

Pre-Budget Submission 2022



THE ALZHEIMER
SOCIETY *of* IRELAND



Introduction

The Alzheimer Society of Ireland (ASI) is calling on the Irish Government to invest €29.3m in urgent infrastructure and community supports for people affected by dementia. These asks are particularly vital in view of the profoundly detrimental impact of COVID-19 on people living with dementia and their family caregivers.

Overview of asks

1. €18m investment in Community Day Services

To enable the provision of dementia-specific Day Services to meet the current unmet need and provide capital investment for the provision of future needs.

2. €2.3m investment in Family Carer Support packages

To meet the significant need for practical and emotional support through the provision of carer support groups, counselling services and family carer training.

3. €1m investment in Younger Onset Dementia supports

To provide a suite of patient-led supports that meet the unique and additional needs of people living with younger onset dementia and their families.

4. €6m investment in Dementia Home Care Supports

To provide home care that is dementia appropriate and can meet growing demand.

5. €1.5m investment in Dementia Research

To build capacity for 'Research Readiness' in Ireland for new developments in drug therapies and to support research infrastructure.

6. €500,000 investment in Prevention through Dementia Inclusive Communities

To run a Public Brain Health Campaign focused on the nine modifiable risk factors that could prevent 40% of dementia cases.

Context

Programme for Government: The current 2020 Programme for Government states a commitment to implementing the National Dementia Strategy¹ (NDS) 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 increased prevalence of dementia in Ireland from 54,000 to 64,000², points to a deepening gap between services and need. The need for services is growing, not only among existing service users but also among those who had not previously been in contact with dementia-specific services.

COVID-19 Impact: Research³ by The ASI throughout the COVID-19 pandemic reveals the disproportionate and detrimental impact of COVID-19 and associated restrictions on people with dementia and their families. There is now a greater need than ever for services and supports for this cohort. Findings from over 250 participants include,

- 54% of family carers reported a decline in their mental health and 40% a decline in their physical health.
- 81% of family carers are concerned about a decline in the condition of their loved one with dementia.
- People with dementia and their families continue to experience pervasive loneliness and social isolation. Both people with dementia and family carers cite loneliness as one of their greatest challenges of COVID-19
- 28% of family carer respondents have considered a move to long term care for the person with dementia over the past year. 65% of these say this move is sooner than expected due to COVID-19. 54% are worried about how they will continue to cope.
- People living with dementia urgently require face-to-face services such as day care centres and social clubs while their families are in desperate need of respite and therapeutic services.

Disease-modifying developments: The recent FDA approval of Aducanumab represents the first new therapy with the potential to prevent or slow the progression of dementia in 21 years. With this and other potential therapies and clinical trials on the horizon, there is an acute need to be ‘Research Ready’ and prepared for the impact of these therapies on the dementia landscape in Ireland.

Broad Consultation: The asks set out in this PBS have been informed by a broad and robust consultation with key stakeholders and relevant research and reports,

- *External consultation:* Surveys completed by 300 members of the public, the majority of whom are family carers.
- *Internal consultation* with front-line service staff including Service Managers, Dementia Advisers, Care Workers etc.
- *Internal reports/ evaluations:* Review of internal research reports, including
 - Three ASI research reports exploring the impact of COVID-19 on family carers and people with dementia undertaken between July 2020 and April 2021.

¹ The Irish National Dementia Strategy (2014) The Department of Health, Dublin

² Pierse, T., O’Shea, E. and Carney, P. (2019) ‘Estimates of the prevalence, incidence and severity of dementia in Ireland’, Irish Journal of Psychological Medicine, 36(2), pp.129-137. Available: [https:// doi.org/10.1017/ipm.2018.31](https://doi.org/10.1017/ipm.2018.31).

³ The Alzheimer Society of Ireland (2021), Caring & Coping with Dementia in COVID-19, Dublin

- Internal evaluations of ASI services provided during COVID-19 including social engagement calls and activity packs, Day Services, online Alzheimer Cafes and online Carer Support Groups.
- *External reports:* Review of external reports relating to post-diagnostic supports and care for family carers and people with dementia.

