



PRE-BUDGET SUBMISSION 2024

Dementia Can't Wait



THE Alzheimer
SOCIETY OF IRELAND

Dementia Supports to Empower Lives

The Alzheimer Society of Ireland (The ASI) is calling on the Government to invest in vital community supports, care services, and social protection for people affected by dementia.

The ASI is urging the Government to honour the Programme for Government, the National Dementia Strategy, and to bring the recently launched Model of Care for Dementia in Ireland from paper to practice.

€2.3
million Investment in **Dementia-specific Day Services** including **Day Care at Home** and **Weekend Activity Clubs**

€5.2
million Investment in **Enhanced Dementia Care** including, **Dementia Nurse Specialists, The Model of Care for Dementia** and **Dementia Research**

€2.2
million Investment in **Therapeutic Support** and **Education** for Family Carers

€1.59
million Investment in **Pay Parity** for **Dementia Care Workers**

€10
million Investment in **Dementia Home Care**

Social Protection Invest in adequate **Social Protection** for **Dementia Carers**

You can find a comprehensive evidence base for these Asks at alzheimer.ie

About The Alzheimer Society of Ireland

A national non-profit organisation, The Alzheimer Society of Ireland is person-centred, rights-based and grassroots led with the voice of the person with dementia and their carer at its core.



National Helpline on 1800 341 341 is open six days a week, Monday to Friday 10am - 5pm and Saturday 10am - 4pm

Submission Context

The Model of Care for Dementia in Ireland: The landmark Model of Care for Dementia in Ireland (1) 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 in Ireland. 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, given by the right team, is a central principle.

Programme for Government: The current 2020 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: The continued rise in the prevalence of dementia in Ireland is leading to a widening gap between services and need. An estimated 64,000 people are living with dementia in Ireland, which is expected to rise to 150,000 by 2045 (5). In 2017, when prevalence was lower, The ASI and National Dementia Office highlighted that no county in Ireland has a minimum standard of services to meet the needs of people with dementia and family caregivers (6).

The rising cost of living: People with dementia and their carers are experiencing significant financial challenges as they contend with the cost of living crisis. Research published by The Alzheimer Society of Ireland in collaboration with Family Carers Ireland in 2022 (7) highlights the disproportionate impact of the cost of living crisis on people with dementia and family carers, with many struggling to make ends meet. Data collected by The ASI in May and June 2023 shows that this trend is continuing (8).

Human Rights: People with dementia face cultural, social and economic barriers to fulfilling their rights. The *Charter of Rights for People with Dementia* (9) 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.

Robust Evidence and Consultation: The Asks in this Pre-Budget Submission (PBS) are informed by a broad and robust consultation with key stakeholders and relevant research and reports.

- *National Research* with 72 people with dementia and 594 current family carers across May and June 2023.
- *Lived Experience of Dementia:* Consultations with people living with dementia from the Irish Dementia Working Group.
- *Internal consultations* with front-line service staff including The ASI Operations team, Dementia Advisers, Helpline Volunteers and volunteer Branch members.
- *A comprehensive review of internal and external reports and research papers.*

Our Asks

1. Invest €2.33 million in Dementia Specific Community Day Services

Further investment in dementia-specific Day Services 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. National Research undertaken by The ASI found that one in four family carers and one in three people with dementia report having 'great difficulty' accessing the services they need.

1.1. Increase funding for Dementia Specific community based Day Care at Home Services by €1,737,720

Day Care at Home provides continuity of care and support to people with dementia and their families for whom attending Day Centres is not possible or of interest. This investment is essential to ensure the sustainability of existing provision and expand the capacity to meet ongoing demand and the unmet needs of this cohort. A further investment of €1,737,720 would increase the funding to these services to €3,475,400. This vital funding increase will enable the number of hours delivered in our Day Care at Home Services increased to 115,848. This equates to providing a service to approximately 400 more people with dementia.

