PRE-BUDGET SUBMISSION 2016

Our Future. Our Choice.

Demand Change in Dementia Care

The Irish health and social care system is failing to provide adequate support to people with dementia and their family carers.

We are asking for your support to ensure Government enables people with dementia to live well at home for as long as possible by implementing these key recommendations:

STAYING AT HOME AS A FIRST OPTION

- 1. Focus investment on community long-term care
- **2.** Fund the equitable provision of intensive dementia-specific care beyond 8 pilot sites to all Local Health Office (LHO) areas at a cost of €30.2m
- Increase funding to The Alzheimer Society of Ireland by €2.1m per annum to cover 75% of total costs

PROMOTING INDEPENDENCE AT HOME

- 4. Fund a national Dementia Adviser service at a cost of €1.56m
- Fund and resource a dementia case worker to cover each LHO area at a cost of €1.92m



Staying at Home as a First Option

RECOMMENDATIONS

1.

Focus investment on community long-term care

2.

Fund the equitable provision of intensive dementia-specific care beyond 8 pilot sites to all Local Health Office (LHO) areas at a cost of €30.2m

<u>3.</u>

Increase funding to The Alzheimer

Society of Ireland by €2.1m per annum
to cover 75% of total costs

"My Dad had dementia and a lot of the carers coming into our home did not have dementia-specific training. The carers that came in from the ASI had been trained in dementia care. When they were with Dad, I felt more relaxed knowing that they knew how to communicate and engage with him. There needs to be more knowledge and understanding of dementia within the carer profession"

Family Carer

People with dementia must be supported to remain at home for as long as possible. 63% of people with dementia live in the community and investment in long-term care should reflect this reality. Nursing home care should only be considered when a person requires a high level of care and not as a result of inadequate community supports.

Dementia-specific home care consists of personcentred, consistent and continuous care, provided by dementia trained staff and in partnership with the person with dementia and their family carer, while promoting independence and inclusion. By empowering the person with dementia and their family members, appropriate home care helps to avoid crises and delays admission to institutional care¹. A difficulty with the current model of generic home care is that it is often task oriented, with high volume contracts and generic measurement of quality. This approach has the potential of creating unnecessary dependence, and further increasing the challenges people face when living with the condition².

In 2014 the The Alzheimer Society of Ireland (ASI) provided over 1 million hours of care to approximately 9,500 people with dementia. However, in the last seven years the ASI has experienced a proportionate decrease in funding from the HSE. In 2008, the HSE grant covered 74.5% of our services and in 2014 this grant covered just 67%. Based on our 2014 accounts a further €2.1m³ is required to reach 75% of total costs enabling us to meet a growing demand, to continue to expand our service geographically, as well as adapt our services to meet the changing needs of people with dementia post-diagnosis.

¹Alzheimer Scotland Delivering integrated Dementia Care: The 8 Pillars model of Community Support. Downloaded from: http://www.alzscot.org/assets/0000/4613/FULL_REPORT_8_Pillars_Model_of_Community_Support.pdf.

²Ibid.

³Government funding (HSE Grant and CE Scheme) totalled €13.6m in 2014. This equated to 65% of income for the year.

Promoting Independence

RECOMMENDATIONS

4.

Fund a national Dementia Adviser service at a cost of €1.56m

5.

Fund and resource a dementia case
worker to cover each LHO area
at a cost of €1.92m

Dementia Advisers play a vital role in efficient dementia care in the community by sign-posting people to relevant services and supports. An evaluation of the Dementia Adviser service in the UK found that the service enabled people with dementia and carers to reframe their lives, finding meaning, value and purpose⁴. The Alzheimer Society of Ireland has eight Dementia Advisers providing a highly responsive and individualised information and signposting service to 1,760 people each year. If this service was extended to each county in Ireland, it could reach 12% of the total population of people with dementia at a total cost of €1.56m. This equates to €271 per person, a relatively low cost intervention.

One of the National Dementia Strategy priority actions is for a primary care worker to play a key role in coordinating the care of each person with dementia and promoting their continuity of care. However, this priority action did not receive any financial provision under the Strategy. This could now be achieved through an investment of €1.92m into a case management approach. Positive evidence outlines the effectiveness of this approach, as it reduces the likelihood of institutionalisation by 18% and improves symptoms of depression in carers⁵. It also reduces the person's use of other community services⁶.



⁴Clarke et al (2014) The National Evaluation of Peer Support Networks and Dementia Advisers in implementation of the National Dementia Strategy for England. Department of Health Policy Research. Downloaded from: https://www.gov.uk/government/up-loads/system/uploads/attachment_data/file/246406/Demonstrator_Sites_Evaluation_-_Final_Report_Master.pdf.
⁵Ibid.

⁶Zabalegui et al (2014) Best Practice Interventions to Improve Quality Care of People with Dementia Living at Home. *Patient Education and Counselling* 95: 175-184.

Dementia is one of the most significant health and social care challenges facing Ireland today.



Dementia is an umbrella term that describes a range of progressive conditions which cause changes and damage to the brain. The scale and profound impact of dementia should not be underestimated. It is a life changing condition both for the person and for their families. Age is the main risk factor for dementia and as a result, the population of those living with dementia will grow exponentially over the coming years. If current trends continue there will be 132,000 people with dementia by 2041⁷.

KEY FACTS ABOUT DEMENTIA

- 48,000 people are living with dementia in Ireland
- The majority of people living with dementia are women⁸
- One in three people aged over 65 will develop dementia9
- The majority (63%) of people with dementia live at home
- There are an estimated 4,000 people aged under 65 in Ireland living with younger onset dementia
- It's estimated that half of people never receive a diagnosis¹⁰
- There are an estimated 50,000 dementia family carers in Ireland

The Alzheimer Society of Ireland works across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their carers. Our vision is an Ireland where no one goes through dementia alone and where policies and services respond appropriately to the person with dementia and their carers, at the times they need support. As a national non-profit organisation, we are person centred, rights-based and grassroots led with the voice of the person with dementia and their carer at its core.

¹⁰Alzheimer Europe (2015).

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https://twitter.com/alzheimersocirl

Alzheimer National Helpline 1800 341 341



Pierce, M. Cahill, S. and O'Shea (2014) Prevalence and Projections of Dementia in Ireland 2011 – 2046. Genio. Downloaded from: http://www.genio.ie/system/files/publications/Dementia Prevalence 2011 2046.pdf.

⁹Trépel, D. (2015) An Economic Analysis of Home Care Services for People with Dementia. Expert Policy Paper independently prepared for the ASI.