Our Asks

1. Invest in Dementia Specific Community Day Services

- a. **€15m Capital Investment:** to enable 12 urgently needed day centres to re-open. These 12 centres cannot be re-opened post-COVID-19. Existing infrastructural challenges have been exacerbated by the need to introduce or upgrade essential areas such as isolation rooms, adequate hygiene facilities and space for social distancing.

€15m will be required to develop centres in locations listed below. Building costs are derived from tender prices for The ASI Drogheda Day Centre (under construction) and site acquisition costs are excluded:

- Cavan town
- Curlew Road, Dublin
- Merlin Park, Galway
- Castlebar, Mayo
- Bandon, Cork
- Mill Lane, Kildare
- Tymon South, Dublin
- Middleton, Cork
- Castlerea, Roscommon
- Oldcastle, Meath
- Fingal, North Dublin
- Mullingar, Westmeath.

- b. **€3m to restore and increase dementia-specific Day Services** to meet current demand and the severe unmet needs of people with dementia and their families who been deeply impacted by the Pandemic. The existing culture of scarcity in Day Service Centre provision must be addressed by restoring existing services and increasing capacity by one third.

We are seeking an investment of €3,000,000 per year to increase places by 400 per year over the next three years. This would be a total cost of €9,000,000 over 3 years to increase ASI Day Care to a 2,300 spaces.

Rationale:

a. Capital Investment

- Of ASI's 47 day centres providing an essential service pre-Covid, only 10 were owned or leased by the ASI. Among the others, 13 were HSE buildings that were rented, leased or that there was partial

use of, 16 were in community halls or similar and eight in privately rented or local authority buildings.

- The temporary nature of these buildings and the sharing of facilities has given rise to a serious capacity reduction in trying to reopen services. It has proven to be unsustainable.
- These existing infrastructural challenges are now exacerbated by the need to introduce or upgrade essential areas such as isolation rooms, adequate hygiene facilities and space for social distancing.
- The outcome is that 12 Day Centres in Ireland will not reopen leaving people with dementia and their families without a service to attend.

b. Service Provision

- The ASI provides 82% of Ireland's Day Services
- In March 2020, 407 people with dementia were on a waiting list for ASI day services.
- Approximately 5.3% of people with dementia in the community need to access dementia-specific Day Services equating to 2,337 places⁴.
- In March 2020, The ASI had 1,100 places meaning a one-third increase is required to meet existing need.
- The vast majority of clients do not get one full place. Instead, The ASI is forced to allocate fractions of places to provide some level of service to people with dementia and their families (i.e. 80% of clients only receive one to two days per week).

Context:

As Sláintecare and overall Government plans focus on a shift to community-based care and pathways, particularly in light of Covid-19, investment in Day Services is essential to allow us to provide safe, vital services for people living with dementia (and respite for families) to support them to remain at home in their communities.

Day Services have been impacted by infrastructural challenges, even before COVID-19. An Independent Evaluation of The ASI's Day Services⁵ found that centres that share their premises with other groups face particular challenges, including a lack of flexibility to set up the facilities in an optimal manner for the client group concerned and having to set up *de nouveau* each morning. Having only one room for activities and no quiet space are also noted as important challenges.

The gap between need and the actual delivery of services is widening. In 2017, The ASI highlighted that no county in Ireland has a minimum standard of services to meet the needs of people with dementia and family caregivers⁵. The COVID-19 Pandemic has decimated services that were previously available and many of these cannot reopen without adequate investment.

A culture of scarcity has been imposed on dementia-specific day services as providers contend with considerable unmet demand for places, reflected in extensive waiting lists and/or requests for additional hours. This all points to significant growing demand it is essential that Day Services can provide enough places and hours upon reopening to address this.

