PRE-BUDGET SUBMISSION 2016

June 2015
**Introduction**

Dementia is one of the most significant health and social care challenges facing Ireland today. We must not underestimate its scale and the profound impact it has on both the person with the condition and their family members. The population of people with dementia will grow exponentially over the coming years; age being the main risk factor. If current trends continue there will be 132,000 people living with dementia by 2041 (see appendix 1).

We need to plan, not only to ensure those living with dementia now have appropriate supports and interventions that can maintain and enhance their lives, we need to put in place structures to ensure those who develop dementia in the future are not met by the current system which is characterised by poor rates of diagnosis, low levels of post-diagnostic support, patchy and inequitable provision of care and a society that pushes them to the margins.

**What we are asking for**

In the first year since the publication of Ireland’s National Dementia Strategy we are calling on Government to take meaningful action on dementia in Budget 2016 enabling people to live well at home for as long as possible.

A way to achieve this is to enable people to stay at home and to promote their independence while they are there. We have six recommendations which fall under these two themes:

**Theme 1: Staying at home as a first option**

1. Focus investment on community rather than institutional 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.
3. Increase funding to the Alzheimer Society of Ireland by €2.1m per annum to cover 75% of total costs.

**Theme 2: Promoting independence at home**

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.

The remainder of this submission provides the evidence-base for these recommendations.

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2. Alzheimer Europe (2015) *Dementia in Europe Yearbook 2014* – Related to all of Europe as there are no figures on rates of diagnosis for Ireland. The consensus here is that receiving a timely diagnosis is the exception rather than the rule (Cahill et al, 2012).
Theme 1: Staying at home as a first option

The people with dementia and their family members who we work with regularly express a desire for care, when it is needed, to be delivered at home. They acknowledge that there are times when residential care is the most appropriate care option, however with 63% of people with dementia living at home they feel strongly that Government is not doing enough to support people with dementia to remain living at home for as long as possible.

1.1 Recommendation: Focus investment on community rather than institutional long-term care

Consecutive government policies have stated that a national priority is to support people to age at home (Care for the Aged Report, 1968; Years Ahead Report, 1988). This was reiterated in the National Positive Ageing Strategy published in 2013 which outlines a commitment to “enable people to age with confidence, security and dignity in their own homes and communities for as long as possible” (page 31). Broader health policy (Future Health; A Strategic Framework for Reform of the Health Service 2012-2015) outlines a commitment to care for more people in their homes for as long as possible. Despite these policy commitments, in recent years we have not seen an investment in community care to meet the growing demand.

Recent Department of Health (April, 2015) investment into long-term care solutions was severely weighted towards institutional care aimed at facilitating more rapid discharge from hospital and to alleviate the A&E crisis, for example:

- €44m was allocated for the Nursing Homes Support Scheme, providing an additional 1,600 long-term care places.
- €30m was allocated to cover the cost of additional transitional care beds (temporary contract beds) and additional community, convalescence and district hospital beds on a permanent basis.

Measures taken previously to this in Budget 2015 were also aimed at long-term residential care:

- €10m providing an additional 300 places under the Nursing Homes Support Scheme.
- €8m to provide access to an additional 115 short-stay beds across the Dublin area.

In comparison to this investment a smaller sum of €5m was given to provide 400 additional Home Care Packages and €2m to expand the community intervention team (CIT) services in primary care across Dublin and the surrounding region.

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We feel strongly that the Government must meet its stated policy objective to support people to live at home for as long as possible and for them to think strategically about the funding of long-term-care, with appropriate weighting of investment to long-term community based care services.

1.2 Recommendation: 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.

A difficulty with the current model of generic home care provision is that it is often task oriented, with high volume contracts and generic quality indicators. Taking a task orientated approach has the potential of creating unnecessary dependence among people with dementia; opportunities to maintain function in activities of daily living can become lost as a result, exacerbating the symptoms of the condition. This is particularly important given loss of independence is correlated with the highest change in demand for home care (Wübker et al, 2014).  