Rationale

- 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 is considered a lifeline by those using the service.
- The service provides a unique opportunity to increase the continuity of care of ASI services earlier or later in the journey for the person living with dementia and provides an alternative to those who do not wish to or are unable to attend Day Centres.
- Day Care at Home is optimally placed to support people affected by Younger Onset Dementia who have significantly different needs and preferences than those diagnosed later in life (10,11).

- An evaluation of this service has highlighted that receiving Day Care at Home is a positively transformative experience for both the person living with dementia and their family and provides a level of flexibility and continuity of care that other services cannot provide (12).

Context

The Model of Care for Dementia (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 psycho-social care needs in their home”. In Ireland, the majority (64%) of people with dementia live at home in their communities (13).

Day Care at Home Services commenced during the COVID-19 Pandemic to meet the urgent needs of people living with dementia and their families by providing variety, stimulation, and personalised fun activities. An evaluation of the service shows the positive impact on those for whom a day centre is not their preferred or suitable choice. Day Care at Home delivers quality psycho-social support, by providing person-centred activities in block hours. An emphasis on meeting needs rather than being task-led is a defining feature of this service.

Preliminary data from an evaluation of The ASI’s Day Care at Home service (12) highlights that Day Care at Home offers a level of flexibility and continuity of care that other services cannot provide and that the service is transformative for people living with dementia and their families. Furthermore, the potential for dual benefit is evident as it supports both the person with dementia and the family.

Research into day services and short-term respite for people with dementia through a personhood lens identified that day services are more acceptable to people with dementia than residential respite admissions, but for some people with dementia, the preferred location of care is in their own home (14).

1.2. Invest €600,000 in the provision of Weekend Activity Clubs

Dementia does not end on a Friday. An investment of €600,000 per year would provide 20 Weekend Activity Clubs with a special focus on Younger Onset Dementia. This will build on the success of The ASI’s current 21 Social Clubs and allow the provision of a much-needed tailored and responsive service to those who are early in their dementia journey and specifically those diagnosed with Young Onset Dementia.

Rationale

- People with Younger Onset Dementia have difficulty fitting into existing dementia 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 (10, 15, 16).
- The Model of Care for Dementia in Ireland (1) recommends that people with Younger Onset Dementia should be encouraged to attend local support groups including peer support groups, but there is a shortage of these services specific to their needs in Ireland.

- Weekend Activity Clubs with a focus on people with Young Onset Dementia and those at earlier stages of their journey will provide people an opportunity to meet socially, within their communities, in a service tailored to their need and age profile with their peers. This will also support family carers by providing respite outside of the usual Monday-to-Friday structure.
- An evaluation of The ASI's Day Centres highlights the great value placed on these services by people with dementia and their families, and the person-centred approach underpinning care (17).

Context

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 (YOD) can be vastly different from older people.

The ASI has successfully piloted Saturday Dementia Day services in Dungarvan and Midleton and would actively pursue potential locations within the six Public Health Areas launched as part of the move toward Sláintecare reforms.

In research by The ASI with 72 people with dementia, 27% reported that they often feel lonely (8), highlighting the need for more activity and interaction. An external evaluation of The ASI's Day Services highlighted that people with dementia attending Day Centres were very positive about their experiences, welcoming the opportunities for social interaction and participation in meaningful activities. Family and other informal caregivers also highly valued the service. These findings are consistent with international research exploring Day Centres from the perspective of people with dementia (18-20) and family carers (21-23). In addition, research recently published by the Centre of Economic and Social Research on Dementia found Day Centres and Short-Break Respite were highly valued among both family carers and the public (24, 25). There are approximately 4,500 people living with Young Onset Dementia (i.e. diagnosed before age 65) in Ireland. People in this cohort often have young families, financial responsibilities and vibrant social lives, which poses unique and complex challenges for them and their families when diagnosed with dementia. People with YOD can feel that they do not fit in with the life stage of those attending more traditional support groups (15, 16). It is imperative to provide age- and stage-appropriate support (26).