⁴ Pierce, M., Cullen, K., & Wynne, R. (2020, unpublished). Evaluation of the Role and Contribution of Dementia-specific Day Care Services in the evolving Dementia Care Landscape. The Alzheimer Society of Ireland, Dublin.

⁵ ASI & NDO (2017). Dementia Specific Services in the Community: Mapping Public and Voluntary Services. Available from <https://alzheimer.ie/wp-content/uploads/2019/10/Final-Report-Dementia-Specific-Services-Mapping-Project.pdf>

The above evaluation highlighted the great value placed on these services and the person-centred approach underpinning care. People with dementia attending daycare were very positive, welcoming the opportunities for social interaction and participation in enjoyable activities. Family and other informal caregivers also highly valued the service. These findings are consistent with the results from international research exploring daycare from the perspective of people with dementia (Aggarwal et al., 2003; Brataas et al., 2010; Rokstad et al., 2017) and family caregivers (Gústafsdóttir, 2014; Tretteteig, 2017a; 2017b).

2. Invest in Support Packages for Family Carers

€2.3m is requested to provide a package of practical and emotional supports to Family Carers of people living with dementia who have shouldered a disproportionate workload over the COVID-19 Pandemic. This package will comprise (a) Family Carer Support Groups, (b) Family Carer Training Programmes and (c) Professional Counselling.

- a. 77 Family Carer Support Groups across at a cost of €140K (1 per 1,000 affected at €1,800 per group)
- b. 190 Family Carer Training Programmes at a cost €950K (1 per 500 affected @ €5,000 per programme)
- c. 15,700 hours of Counselling at a cost of €1.26m (100 hours per 1,000 affected at €80 per hour)

Rationale

- The ASI provides 78% of Carer Support Groups and 78% of Dementia Family Carer training Programmes which are currently oversubscribed. For example, in June 2021, 325 people were on a waiting list for family carer training despite a 43% increase in course delivery this year.
- Evidence suggests that participating in psychoeducational interventions, incorporating skills training, peer support programmes, psychological therapies and counselling, has highly positive effects on caregivers of people with dementia^{6 7}.
- Our current health and social care system depend 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.
- The ASI's recent COVID-19 Report highlights the profound impact of the Pandemic and the closure of services of the physical and mental health of family carers and the toll of the caring workload, leading to exhaustion, burnout and despair.

Context:

The ASI's recent COVID Research Report acknowledges that public policy should centre on supporting family carers who are now contending with the aftermath of the burden of the COVID-19 Pandemic. It should be noted that caring in Ireland was associated with poor health outcomes for the family caregiver long before COVID-19⁸. Family caregivers of people with dementia were previously struggling with stress, burnout, health challenges and experiencing immense difficulties accessing appropriate dementia services. The

⁶ O'Shea, E., Keogh, F. and Heneghan, C. (2018) Post-Diagnostic Support for People with Dementia and their Carers. Centre for Economic and Social Research on Dementia, NUI Galway. Available: <https://www.understandtogether.ie/news-and-events/news/Dementia-Post-diagnosticSupport-Literature-Review.pdf>

⁷ Bressan, V., Visintini, C., & Palese, A. (2020). What do family caregivers of people with dementia need? A mixed-method systematic review. *Health & Social Care in the Community*, 28(6), 1942-1960. <https://doi.org/10.1111/hsc.13048>

⁸ Brennan, S., Lawlor, B., Pertl, M.M., O'Sullivan, M., Begley, E. and O'Connell, C., 2017. De-Stress: A study to assess health and well-being of spousal carers of people living with dementia in Ireland. Dublin, Ireland: Alzheimer Society of Ireland.

prevalence of clinical depression for family caregivers of persons with dementia is three times the Irish national average.

The importance of family carers to the overall health and social care system in Ireland cannot be underestimated. An evaluation of Intensive Home Care Packages⁹ found that while these packages are very beneficial for people with dementia, it does not significantly reduce the burden on family carers. Given the high level of burden placed on family carers throughout COVID-19, there is now a greater need than ever to ensure that home care packages are coupled with a set of supports for family carers. The majority of carers are willing to provide care for their loved one with dementia, but they are not able to do this without support.

