles in acute settings

### Impact:

Enhanced access to specialist support in the acute setting.

There are currently **22 acute hospitals** requiring a Clinical Nurse Specialist in Dementia and The HSE estimate the cost of these positions at €85,425 (20). Dementia-specific nurse specialist roles are crucial to improving the provision of dementia care and in the implementation of other national guidelines relating to acute hospital dementia care.

Clinical Nurse Specialists in dementia can make hospitals safer, more dementia inclusive, and make the experience of being in an acute setting significantly less distressing for people with dementia and their families (15, 21, 22).

Work commissioned by The ASI exploring the case for Clinical Nurse Specialists in Dementia in Ireland highlights the substantial improvements these roles have on the experience of people with dementia and their families in acute settings (15).

The ASI welcomes the recent recruitment of six Assistant Director of Nursing Level posts across the hospital groups. These posts can provide support for the Clinical Nurse Specialist roles and ensure dementia awareness and expertise is integrated in the hospital network to enhance the impact of those roles.





**(f) Progress the Development of a National Dementia Registry**

The development of a National Dementia Registry is essential to support the development, operation and quality of dementia-related health and social care services. In 2016, The ASI commissioned a study establishing the feasibility of a National Dementia Registry (23). A report (24) published by The HSE in 2021 outlines a National Dementia Registry Model, the required minimum dataset, costs and recommendations.

**Impact:**

**Responsive and appropriate allocation of resources and service planning.**

The ability to quantify the number of people diagnosed with dementia in Ireland and where they live will facilitate *responsive and appropriate allocation of resources and service planning*. A National Dementia Registry will underpin all aspects of dementia service provision and planning and ensure an equitable approach.

**Target 6 of the Model of Care For Dementia in Ireland** (1) states that *The collection of data on dementia is to be standardised at (i) Level 2 MASS, (ii) Cognitive / behavioural Neurology Clinics, (iii) Specialist non-dedicated Services and at (iv) Level 3 Regional Specialist Memory Clinics with proposed use of the dementia minimum dataset.*





## 2 Challenge: People affected by dementia are struggling financially

The ASI is concerned that the financial struggle of family carers is not being adequately addressed. The already stressful and complex situation of family care, with significant health risks, is exacerbated by financial strain.

In *The Cost of Living While Caring* report (7), which was published in April 2023 in collaboration with Family Carers Ireland, family carers of people with dementia reported serious financial struggles. 51% of carers reported difficulty making ends meet with many cutting back on household essentials and reducing social interactions with friends and family. Some reported being in arrears with mortgages and household bills.

In The ASI research published in September 2023 (8) this struggle was reiterated, with 50% of family carers reported having difficulty making ends meet, with almost one in ten having 'great difficulty'. While MESL costs stabilised in 2024, with a slight reduction, the MESL 2024 data (25) points to the ongoing cumulative impact of rising household costs. Forecasts indicate that prices are likely to continue increasing this year and next, albeit at a slower rate.

In work published by The ASI in June 2022, families affected by Younger Onset Dementia highlighted the financial burden of supports and interventions (11). They report the costs associated with caring are rising and are not properly understood in the context of assessment for social protection.



Dementia carers urgently need meaningful increases in social protections and the significant cost of caring must be taken into account. Budget 2025 must be part of a broader strategy to benchmark our system to an adequate level, ensuring that those who care for people with dementia can live with dignity.

## Solutions

- (a) Increase the Carers Allowance to €325
- (b) Make Carers Allowance a qualifying payment for the Fuel Allowance

Our current health and social care system depends largely on family caregivers who provide the main bulk of care; it's estimated value to the State is in the region of €807m per annum (26). Yet those who provide that care are not adequately supported.

Caring in Ireland has long been associated with poor health outcomes. Findings from The ASI research conducted in 2023 showed that 43% of family carers of people with dementia visited a healthcare professional in the last month on account of their own health, with 43% rating their mental health as 'Poor/Fair' and 34% rating their physical health as 'Poor/Fair' (8). Financial worry is exacerbating these challenges and increased social protection is urgently required.

Increasing the Carer's Allowance to €325 has the potential to significantly reduce the above.

The most recent MESL data indicates that the cost of household energy from 2020 to 2024 has risen by 64.5% Making the Carers Allowance a qualifying payment for the Fuel Allowance can alleviate the pressure associated with this huge increase and decrease risk of fuel poverty for households impacted by dementia.

### Impact:

Decreased risk of poverty including fuel poverty and associated poor health outcomes for family carers





### 3 Challenge: People with dementia and family carers are struggling with their mental health

Dementia is a life-changing diagnosis, both for the person and their family. Depression and anxiety are common amongst people with dementia and family carers (27, 28) and are linked to poorer outcomes (29, 30). Access to low-cost, dementia-specific professional counselling services has consistently stood out as a critical support gap in our research and consultations across Ireland.