Supportive interactions in the community are critical for reducing isolation among this cohort, and research highlights the importance of social approaches and active participation opportunities for people with YOD post-diagnosis (27). Research published by The Alzheimer Society of Ireland highlights that YOD Peer Support Groups founded upon social networks benefit people with YOD and their families however, they are under-resourced, lacking geographical equity, and reactive in nature (11). In National Research conducted by The ASI (8), the most requested new service among those affected by YOD and those in the earlier stages of dementia is support groups and opportunities to socialise with people in similar situations.

Effective community support for people affected by YOD must be flexible, consistent, sustainable and delivered by dementia-trained personnel (11, 16, 28, 29). A Weekend Activity Club can empower

people with Younger Onset Dementia and those at the earlier stages of their journey to remain active, connected and supported within their communities. The weekend service will provide opportunities for social engagement with the support of trained staff to empower them to live well at home outside of service hours. This service offers links to available support at an earlier stage, ensuring their entire journey and that of their family is supported within the ASI continuum of services. Similarly, it will enable The ASI to reach deeper into many of the most rural parts of the country where historically there has been a shortage of dementia-specific services through accessing local Community Hospitals, Older Persons Services and other suitable locations while also capitalising on existing ASI premises that are not in use at the weekends.

2. Invest €2.2 million in Therapeutic Support and Education for Family Carers

A diagnosis of dementia is life-changing for both the person and their family. €2.2 million is requested to provide therapeutic and emotional support to family carers of people with dementia, including support ring-fenced for families affected by Young Onset Dementia (YOD).

- a. *15,700 hours of Counselling at a cost of €1.26m (100 hours per 1,000 affected at €80 per hour).*
- b. *190 Family Carer Training Programmes at a cost of €950K (1 per 500 affected @ €5,000 per programme).*

Rationale

- The Model of Care for Dementia in Ireland (1) states that ‘100% of supporters/family carers of people with dementia should be informed about and offered education and skills training’. Similarly, the National Carers Strategy (30) states that Family Carers should be supported to maintain their own health and wellbeing and to care with confidence.
- Caring in Ireland has long been associated with poor health outcomes and it is essential to provide adequate support to this cohort (31). Recent ASI research with family carers of people with dementia tells us that 43% of carers have visited a healthcare professional in the last month on account of their own health; 43% rating their mental health as ‘Poor/Fair’ and 34% rating their physical health as ‘Poor/Fair’ (8).
- Evidence suggests that an optimal mix of participating in psychoeducational interventions incorporating skills training (in a peer-group setting), psychological therapies, and counselling has highly positive effects on caregivers of people with dementia (32-35).

Context

There are an estimated 180,000 Family Carers in Ireland. For every person with dementia, there are three others supporting that person and providing care (36). Family Carers of people with dementia are known to struggle with stress, burnout and health challenges related to caring (31, 37, 38). Unmet needs of the carer can significantly impact their quality of life, including loss of self, loss of companionship/friendship, and loss of freedom (39). In National Research undertaken by The ASI,

38% of family carers said they are struggling with their caring responsibilities while one in five said they feel depressed by their situation 'all of the time' or 'most of the time'.

Target 37 of the Model of Care for Dementia in Ireland (1) states that '100% of supporters/family carers of people with dementia should be informed about and offered education and skills training'. The ASI currently provides 78% family carer training programmes which are award-winning and consistently oversubscribed. For example, in May 2023, 311 people were on a waiting list for family carer training.

Professional counselling services and psychotherapeutic interventions have consistently stood out as a critical support gap in The ASI's national research and Pre Budget Consultations with family carers and Dementia Advisers. In our national research [8], 71% of family carers stated that if counselling services were offered, they and/or their family would avail of this service. 48% of people living with dementia also reported their willingness to engage in counselling services if they were available (8). Counselling is highly effective in reducing depressive symptoms and anxiety in carers of people with dementia (40, 41).

The vast majority of carers are very willing to provide care for their loved ones with dementia, but they cannot do this without support.