Significant investment in psycho-educational programmes for carers can also lead to potential economic benefits resulting from fewer people with dementia being admitted to residential care. Evaluations of ASI Services such as Family Carer Training in Advanced Dementia, Online Carer Support Groups and the 1:1 Dementia Nurse Service highlight the positive impact and experience of these types of services for family carers.

3. Invest in Younger Onset Dementia Supports

The ASI calls on the Irish Government to invest €1m to provide a flexible and person-led suite of tailored services to people with younger-onset dementia (YOD) and their families.

This fund will be used to develop and deliver a suite of services and supports designed by and for people with YOD encompassing a range of supports across the trajectory of dementia. This might include YOD specific spaces, hiking clubs, information support (e.g. appointments with financial/legal advisor), family support, counselling etc.

This will be implemented at CHO level with €100,000 provided via each of the nine CHO areas and central coordination at a cost of €100,000.

Rationale

- It is estimated that up to 4,311 people are living with YOD in Ireland (Pierse et al., 2019)¹⁰
- A recent Irish report (2020) commissioned by The National Dementia Office, '*Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways*¹¹' highlights that people with YOD and their family members are significantly disadvantaged in the Irish health and social care system, where there is a dearth of age-appropriate services.
- The report recommends the individual and unique needs and experiences of every person with YOD must be a central consideration from diagnosis, to the timing and planning of post-diagnostic models of supports in the community to long term residential care and to end of life care.

⁹ Keogh, F., Pierce, M., Neylon, K. Fleming, P. Carter, L. O'Neill, S. & O'Shea, E (2018). Supporting Older People with Complex Needs at Home: Report 1: Evaluation of the HSE Intensive Home Care Package Initiative. Available <https://cesrd.ie/wp-content/uploads/2019/11/Supporting-Older-People-with-Complex-Needs-at-Home-Report-1-Evaluation-of-the-HSE-Intensive-Home-Care-Package-Initiative.pdf>

¹⁰ Pierse, T., O'Shea, E. and Carney, P. (2019) 'Estimates of the prevalence, incidence and severity of dementia in Ireland', *Irish Journal of Psychological Medicine*, 36(2), pp.129-137. Available: <https://doi.org/10.1017/ipm.2018.31>.

¹¹ Fox, S. Cahill, S, McGown, R. and Kilty C. (2020) *Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways*. National Dementia Office: Tullamore.

Context

The National Dementia Strategy 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 YOD can be vastly different from older people. Many are still employed in the labour market and have financial and personal responsibilities such as mortgages and young families. It states that people with YOD have greater difficulty fitting into existing dementia service provision, which is generally tailored to the needs of older people.

The Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways identified that there is broad agreement in the research literature that outcome variables of YOD are poorer, both for the person and for their families compared to later-onset dementia. Similarly, the families of people with YOD experience unique challenges and needs that require timely and flexible supports and services. In addition to dedicated dementia models of care, consideration should be given to non-dementia supports that will facilitate people with YOD to live well and to continue their own preferred and usual roles, occupation and interests.

4. Invest €6m in Dementia Home Care Supports

The ASI is calling for an investment of €6m in dementia-specific home care supports to meet existing and growing demand. Home care that is dementia appropriate and offered by home care workers with adequate dementia training is crucially needed.

Rationale

- The investment of 250,000 hours of dementia home support in Budget 2021 has only served a small fraction of need.
- Currently, need is so high that hours are urgently required across Ireland, even in advance of the pilot statutory home care scheme rollout.

Context:

State policy is that older and infirm people should be catered for in the comfort and security of their own homes. The majority of people with dementia want to live at home, in a familiar environment linked to their communities. During the COVID-19 pandemic, the home was deemed the safest place for older people. As we learn to live with COVID-19, admission to the acute system and long-term care must be delayed through the availability of adequate and appropriate community care which should be viewed as an integral part of the health system in itself.