Flexible dementia specific home care has the potential to facilitate resilience and promote independence; continuing to empower the person with dementia and their family members to remain in control throughout the duration of the illness – thus helping to avoid crises and assisting in delaying the need for admission to institutional care (Alzheimer Scotland, 2013). This type of home care is crucial given the broad and often diverse range of symptoms experienced by people with dementia and their ever changing care needs as the condition progresses. Particularly important as receiving an inappropriate service can exacerbate the challenge of living with dementia (Alzheimer Scotland, 2012). In addition, it is perceived by service users, carers and care workers to deliver better quality care than standard services (Rothera et al, 2008).

Recent investment by Atlantic Philanthropies (see appendix 1), the Department of Health and the HSE (€22.7m) is being used to fund intensive home care packages for people with dementia linked to the hospital discharge crisis. However, the provision has only been sufficient to service eight areas – North Dublin, Dublin North City, Dublin South West, Dublin South East, Cork City, Waterford, Limerick and Galway. The rationale given by the HSE and the Department of Health for investing in these sites is to alleviate pressure on acute hospitals, as a support measure around delayed discharge.

While this investment is welcome and the first of its kind, it has limitations. The money will meet the needs of 500 people with dementia across three years; when the prevalence rate of dementia is currently 48,000 people.

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7 Ibid
8 Ibid
9 Ibid.
In addition, the selection of sites was determined by the acute hospital crisis. We feel a more holistic approach to the long-term care infrastructure for people with dementia is required and these intensive home care packages should be extended to all LHO regions available to people living in the community and not only to those in acute settings. Based on Department of Health costings for these pilot sites this would require an annual investment of €30.2m for dementia-specialist intensive home care packages.

1.3 Recommendation: Increase funding to the Alzheimer Society of Ireland by €2.1m per annum to cover 75% of total costs.

The Alzheimer Society of Ireland (ASI) is the main provider of dementia-specific supports, including day and home care, social clubs, Alzheimer cafes, cognitive stimulation therapy, dementia advisers, family carer training, a national helpline, carers support groups etc. In 2014 we provided just over 1 million hours of care to approximately 9,500 people with dementia. This is 20% of the total population of people currently living with dementia in Ireland.

We have already seen an increase in demand for services in recent years due in part to the increased number of people living with dementia and to greater awareness of the condition among the general population. Under the National Dementia Strategy the Government has committed to undertake a national dementia awareness campaign in 2015 and 2016. A successful campaign will create even greater demand for appropriate, quality supports.

We have experienced a proportionate decrease in funding from the HSE over the last seven years. In 2008, the HSE grant covered 74.5% of our services and in 2014 this grant covered just 67%. We are making every effort to meet the demand, taking a client-focused approach, expanding our services geographically as well as extending our services to meet the changing needs of the person throughout the whole journey. For example, in the last year we have focused on meeting the needs of people with dementia post diagnosis with the development of a dementia adviser service and the delivery of cognitive stimulation therapy. Meeting this growing demand will not be possible without additional funding to sustain quality services; an increase in funding to cover 75% of costs is required. Based on our 2014 accounts this equates to a €2.1m increase.

Theme 2: Promoting Independence at Home

Support to the person with dementia to manage their condition should start as early as possible. A first step to achieving this is timely diagnosis; a stated objective of the National Dementia Strategy (2014). Evidence shows that people prefer to know their diagnosis to enable them to access appropriate supports and treatment and to plan for the future (Ilife et al, 2009)\textsuperscript{13}. However, in the absence of a cure, it has been reported that there is a professional belief that nothing can be done and this has contributed to delays in diagnosis (Ilife et al, 2009)\textsuperscript{14}.

Through the implementation of the National Dementia Strategy steps are being taken to address this as funding has been made available for GP training and awareness. This investment is expected to increase rates of

\textsuperscript{12} Government funding (HSE Grant and CE Scheme) totalled €13.6m in 2014. This equated to 65% of income for the year.


\textsuperscript{14} Ibid
diagnosis. Also in the strategy is the statement that ‘local well-coordinated support services are needed to assist people and their families to cope with the choices and dilemmas confronting them at this often distressing and challenging time’ (page 21). However, no funding has been made available to support the person to adapt to their life-changing condition post diagnosis.