3. Invest €10 million in Dementia-specific Home Care and address the current Home Care Staffing Crisis

The ASI calls for an investment of €10 million in dementia-specific home care and for the Government to take immediate action to address the staffing crisis in the sector. Home care that is dementia appropriate and provided by dementia-trained staff is a vital lifeline for people with dementia and their families.

Rationale

- Demand for dementia-specific home care continues to rise significantly and further investment in quality home care services is needed to keep pace with this. The ASI acknowledges the increased investment by this Government in home care for people with dementia but need continues to soar.
- Dementia-specific home care is considered a lifeline by people with dementia and their families. It supports the person with dementia to have their needs met and continue living in their community for as long as possible while providing respite to their families.
- National Research undertaken by The ASI in 2023 has 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).

Context

State policy is that older people should be catered for in the comfort and security of their own homes. The current Programme for Government states that the Government will “ensure that home support is adaptable and responsive to the needs of those with dementia” (4)

People with dementia have the right to live as independently as possible, in a familiar environment linked to their communities (9). Enactment of the Statutory Home Care Scheme (42) will significantly address access to home care and the current Programme for Government states a commitment to introducing this. In the interim, there must be continued and increased investment in home care.

Dementia-specific home care consists of person-centred, consistent, and continuous care, provided by dementia-trained staff and in partnership with the person with dementia and their carer, while promoting independence and inclusion. Quality home care is flexible, responsive and takes the needs of the home care recipient and their families into account.

The home care staffing crisis is deeply impacting the ability to provide dementia-specific home care. Dementia-specific home care is highly skilled work and strongly valued by those who receive it. However, it is low-paid, and the additional skills and expertise required in delivering dementia-specific home care are often not reflected in remuneration (43). There is a critical need to standardise home care rates of pay and benefits across Ireland as well as introduce meaningful career progression opportunities.

The consistent loss of the nonprofit home care workforce to the HSE due to the inequality of terms and conditions between the state and the nonprofit sector is a significant obstacle in recruitment and retention. Research undertaken by The ASI (8) has found that of 236 families in receipt of home care, 63% have experienced a reduction or delay in home care due to this staffing crisis. Many regularly receive significantly fewer hours than they are allocated as there simply are not enough staff to deliver them. Similarly, families in certain areas cannot receive any home care as there are no staff available. Home care is in crisis, and The ASI is calling on the Government to act fast to protect this vital service.

4. Invest €5.2 million in Enhanced Dementia Care

4.1. €2.8 million investment in Dementia Nurse Specialist roles in acute hospitals

The ASI is calling on the Irish Government to invest €2.8m to provide at least one Clinical Dementia Nurse Specialist role in every acute hospital in Ireland. Clinical Dementia Nurse Specialists work across a spectrum of functions and greatly improve hospital stay experiences for people with dementia and their families.

Rationale

- People with dementia make up approximately one-third of hospital admissions among over 70s (44, 45).

- People living with dementia experience substantially more extended hospital stays, more adverse events and poorer outcomes than similar patients without dementia (46, 47).
- A Dementia Clinical Nurse Specialist can significantly benefit people with dementia in an acute setting (48-50).
- Recent research commissioned by The Alzheimer Society of Ireland (50) presents a strong case for further investment in the Dementia CNS role in Ireland, highlighting the substantial value of these roles in improving patient experience in hospital, better supporting family carers, providing training and education, enhancing communication and decreasing adverse outcomes.

Context

Admission to an acute hospital can be distressing and disorientating for a person with dementia and is often associated with a decline in their cognitive ability, levels of functioning, and quality of life (51, 52). Similarly, people with dementia in hospital are more likely to experience adverse events such as dehydration, falls, and malnutrition. They are also more likely to be readmitted than those who do not have dementia (53).