COVID-19 has led to an increased demand for home care. As the number of people with dementia increases, there is an urgent need for substantial investment in-home care services to keep pace with demand. Enactment of the Statutory Home Care Scheme, which is soon to be piloted, will significantly address access to Home Care. The current Programme for Government states a commitment to introducing this. In the meanwhile, additional home care hours are badly needed.

Intensive Home Care Packages have been linked to delayed discharge and offer a flexible and person-centred approach to support people with dementia in their own homes and to remain at home for longer, reducing the need for admission into long-stay residential care¹². However, if home support services are to act as a realistic alternative to long term care or a means of facilitating timely discharge and the avoidance of inappropriate admissions, increased funding for Home Support Services are required to meet existing and growing demand.

¹²Keogh, F., Pierce, M., Neylon, K. Fleming, P. Carter, L. O'Neill, S. & O'Shea, E (2018). Supporting Older People with Complex Needs at Home: Report 2: What Works for People with Dementia? Available <https://cesrd.ie/wp-content/uploads/2019/11/Supporting-Older-People-with-Complex-Needs-at-Home-Report-2-What-Works-for-People-with-Dementia.pdf>

The economic merit of investment in IHCPs should be noted: the average weekly cost of a nursing home bed is c.€1,149 and c. €5,992 for a bed in an acute hospital. In contrast, the average cost of an IHCP for a person with dementia is c. €925 per week with an average of 39 carer work hours¹³.

Indeed, the HSE's aim of introducing IHCPs for people with dementia was to facilitate timely discharge home from acute hospitals and to prevent unnecessary hospital admission. Dementia is common among older people admitted to acute hospitals; about 29% of older people admitted to public hospitals in Ireland have dementia¹⁴. A comprehensive and well-resourced system of community support services, including home care, is necessary to support people with dementia to remain living at home for as long as possible.

4. Invest in Dementia Research

The ASI is calling on the Irish Government to invest €1.5m to support Ireland to be 'Research Ready' for new developments in drug therapies and to support research infrastructure.

The ASI proposes an initial investment of €1.5m for dementia researchers to develop programmes of work that cover key priority areas, to embed a culture of research, evidence-based practice and innovation so that research becomes a critical enabler of dementia prevention, diagnosis and care. Across Ireland, there is an existing network of institutions with expertise in dementia and neurodegenerative disease research and with facilities to undertake dementia research. Similarly, the continued development of Research Infrastructure provided by The ASI will support the research community in these endeavours (i.e. TeamUp For Dementia Research and the Dementia Research Advisory Team).

Rationale:

- Recent and upcoming developments in disease-modifying therapies require research readiness and infrastructure to ensure that services, supports and therapies will be readily available to people with and at risk of dementia.
- Funding is urgently needed to provide a comprehensive and translational research platform to address new developments.

Context

The recent FDA approval of Aduhelm represents the first new therapy for Alzheimer's Disease in 21 years. This is a significant step towards the prevention and treatment of dementia and it should be noted that other potential therapies are on the horizon (e.g. Donanemab, Lecanemab). Considering these recent and upcoming landmark developments, Ireland needs to be 'Research Ready' and funding is required to design and deliver high quality, patient-driven translational dementia research across the spectrum of basic science, prevention, clinical and social research, and help support the development of existing essential ASI research infrastructure.

This includes the recently launched TeamUp For Dementia Research, a new service in collaboration with Dementia Research Network Ireland that aims make research more accessible and to build capacity in Irish dementia research by breaking down barriers to recruitment and participation. Similarly, The ASI has a well-developed PPI initiative led by the Dementia Research Advisory Team. These experts by experience ensure that research is patient-led and relevant to people living with dementia and their families (best practice). Investment

¹³Keogh, F., Pierce, M., Neylon, K., Fleming, P. (2018) Intensive home care packages for people with dementia: a realist evaluation protocol (2018) BMC Health Services Research.