Post-diagnostic support includes not only traditional methods of care but also additional interventions that help to maintain the person’s independence. This is important as already stated losing independence is correlated with the highest change in demand for home care (Wübker et al, 2014)\(^\text{15}\). An emphasis of Government health spending must be on these types of interventions.

2.1 Recommendation: Fund a national dementia adviser service at a cost of €1.56m

Information is power

Something people with dementia and carers say time and time again is that information is critical, especially at the point of diagnosis. A recently published report by Alzheimer Europe (2014)\(^\text{16}\) states that the provision of high-quality information is essential for helping the individual adjust to the life-changing diagnosis of dementia and to facilitate access to adequate supports and services. They quote numerous research studies showing the important role of post-diagnostic information, including how a lack of information or information received in a “haphazard” fashion may hinder access to relevant services (Brodaty et al., 2005)\(^\text{17}\). Research shows that people living with dementia would welcome more information about available supports in their local communities (Georges et al., 2008\(^\text{18}\); Innes, Szymczynska and Starket 2014\(^\text{19}\); Robinson et al., 2009\(^\text{20}\)).

Dementia Advisers play a pivotal role in efficient dementia care in the community by sign-posting to the relevant services and supports available. Their role is to work with individuals and their families, giving information and advice in a timely manner, directing people to appropriate agencies and supporting them throughout their Journey (de Siún, 2013\(^\text{21}\)).

An evaluation of the Dementia Adviser service in the UK undertaken by Clarke et al (2013)\(^\text{22}\) found that this service had a significant role in enabling people with dementia and carers to re-narrate their lives, finding a new life which, though different from life prior to dementia, had meaning, value and purpose.

The ASI currently has eight dementia advisers operating across the country working with people with dementia, their families and carers to provide a highly responsive and individualised information and signposting service.

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\(^\text{15}\) Ibid


This or a similar service should be available to anyone with dementia that needs it and should be provided across each county. The eight advisers currently deliver a service to 1,760 people with dementia/carers of someone with dementia per annum. If this service was extended to each county it could reach 12% of the total population of people with dementia at a total cost of €1.56m - €271 per person, a relatively low cost intervention.

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

Case management to close the ‘caring gap’

In 2015 the ASI commissioned an expert policy paper, An Economic Analysis of Home Care Services for People with Dementia, independently prepared for the ASI by Dominic Trépel, PhD, Health Economist with the University of York. Trépel (2015\(^{23}\)) reports that the dynamics of home care services are commonly poorly coordinated. He identified case management and collaborative care as important factors to improve overall societal welfare. By addressing sources of inefficiency in dementia care, this analysis recommends investment into home care services that also address system level effects.

Trépel (2015\(^{24}\)) argues that, while substantial benefits exist by remaining in one’s own homes, community care is less structured to enable this and may require focused effort to organise. He maintains that this gap could be tackled by addressing the system-level inefficiency related to the care of people with dementia. Collaborative care monitors and co-ordinates the range of care providers involved in dementia care (e.g. family carers, public, private and voluntary care providers).

There is positive evidence also to show the effectiveness of a case management approach – case management reduces the likelihood of institutionalisation by 18% and improves symptoms of depression in carers (O’Reilly et al, 2015)\(^{25}\). It also reduces the person’s use of other community services (Zabalegui et al, 2014)\(^{26}\). It provides for a collaborative management plan while systematically scheduling health and social care follow-ups and enhancing communication and supervision.

The National Dementia Strategy outlines a priority action within primary care services of a worker to play a key role in coordinating the care of each person with dementia and promoting their continuity of care (page 15). However, this priority action did not receive any financial provision. The ASI feels it is of paramount importance that this ‘case management’ role is implemented but to enable appropriate reach the role should cover each LHO area at an annual cost of €1.92m.


\(^{24}\) Ibid


Who we are

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.

What is dementia?

Dementia is an umbrella term used to describe a range of conditions which result in changes and damage to the brain. These conditions are characterised by progressive cognitive decline which can affect not only memory but communication, functional ability and behaviour.

The most common form of dementia is Alzheimer’s disease, with lesser common causes as a result of vascular dementia, mixed Alzheimer’s and vascular dementia, Dementia with Lewy bodies, frontotemporal dementia among others.