Based on hospital-level INAD-2 data (54), Dementia-specific nurse specialist roles are crucial to improve the provision of dementia care and in the implementation of other national guidelines relating to acute hospital dementia care. The Clinical Nurse Specialist role is specifically aligned to the targets of care for people living with dementia in multiple national clinical programmes and strategies including the Integrated Care Programme for Older People, National Dementia Strategy, the Sláintecare Action Plan, and the Irish National Dementia Audits. The Dementia CNS role is important for the successful implementation of the Model of Care for Dementia with the concepts of Clinical Focus, Advocacy, Education, Research and Consultation vital for the delivery of an integrated, person-centred and timely clinical service.

A Dementia Clinical Nurse Specialist can significantly benefit people with dementia in an acute setting (48-50). Work commissioned by The Alzheimer Society of Ireland exploring the case for clinical dementia nurse specialists in Ireland highlights the substantial improvements these roles have on the experience of people with dementia and their families in acute settings (50). Evidence from this report presents a comprehensive view of the practical experience of healthcare staff, patients and family support networks in relation to these roles, and demonstrates a strong case for further investment. Clinical Dementia Nurse Specialists can make hospitals safer, more dementia friendly, and make the experience of being in an acute setting significantly less distressing for people with dementia and their families.

4.2. Implement the Model of Care for Dementia in Ireland and continued investment of €1.4 million in Memory Assessment Support Services

The ASI calls on the Irish Government to implement the Model of Dementia Care in Ireland (1). A fundamental element of the successful implementation of this model is an investment in Memory

Assessment Support Services (MASS). We are asking the Government to fund a further two further MASS teams (at a cost of €700,000 each) across communities in Ireland where the need is the highest.

Rationale

- Target 1 of the Model of Care for Dementia in Ireland (1) is to provide a minimum of one MASS per local population of 150,000 people performing approximately 300 assessments per year.
- The MASS is a fundamental component of the three-level diagnostic model outlined in the Model of Care for Dementia in Ireland.
- The diagnostic assessment in a MASS is comprehensive and capable of diagnosing complex presentations, including Young Onset Dementia. In addition, people with significant risk factors for dementia or who are diagnosed with Subjective Cognitive Impairment, Mild Cognitive Impairment or dementia, can access a brain health (risk reduction) service through the MASS.

Context

The MASS is a space where a comprehensive assessment is carried out by a multidisciplinary team (MDT) where there are concerns about suspected dementia or a mild cognitive impairment. Importantly the MASS also provides post-diagnostic support and follow-up through (i) a specialist dementia post-diagnostic service and (ii) a brain health service, with a comprehensive care and support plan developed for each person.

The MASS post-diagnostic service can provide personalised assessment, risk reduction intervention, care planning, referral PDS intervention and arrange a point of contact and follow-up. Attendance at this service will provide an opportunity for the person to discuss any concerns following their diagnosis and for the MDT to provide further therapeutic interventions alongside information and guidance.

There has been significant investment in Memory Assessment & Support Services (MASS). To date, 10 MASS sites have been funded through the National Service Plan¹ 2021, 2022 and 2023. It is essential to continue investing in this infrastructure to realise the vision of diagnostic services outlined in the Model of Care for Dementia in Ireland.

4.3. Invest €1 million in Dementia Research

The ASI is calling on the Government to invest €1m in dementia-specific research funding, which will support dementia research professionals and clinicians to explore and develop programmes of work to embed a culture of research, evidence-based practice and innovation so that research becomes a critical enabler of dementia prevention, diagnosis, care and cure.

¹ <https://www.hse.ie/eng/services/publications/serviceplans/>

Rationale

- Dementia research continues to be poorly funded relative to its importance and the significant impact of the disease on both an individual and societal level.
- Ireland has strong research infrastructure meaning it is well-prepared for high-quality, patient-driven translational dementia research. Now, there is a need for funding to undertake and implement this work.
- The importance of research is highlighted in national policy and strategy (3), yet there continues to be no dementia-specific research funding stream available in Ireland. For example, a key objective of the National Dementia Strategy (2) is “Funding for clinical, non-clinical (including psychosocial research) and health service research on dementia”
- 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”.