In national ASI research with 72 people with dementia and 597 informal carers, 43% of family carers reported below-average mental health, with 16% experiencing poor mental health. 14% of family carers reported feeling depressed most of the time while one in ten reported that they 'never' enjoy life. Among respondents with dementia, 31% rated their mental health as 'poor', and 20% stated that, in the last week, they have not felt any enjoyment in life at all (8).

Participants with dementia described their need for support to come to terms with their diagnosis and managing their feelings around changes to life and worsening symptoms. Family carers describe needing support to manage their deteriorating mental health and to cope with their caring responsibilities alongside their busy lives. When asked, 71% of family carers and 84% of people with dementia said they would avail of counselling services if provided.



## Solutions

### (a) Develop a dementia-specific counselling service (€62,000)

The positive impact of counselling services for family carers is very well established, while the evidence for the impact on the person living with dementia is growing (31).

The recruitment of a full-time Project Lead dedicated to exploring the development of dementia-specific counselling services is required. The development work will include cost analyses, the development of a service framework, identifying training requirements and multi-stakeholder consultation and research.

#### **Impact:**

**People with dementia and their families will have access to dementia-specific counselling services to support their unique psychological and emotional needs.**

By investing in affordable, specialised counselling services tailored specifically for people affected by dementia, both people living with dementia and their families will receive **vital support in managing their emotional & psychological well-being, self-acceptance, and better family communication.**

This investment will contribute to an overall improvement in their quality of life, fostering greater resilience and well-being for all involved.

*Supporting emotional wellbeing* is one of the five strands of post diagnostic support outlined for **The Model of Care for Dementia in Ireland** (1).





*“It’s really important to be at the heart and the pulse of research, One for me to gain knowledge and secondly for me to share my knowledge. Because when you’re caring for somebody with dementia, Alzheimer’s, you, you have an inside perspective, but also the person does too.”* **Agnes, TeamUp for Dementia Research member & family carer, and her mum, Alice Senior, now deceased.**



## 4 Challenge: The Dementia Research Landscape is advancing rapidly, and Irish researchers should be supported to keep pace

The global dementia landscape is rapidly evolving, with advancements in diagnostics, brain health, and Disease Modifying Therapies. There are credible treatment options for Alzheimer's Disease currently under consideration by the European Medicines Agency.

In the 2023 European Dementia Monitor (32), Ireland ranked average among 37 European Countries in pan-European Research Initiatives. Ireland was ranked 6th out of seven countries on the public's ability to participate in Phase III clinical trials.

Dementia research faces challenges in participant recruitment despite a willingness among people living with dementia and carers to engage in clinical trials. For example, in our national research, The ASI found that most people with dementia (85%) and carers (79%) would take part in a clinical trial (8).

Research and innovation is a key focus for the WHO Global Action Plan for Dementia 2017-2025 (33), calling for a doubling of dementia research by 2025, and for countries to 'increase investment in dementia research and innovative health technologies and improve research governance'. Research is cited as one of the six Priority Action Areas of the National Dementia Strategy (2).

In recent years, Ireland has developed a solid foundation in dementia research. Continued investment is vital to capitalise on expertise and knowledge that has been developed which can be passed on to future generations.



## (a) Support Dementia Researchers by expanding investment in Dementia Research Network Ireland (€1 million)

Dementia Research Network Ireland (DRNI) is an innovative all-Ireland interdisciplinary dementia and neurodegenerative research initiative. It acts as a single conduit for dementia and neurodegenerative disease research in Ireland, providing leadership in defining and addressing research priorities in Ireland. DRNI links researchers from the basic, clinical and social sciences, working closely with the HSE, The ASI and National Clinical Programmes, to impact on policy and practice in dementia and neurodegeneration and support the implementation of the National Dementia Strategy. DRNI enhances the visibility of the dementia research framework in Ireland, resulting in increased national and international relationship building and collaborations, as well as interest from industry.

Dementia Research Network Ireland is funded by the Health Research Board (€248,000 over three years). Given the changing dementia landscape, and success of the initiative, this funding must be enhanced and continued after 2024.

### Impact:

Continued and enhanced funding will enable the network to **build on its success** so far and diversify the support it provides across Irish research. **DRNI provides an umbrella infrastructure to capitalise on the immense research talent across Ireland** by supporting researchers across Ireland to build relationships, collaborate, and play a greater role in research internationally.