Dementia is a progressive condition with no guaranteed trajectory. As a result the experience will differ from person to person and their care needs will change overtime.

The level of disability associated with dementia has significant implications for the person, their families and the health and social care system (IPH, 2015)\textsuperscript{27}. It is recognized as the leading chronic disease contributor to disability among older people; cognitive impairment and dementia making the largest contribution to need for care, much more so than other types of impairment and other chronic diseases (World Health Organisation, 2015)\textsuperscript{28}.


Appendix 1:

Table 1: Estimates of number of people with dementia in Ireland

<table>
<thead>
<tr>
<th>Age Group</th>
<th>2011</th>
<th>2016</th>
<th>2021</th>
<th>2026</th>
<th>2031</th>
<th>2036</th>
<th>2041</th>
<th>2046</th>
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<tbody>
<tr>
<td>30 – 59</td>
<td>2,866</td>
<td>2,935</td>
<td>2,934</td>
<td>2,869</td>
<td>2,854</td>
<td>2,864</td>
<td>2,889</td>
<td>2,991</td>
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<tr>
<td>60 – 64</td>
<td>1,200</td>
<td>1,301</td>
<td>1,449</td>
<td>1,615</td>
<td>1,738</td>
<td>1,906</td>
<td>2,044</td>
<td>1,896</td>
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<tr>
<td>65 – 69</td>
<td>2,776</td>
<td>3,287</td>
<td>3,827</td>
<td>4,020</td>
<td>4,485</td>
<td>4,876</td>
<td>5,315</td>
<td>5,645</td>
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<tr>
<td>70 – 74</td>
<td>4,604</td>
<td>5,532</td>
<td>7,013</td>
<td>7,442</td>
<td>8,367</td>
<td>9,378</td>
<td>10,211</td>
<td>11,188</td>
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<tr>
<td>75 – 79</td>
<td>7,475</td>
<td>8,213</td>
<td>11,298</td>
<td>12,560</td>
<td>14,055</td>
<td>15,928</td>
<td>17,968</td>
<td>19,692</td>
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<tr>
<td>80 – 84</td>
<td>10,958</td>
<td>12,265</td>
<td>16,099</td>
<td>17,868</td>
<td>22,348</td>
<td>25,364</td>
<td>29,102</td>
<td>33,196</td>
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<tr>
<td>85+</td>
<td>17,970</td>
<td>21,260</td>
<td>25,595</td>
<td>31,085</td>
<td>40,195</td>
<td>52,512</td>
<td>64,654</td>
<td>77,549</td>
</tr>
<tr>
<td>Total</td>
<td>47,849</td>
<td>54,793</td>
<td>68,216</td>
<td>77,460</td>
<td>94,042</td>
<td>112,828</td>
<td>132,182</td>
<td>152,157</td>
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Appendix 2:

FINANCIAL INVESTMENT TO IMPLEMENT THE NATIONAL DEMENTIA STRATEGY

<table>
<thead>
<tr>
<th></th>
<th>Total €</th>
<th>HSE/DOH €</th>
<th>AP €</th>
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</thead>
<tbody>
<tr>
<td>Leadership/oversight – secretariat &amp; evaluation</td>
<td>1.5</td>
<td>1.35</td>
<td>0.15</td>
</tr>
<tr>
<td>Intensive home care support</td>
<td>22.1</td>
<td>12.8</td>
<td>9.3</td>
</tr>
<tr>
<td>(a) dementia homecare package</td>
<td>20.5</td>
<td>12.0</td>
<td>8.5</td>
</tr>
<tr>
<td>(b) Genio</td>
<td>1.6</td>
<td>0.8</td>
<td>0.8</td>
</tr>
<tr>
<td>GP activation</td>
<td>1.2</td>
<td>0.6</td>
<td>0.6</td>
</tr>
<tr>
<td>Stigma, information and promoting inclusion</td>
<td>2.7</td>
<td>0.75</td>
<td>1.95</td>
</tr>
<tr>
<td>Total</td>
<td>27.5</td>
<td>15.5</td>
<td>12.0</td>
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