

# Deliver on Dementia - Make a Pledge to

# **Keep Dementia a Priority for the New Government**







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# **Summary of Asks**

- Resource of the Model of Care for Dementia
- Develop a National Dementia Registry
- Make Brain Health a Public Health Priority
- Deliver a Dementia Workforce for the Future
- Implement the Statutory Home Support Scheme
- Appoint an Independent Commissioner for Older People





Andy Heffernan CEO, The Alzheimer Society of Ireland

64,000 people in Ireland live with dementia.

"It's crucial that we look at the need for a new dementia strategy with achievable targets."

#### Dear Candidate,

Support for people with dementia and their family carers has made significant strides since the last election, thanks to increased political backing. However, much more remains to be done.

It is essential now that momentum is not lost and that the needs of so many remain a priority on the political agenda and that dementia services are delivered in a fair and equal way.

Currently, an estimated 64,000 people in Ireland live with dementia, with another 50,000 family carers to help them live as well as possible, and for as long as possible at home. By 2045, the number of people diagnosed with dementia is expected to rise to 150,000, underscoring the need for society to prepare for the future.

We have seen great progress in dementia supports, services and the wider understanding of dementia in the last decade. Ireland's first National Dementia Strategy, launched in 2014, was a significant milestone culminating in a key cornerstone of that strategy, the Model of Care for Dementia in 2023, which offers a crucial pathway of care and support for so many people.

It is now a decade since the dementia strategy was first introduced. A mid-term review on the progress of the strategy was published in 2018; however, a full review needs to be completed in the near future. It's crucial that we look at the need for a new dementia strategy with achievable targets. Yes, strategies need to be aspirational – they must also be realistic. The next Government has a responsibility to review the current strategy, build on existing progress, and plot a realistic path forward that best supports people who are impacted by dementia in Ireland.

Those who we advocate for tell us daily that living with dementia can lead to isolation as they struggle to access critical services like home care and community care, particularly in rural Ireland. Many carers also face significant financial difficulties and grapple with rising costs.

The new Government must also prioritise support for dementia research and ensure that any innovations in treatments, diagnostics and Disease Modifying Therapies (DMTs) are accessible to all who need them. By fostering a dementia-inclusive Ireland, we can create a society where those affected feel supported, not sidelined.

The Alzheimer Society of Ireland is committed to working with the new Government and the All-Party Oireachtas Group on Dementia and people affected by dementia to meet the challenges that the condition presents in Irish society.

Given the rising need for dementia supports and services, we need to build on the investment in recent years and continue to address-the challenges faced by people impacted by dementia.

We are calling on all General Election candidates to pledge their support for those living with dementia and their family carers by committing to the six priorities outlined in our manifesto.

Together, these actions have the potential to make a difference in every community across Ireland.

Thank you,

Andy Heffernan CEO, The Alzheimer Society of Ireland

# **Responding to an Ageing Population**



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

# **What They Say**



**63%** of family carers report difficulty accessing services.

(The ASI, 2023)

# **Living at Home**



63% of people living with dementia are living at home.

(Pierse et al, 2019; The ASI 2023)

# **Access to Services**

33% of people living with dementia say they do not have access to the services they need.



(The ASI, 2023)

## **Young-Onset Dementia**



An estimated **5,200 people** are under 65. (HSE, 2023)

## **Making Ends Meet**



**50% of Carers** report having difficulties making ends meet.

(The ASI, 2023)

#### Kanturk, Co Cork

"Despite my dementia,
I still have much to enjoy,
thanks to my family and
community. But we urgently
need joined-up thinking
and clear service provision
to support us all."



Chair of the Irish Dementia
 Working Group (IDWG), Kevin
 Quaid, diagnosed with Lewy
 Body dementia at the age of
 53 in 2017.

"Family carers are saving the economy billions, but many feel isolated and are struggling. We must be a priority for the Government and have our needs met."



 Chair of the Dementia Carers Campaign Network (DCCN), Helena Quaid, carer for husband, Kevin, who is living with Lewy Body Dementia.

# Resource of the Model of Care for Dementia

The Model of Care for Dementia in Ireland, published in 2023, outlines 37 targets to improve assessment, treatment, care, and support for people with dementia and their families. It integrates best practices in diagnosis, communication, and post-diagnostic support, aiming to deliver the right care, in the right place, at the right time, by the right team. This model has the potential to transform the entire dementia care pathway for both patients and families.

Its implementation must not be hindered by budgetary constraints. The new Government must ensure adequate resources, including addressing structural issues like workforce shortages and any future HSE staff embargos, to move this plan from paper to practice.

While the development funding in Budget 2025 for recruiting six Consultants to Memory Assessment and Support Services is a positive step, significantly more funding and structural reforms are needed to fully implement the model for people with dementia and their carers.

## **New Government Must:**

Commit to long-term planning, reform, and sustained financing for the Model of Care in all communities, ensuring funding is protected and sufficient to continue its rollout.

# Develop a National Dementia Registry

Access to dementia services, such as Day Care, Home Care, and medical support, remains unequal across Ireland, with rural areas particularly underserved. The new Government must ensure these vital services are available nationwide, not just in major cities.

A well-funded National Dementia Registry is crucial to mapping services, identifying needs, and ensuring equitable access. It would guide all aspects of dementia service provision and planning. Significant groundwork, including a registry model, minimum dataset, and cost estimates, has already been completed.

While the allocation in Budget 2025 for the registry is a positive step, this falls short of the funding required to develop it fully. Greater political support is essential to bring this tool to fruition.

## **New Government Must:**

Commit to developing a dementia registry to ensure equal access to supports and services across Ireland, particularly in rural areas.