Expanding investment in Dementia Research Network Ireland will facilitate a strong and more cohesive research focus across all disciplines involved in dementia research. Quality research and innovation lead to better outcomes for people affected by dementia.





## (b) Invest €59,000 to support people affected by dementia to participate in quality dementia research

TeamUp for Dementia Research (TUDR) is an ASI service that connects people living with dementia and informal carers with opportunities to take part in ethically approved dementia research. Established in July 2021, the service makes research participation accessible and provides a safe and supported way for members to consider research participation opportunities. TUDR is a touchpoint that enables The ASI to connect with people affected by dementia earlier in their journey. Many TUDR members contacted the service soon after diagnosis, to be proactive and in search of hope.

TUDR has a dual benefit; it also provides a research recruitment service to research teams across Ireland. This service has supported ten research studies so far this year. This service is managed by The ASI and was created in collaboration with Dementia Research Network Ireland.

Membership of the TUDR service has grown by 400% since 2022 (from 70 members to 350 members). The service is now operating a waiting list as membership has reached capacity within the current resource allocation. The TUDR service requires one FTE post and funding for promotional activities to expand the service.

### Impact:

Increased access to research participation for people impacted by dementia

This investment will enable The ASI to *expand and diversify the TUDR membership to ~700 people* with dementia and family carers while providing *recruitment support to significantly more research teams*. This will make Irish dementia research more effective, efficient, and competitive.

**Target 27 of the Model of Care for Dementia in Ireland** (1) states that *As part of care planning and early post-diagnostic support, 100% of people with dementia, irrespective of age or dementia subtype, and their supporters / family carers should be offered information about relevant and appropriate research opportunities. Similarly, 100% of people with MCI should be offered signposting to research participation.*





## 5 Challenge: Unsustainable Workforce in the Dementia Sector

As a Section 39 organisation, there is an inequality in terms and conditions for all ASI employees as the team receives less favourable terms and conditions when compared to public sector workers who are engaged in comparable work.

Notwithstanding the Government's 8% increase in funding for wages for Section 39 organisations in recent times, huge challenges and inequalities remain. This is resulting in recruitment and retention challenges and concerns regarding the sustainability of the services.

The challenges around pay inequality for Section 39 employees has been very well documented in recent years (34-36). For example, The Future of Public Service Delivery by the Community and Voluntary Sector 2023 report from The Wheel (34) found that the demand for services delivered by not-for-profit organisations is growing and becoming more complex, while at the same time, staff turnover and vacancies is putting these vital services at serious risk.

In addition, there are specific concerns in relation to home care workers which is impacting the provision of dementia-specific home care. Home care, while highly skilled and highly valued, is low-paid, and the additional skills and expertise required in delivering dementia-specific home care is not reflected in remuneration.





*“The Care Workers who come into my home to help me every day mean I can stay at home and be independent, they put my family’s mind at ease. Those workers are so important” Kathleen living with dementia & her sister, Elizabeth*

## Solutions

### (a) Pay Parity for All Section 39 Employees and Inclusion in Public Sector Pay Deals

The ASI is calling on the Government to address the inequality in terms and conditions for all Section 39 employees by including these employees in public sector pay deals and funding organisations to apply those increases, including increments.

Our organisation is ambitious for the lives of people living with dementia and we are continuously innovating and expanding service provision. To do this we must have a stable workforce and the recent implementation of the Workforce Relations Commission decision and resultant pay increase has supported that stability. We now call for continued application of that principle of equity for all workers to allow The ASI to continue to plan future service provision and play our part in implementing the Model of Care for Dementia in Ireland.

#### Impact:

#### Sustainable provision of dementia services

Should the Government take swift action to address the challenges around pay inequality for Section 39 employees, it would ensure sustainable dementia service provision into the future.

Dementia employees would feel more valued should pay parity be established with counterparts in other public sector organisations. This will create a more stable staff team which would be better equipped to support people affected by dementia in communities and would reduce staff turnover.

### (b) Standardise rates of pay for home care workers

In relation to dementia-specific home care workers, there is a need to standardise home care rates of pay and benefits across Ireland as well as introduce meaningful career progression opportunities for these workers.

#### Impact:

#### Sustainable delivery of home care



Addressing the challenges around dementia-specific home care would reduce the impact on the provision of dementia-specific home care. Research undertaken by The ASI in 2023 uncovered that almost two-thirds of respondents in receipt of home care experienced a delay or reduction in this service over the last two years due to the home care staffing crisis (8).

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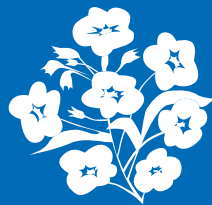
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- ✉ email: [advocacy@alzheimer.ie](mailto:advocacy@alzheimer.ie)
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