



All-Party **Oireachtas Group**
on **Dementia**

The All-Party Oireachtas Group on Dementia Budget Proposals **July 2018**

Over the last year a diverse group of TDs and Senators from all parties and none have been actively working together to enhance the lives of people with dementia and their carers. Members have heard first hand from people with dementia and family carers and we have heard evidence from leading academics, frontline workers, the National Dementia Office, Department of Health officials and others. All of this has helped to inform and shape our second Budget Submission.

The All-Party Oireachtas Group on Dementia recognise that there is a pressing and pertinent need to mainstream funding for dementia services, and that such funding should be ring fenced on an annual basis. This urgency of this need has been highlighted by Minister Jim Daly who at the recent launch of the mid-term review of the National Dementia Strategy¹, affirmed dementia as *"the single greatest challenge facing society"* and *"a condition that affects more and more families across the country."*

We are advising the Government that the following should be prioritised in the forthcoming budget:

1. €7.415m to address the community service gap
2. Investment in Post Diagnostic Supports:
 - €1.4 for Dementia Advisers: Increase from 9 posts to 20 posts as at €70,000 full cost per post
3. €1m for Regional Centers of Excellence for people with Down syndrome and dementia
4. €6m for dementia home care, moving towards €30m by 2021

There are currently 55,000 people with dementia in Ireland. This is expected to rise dramatically to 68,216 by 2021 and 132,828 by 2041². Now is the time to begin investing in services and technology that will support people living with dementia and their carers and save money in the long run. These services and supports should be made available to all people with dementia including the 4,000 people under 65.

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

² Ibid

1. €7.415m to Invest in Community Service Gap

A recent 2018 report entitled, *Dementia Specific Services in the Community: Mapping Public and Voluntary Services*³, collaboratively developed by the HSE and ASI, identifies gaps in existing dementia service provision. This Mapping report indicates significant geographical inequity across all counties in terms of availability of dementia services.

The All-Party Oireachtas Group on Dementia is of the view that there should be parity of access to dementia services in all counties and CHOs. Geographical equity and consistency in service provision needs to be addressed so that people with dementia and their carers can equitably access person-centred dementia care from the services, including Alzheimer cafes, DA services, support groups, social clubs, family carer programmes, counselling services and cognitive therapy programmes. **The All-Party Oireachtas Group on Dementia proposes investment of €7.415m to start to bridge the acute discrepancy between existing available services and services required in order to achieve geographical equity and ensure a minimum standard dementia care is available for all. This investment should be made over a three year time frame.**

2. Post diagnostic supports

€1.4m for Dementia Advisers: Post Diagnostic Supports

On our study trip to Scotland in 2017 we saw first-hand people's entitlement to and the positive impact of the national 'Link Workers' network. Dementia Advisers signpost people to services and provide much needed support, training and information to families and communities. **The All-Party Oireachtas Group on Dementia is calling for an increase in the number of Dementia Advisers from 9 to 20 Dementia Advisers in Budget 2019 at a total cost of €1.4m or €70,000 per post. This increased funding should grow in each annual budget thereafter to 90 posts over a five year period, to achieve one for each primary care network, by mid-2023.**

Note: The cost of €70,000 includes salary and associated costs, employer costs and expenses including travel expenses and is in line with current post costs.

3. €1m for Regional Centres of Excellence for people with Down syndrome and Dementia

People with Down syndrome are at a much higher risk of developing dementia and an estimated 700 people with dementia and Down syndrome live at home with aging parents. Professor Mary McCarron who presented to our group in 2017 estimated that 88% of people with Down syndrome will develop dementia compared to 7% of the general population. At the moment Ireland is not prepared for the challenge this poses. The National Dementia Strategy recognised that there is a need for special consideration for people with Down syndrome due to the increased risk, and that targeted screening for this population would be useful. **The All-Party Oireachtas Group on Dementia recommends that funding of €1m should be provided to begin establishing Regional Centres of Excellence with trained and experienced staff to complete assessments and to offer advice and support to people with Down syndrome living with dementia and their family**

³ Department of Health (2018) *Dementia Specific Services in the Community: Mapping Public and Voluntary Services*.

members, as well as providing supports to allied healthcare professionals and medical professionals in the region.

4. €6m for Dementia Home Care: Progressive increase towards €30m by 2022

The Department of Health acknowledges that home care supports can be a preferred and cost-effective alternative to long-term residential care for some older people. The majority of people with dementia want to live at home, in a familiar environment linked to their communities⁴. Limited funding and access has been provided under the National Dementia Strategy for Intensive Home Care Packages for people with dementia. An additional €6m must be invested in dementia home care in Budget 2018, moving towards €30m by 2021.

This funding must be ring-fenced and there must be equality of access, with Intensive Home Care Packages being made available to people with dementia under the age of 65. To ensure such equality of access, the HSE should be required to report on a quarterly basis the number of people under the age of 65 who are in receipt of an Intensive Home Care Package. **The All-Party Oireachtas Group on Dementia proposes an additional investment of €6m in Budget 2019 to enable the HSE to expand the number of Intensive Home Care Packages. This increased funding should be matched in Budget 2020, Budget 2021 and Budget 2022 to reach at least €30m for dementia home care.**

APPENDIX 1

Dementia specific services mapping data. See attachment.

⁴Meeting Older People's Preference for Care: Policy, But What About Practice?, (2016) IASW, Age Action, ASI and UCD