There is an urgent need for investment in Dementia Research across the spectrum of basic science, prevention, clinical and social research to create tangible change for people with dementia and their families. There are approximately 187 Clinical Trials for Alzheimer’s Disease and Mild Cognitive Impairment underway worldwide, of which many are in later-stage clinical trials (55) and high optimism that some of these will be licensed for use over the coming years. There is an acute need to invest in Research so that Ireland can begin preparing for the impact of these therapies and significant advancements in diagnostics that will significantly alter the dementia landscape.

Across Ireland, there is an existing network of institutions and individuals with expertise in dementia and facilities to undertake essential dementia research aimed at preventing dementia and supporting those with the disease to live as well as possible. Over the past two years, Ireland’s Research Infrastructure has grown meaning Ireland is better prepared for high-quality, patient-driven translational dementia research. This infrastructure includes TeamUp For Dementia Research², The ASI’s well-developed PPI Initiative³, strong investment in Dementia Trials Ireland⁴ and Dementia Research Network Ireland⁵. Now, there is now a need for funding to undertake and implement quality research.

Research and innovation is a key focus for the WHO Global Action Plan for Dementia 2017-2025 (56), and given the significant scientific, medical and socioeconomic challenge dementia poses for Ireland, we must invest in dementia research.

² TeamUp For Dementia Research is a service managed by The Alzheimer Society of Ireland in collaboration with Dementia Research Network Ireland. This service makes research more accessible by breaking down barriers to recruitment and participation. www.teamupfordementia.ie

³ The Dementia Research Advisory Team is a Person & Public Involvement panel of people with dementia and family carers that is supported by The ASI. These experts by experience ensure that research is patient-led and relevant.

⁴ Strong investment secured by Dementia Trials Ireland in 2021 is a significant step in maintaining Ireland’s credibility in this area and will help prepare Ireland for undertaking and delivering clinical trials.

⁵ Dementia Research Network Ireland links researchers across disciplines in the areas of dementia and neurodegenerative diseases with the objective of enhancing research co-operation and coordination in Ireland.

Furthermore, research is important to people with dementia and family carers. In a national survey, 73% of people with dementia and 87% of family carers agreed that clinical trials are necessary to make progress in health care while the majority would be open to taking part in clinical trials.

5. Invest €1.59 million in Pay Parity for Dementia Care Workers

The ASI is calling on the Irish Government to invest €1.59 million to address the inequality in terms and conditions for workers in dementia care via an uplift in funding to the organisation.

Rationale

- The ASI team who provide the majority of dementia-specific services throughout Ireland receive less favourable terms and conditions than public sector workers engaged in comparable work. This has led to growing recruitment and retention issues and concern regarding the sustainability of the services which the organisation provides to people affected by dementia.
- The Future of Public Service Delivery by the Community and Voluntary Sector 2023 report from The Wheel (57) has 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.
- The Building Momentum - A New Public Service Agreement 2021-2022 (58) was extended to 2023, providing public sector workers with increased rates of pay. This has widened the gap between workers in The ASI and those in the public sector who engage in the same work.
- The inequitable situation for Section 39 workers has been acknowledged by the government. In October 2022 the now Taoiseach said in the Dáil ‘there are staff working in section 39 bodies who are at a disadvantage compared to people doing the same work in a HSE-provided body. That is unfair and is something we want to rectify, first, by making sure the block grants of those bodies are adequate to cover the pay increases that will be paid in the public sector, which is only fair[2]’.

Context

Under section 39 of the Health Act⁶, the HSE provides financial assistance to organisations delivering services similar or ancillary to services which the HSE would otherwise be providing. The ASI is funded via section 39 and our workers are excluded from public sector pay deals and cannot benefit from collective bargaining arrangements.

This situation has resulted in a situation where The ASI workers feel undervalued and are underpaid. The frustration of the team throughout the organisation is palpable, and the need for pay parity has become urgent. The strength of The ASI is the team who support people affected by dementia in communities throughout Ireland, without a stable team the sustainability of these vital supports is at grave risk.