# Make Brain Health a Public Health Priority

Up to 40% of dementia cases could be prevented or delayed by addressing factors such as health, socioeconomic status, lifestyle, and environment. However, public awareness of preventive steps is limited. Dementia risk begins early and persists throughout life, making brain health a lifelong priority.

The Government must lead efforts to reduce dementia risk by implementing public health strategies that target the 14 modifiable risk factors, including hypertension, smoking, physical inactivity, air pollution, and low education. Many of these risk factors are linked to inequalities in poverty, ethnicity, and locality, requiring both health promotion and societal change to address.

While some factors are within individual control (e.g., smoking), others require Government and community action (e.g., air pollution). A comprehensive approach is needed to tackle these issues and improve the conditions that influence brain health.

#### **New Government Must:**

Develop and implement a national brain health strategy to address risk factors and reduce dementia incidence.

# 4

# **Deliver a Dementia Workforce for the Future**

Staff that deliver life-enhancing care to charities such as The Alzheimer Society of Ireland (with over 700 employees) face significant pay disparities compared to public sector workers performing similar roles. This inequality has led to recruitment and retention challenges, particularly in home care, where staffing shortages are severely impacting service delivery for people with dementia and their families.

A stable workforce is essential for ensuring quality, continuous care, and the sustainability of dementia services. The Government must address this pay disparity by including the estimated 84,000 Section 39 employees in public sector pay agreements and providing funding for salary increases, including increments. In dementia-specific home care, there is also a need to standardise pay rates and introduce meaningful career progression opportunities.

#### **New Government Must:**

Eliminate the two-tier pay system for charity staff, include Section 39 employees in public sector pay agreements, and address concerns for home care workers.

#### Shannon, Co Clare

"Many carers, by putting their family needs first, struggle to make ends meet. Politicians need to understand that we need fair allowances that keep up with the cost of living and recognise the valuable contribution we make to society."



 Vice-Chair of the Dementia Carers Campaign Network (DCCN), Susan Crampton, carer for her mom, Anne, between 2010 and 2017.

# Implement the Statutory Home Support Scheme

In Ireland, 63% of people living with dementia live at home in their communities, where they feel most comfortable. Despite being first promised in the 2016 Programme for Government, the Statutory Home Support Scheme – a guarantee of consistent, high-quality home care seven days a week – has yet to be delivered.

Nearly a decade later, many people with dementia and their carers still have little or no access to essential services. While some limited progress has been made in relation to licensing of home care providers and in relation to improving workforce pay to address recruitment and retention issues, we remain no closer to implementing the scheme than we were after the 2020 General Election.

A key obstacle is the workforce crisis in home care. This shortage is particularly severe in rural areas, further delaying the scheme's implementation. Addressing these staffing challenges must be a priority for the next Government.

#### **New Government Must:**

Commit to implementing a statutory home support scheme which is sufficiently staffed and funded and accessible to everyone who needs it.

# **Tubbercurry, Co Sligo**

"I've contributed to society all my life, and now, after my diagnosis, I need to feel that the Government and health services can support me in my rural community."



Vice-Chair of the Irish
 Dementia Working Group
 (IDWG), Helen Rochford
 Brennan, diagnosed with
 Young Onset Dementia in
 2012.

# Appoint an Independent Commissioner for Older People

Ireland's older adult population is the fastest-growing demographic of the 21st century, with one in four adults aged 60 or older. This highlights the urgent need for a well-coordinated, whole-of-government response. While many older adults are living longer, healthier lives, significant inequalities persist.

As part of the NGO Age Sector Alliance, The ASI calls for the appointment of an Independent Commissioner for Older People. This role would have a broad mandate to advocate for older adults' diverse needs and rights across all areas of life, including health, care, and beyond. The Commissioner would also ensure that Ireland's policy commitments to older people are effectively monitored and upheld.

#### **New Government Must:**

Establish an Independent Commissioner to ensure the protection and promotion of the rights and needs of older adults.

# **Understanding Dementia**

Dementia is an umbrella term that describes a range of cognitive, behavioural, and psychological symptoms, including memory loss, problems with reasoning and communication, and changes in personality that impair a person's ability to carry out daily activities (NICE, 2018).

Dementia is also **extremely individualised**, and each person's **needs will differ**, depending on their **experience of symptoms**, their **social situation**, their age at the onset of dementia, their overall health status, their personality, and their preferences.

Dementia is **progressive**. Dementia is not simply a health issue but a social issue that requires a community response.

- There are over 400 subtypes of dementia, with the most common form being Alzheimer's disease, followed by vascular dementia and mixed Alzheimer's and vascular dementia
- Dementia affects more women than men
- The majority of people with dementia (63%) live at home in the community
- The overall cost of dementia care in Ireland is just over €1.69 billion per annum; 48% of this is attributable to family care which is essential to remaining in the community

For footnotes and references, please go to www.dementiapledge.ie



Across Ireland candidates in the General Election have the opportunity to

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for the New Government

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or **scan here** 





And let your supporters know you support #dementiapledge









# **About The Alzheimer Society of Ireland**

The Alzheimer Society of Ireland is a national service delivery and advocacy organisation. It is person centred, rights based and grassroots led with the voice of the person living with dementia and their carer at its core.



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www.alzheimer.ie



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The Alzheimer Society of Ireland Helpline is open six days a week

Monday to Friday 10 am - 5 pm and Saturday 10 am - 4 pm

Call 1800 341 341 or email helpline@alzheimer.ie

The Alzheimer Society of Ireland, National Office, Temple Road, Blackrock, Co Dublin. A94 N8Y0