¹⁴ Timmons, S, Manning, E., Barrett., A, Brady, N., Browne., V., O'Shea, E., Molloy DW., (2015) Dementia in older people admitted to hospital: a regional multi-hospital observational study of prevalence, associations and case recognition. Age and Ageing. 2015;44(6):993–999.

recently secured by Dementia Trials Ireland is a significant step in maintaining Ireland's credibility in this area and will help prepare Ireland for undertaking and delivering clinical trials.

Research and innovation is a key focus for the Global Action Plan for Dementia (2017-2025), and given the significant scientific, medical and socioeconomic challenge dementia poses for Ireland, it is vital that we continue to invest in dementia research across the spectrum of basic science, prevention, clinical and social research.

ASI, in partnership with Dementia Research Network Ireland (DRNI), held an extensive consultation in 2019/20 with the research community, clinicians and AHCPs as well as people with dementia and family carers to identify key research priorities that urgently require funding. These include:

- Prevention, Identification, and Reduction of Risk
- Public Awareness and Understanding
- Diagnosis, Biomarker Development, Disease Monitoring

5. Invest in Prevention through a Brain Health campaign

The ASI is requesting an investment of €500k in dementia prevention in the form of a Brain Health Awareness campaign delivered through *Dementia: Understand Together*. It is envisaged that this campaign will focus on the nine modifiable risk factors of dementia.

Rationale

- Modifiable risk factors might prevent or delay up to 40% of dementias¹⁶. We now understand more than ever about ways to prevent dementia but this information is not widely known in the public domain.
- Contributions to the risk and mitigation of dementia begin early and continue throughout life, so it is never too early or too late.
- *Dementia: Understand Together* is optimally placed to develop and implement this campaign through the Dementia Inclusive Communities initiative and in partnership with its four key partners: The HSE, Healthy Ireland, Age Friendly Ireland and The Alzheimer Society of Ireland.

Context

The number of older people, including those living with dementia, is increasing as younger age mortality declines. However, the age-specific incidence of dementia has fallen in many countries, most likely as a result of improvements in education, nutrition, health care, and lifestyle changes. Compelling evidence supports the existence of nine modifiable risk factors for dementia modelled by the 2017 and 2020 *Lancet* Commissions¹⁵ on dementia prevention, intervention and cure. These modifiable risk factors include less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury and air pollution.

There is an onus to implement public health strategies targeting the main lifestyle, clinical, and social risk factors identified in this Commission to reduce the incidence of dementia or substantially delay its onset. Research¹⁶ indicates that there is substantial scope for encouraging positive change in the population by

¹⁵ Livingston G, Sommerlad A, Orgeta V, et al. Dementia Prevention, Intervention, and Care. *Lancet* 2017; 390: 2673–734.

¹⁶ Hickey, D., (2019) The Impact of a National Public Awareness Campaign on Dementia Knowledge and Help-Seeking Intention in Ireland. Available:

<http://dementiapathways.ie/permacache/fdd/cf3/38c/fcb99cb27cdb95a9038a46ee53d89ae7.pdf>

highlighting the potential benefits of early diagnosis and the importance of seeking help if early dementia is suspected.

Dementia: Understand Together aims to develop communities that are dementia inclusive and create awareness of dementia and associated risk factors. It has over 40 partner organisations across retail, transport, banking, health and the community sector and as such as in a key position to focus on this topic as part of its dementia awareness and dementia inclusive community development work.

Conclusion

To conclude, we are calling on The Irish Government can invest €29.3m in these urgent and vital asks to support people living with dementia and their families without delay.

Total €29.3m

- 1. Invest €18m in Community Day Services**
- 2. Invest €2.3m in Family Carer Support packages**
- 3. Invest €1m in Younger Onset Dementia supports**
- 4. Invest €6m in Home Care Supports**
- 5. Invest €1.5m in Dementia Research**
- 6. Invest €500k in Dementia Inclusive Communities brain health campaign**