⁶ <https://www.irishstatutebook.ie/eli/2004/act/42/section/39/enacted/en/html>

The report from The Wheel in 2023 is not the first to raise the matter of pay parity for section 39 workers. In 2019 (59) the Just Economics Breaking Point Report found a funding environment which was ‘rapidly becoming unsustainable’.

In 2021 Forsa in its report A New Systemic Funding Model: The Community and Voluntary Sector in the 2020’s (60) again pointed out the unsustainable funding model. This report also provided stark testimony from section 39 workers regarding the impact of unequal pay. It outlined workers' feeling of demoralisation; ‘Many spoke of feeling ‘demoralised, ignored and worthless’. One referred to ‘low morale, anger, distrust, loss of enthusiasm’. ‘People feel tired, exhausted, used’.

It is now beyond time for the government to take swift action to address the pay inequality for section 39 workers to ensure sustainable dementia service provision into the future.

6. Invest in Adequate Social Protection for Dementia Carers who receive Carers Allowance

The ASI calls on government to

- a) Increase the Carers Allowance by a minimum of €27.50.
- b) Make Carers Allowance a qualifying payment for the Fuel Allowance
- c) Recognise the costs of caring in the allowable deductions for Carer’s Allowance, including medical expenses and fuel, and assess income on net value.

Rationale

- Our current health and social care system depends largely on family caregivers who provide the main bulk of care; its estimated value to the State is in the region of €807m per annum (61). Providing those carers with an adequate and dignified standard of living must be a priority.
- Due to the current cost-of-living crisis, anything less than a €27.50 adjustment in core social welfare rates will be a real-term cut⁷. This is the absolute minimum required to prevent individuals and families being pulled deeper into poverty.
- In its report published in 2023 in collaboration with Family Carers Ireland, The Cost of Living While Caring (7), The ASI found serious financial struggles for family carers of people with dementia. The report found 51% of carers were having difficulty making ends meet; many were cutting back on household essentials and reducing social interactions with friends and family, while some were in arrears with mortgages and household bills. This trend is continuing in 2023 evidenced by data collected from almost 600 family carers by The ASI in May and June (8).

Context

⁷ Data from the Vincentian MESL Research Centre shows that an adjustment of €27.50 is needed to restore the real value of core working age payments to 2020 levels but may need to rise to €31 at the end of 2024 depending on forecast inflation. The cost of the basket of goods needed to ensure Minimum Essential Standard of Living has risen by 18.9% since 2020. https://www.budgeting.ie/download/pdf/mesl_2023_-_annual_update_report.pdf

The ASI team throughout the country is hearing from dementia carers in financial difficulty; calls to the National Helpline regarding financial issues have increased and we are concerned that the well-being of people who care for loved ones living with dementia is at serious risk of deteriorating as Ireland navigates the current cost of living crisis. An already stressful and complex situation with significant health risks is exacerbated by financial strain.

The annual MESL update (62) in June 2023 points to income inadequacy widening to include more household types, and deepening its impact. This is evident in research undertaken by The ASI in May and June 2023 (8) with family carers, which uncovered that, of 324 people who responded to this topic, 50% are having difficulty making ends meet with almost one in ten having 'great difficulty' with this. As a result of this, they report feeling stressed and anxious and having to cut back on social outings and spending money on their children.

Household Energy was the MESL category with the largest increase in cost in 2023. The update found; 'income supports have failed to progress at the same rate as soaring energy costs, broadening the gap between MESL Household Energy needs and related social welfare supports. The government can support dementia carers with rising energy costs by making Carers Allowance a qualifying payment for the Fuel Allowance.

In work published by The ASI in June 2022, families affected by Younger Onset Dementia highlighted the financial burden of supports and interventions during the current challenging economic climate (11). They report the costs associated with caring are rising and are not properly understood in the context of assessment for social protection. Until those costs are allowable deductions for assessment for the Carers Allowance dementia carers will be at considerable risk of poverty.

Dementia carers urgently need meaningful increases in social protections, not once-off measures. Budget 2024 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.

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