



THE ALZHEIMER
SOCIETY *of* IRELAND

Pre-Budget Submission 2011

Making dementia a national health priority

2011 funding for the Alzheimer Society of Ireland services and developments

This submission outlines the investment that the Alzheimer Society of Ireland needs to maintain its service levels in 2011. The Alzheimer Society of Ireland fully recognises the challenges of the current economic situation. However, it is imperative that services to current service users of the Alzheimer Society of Ireland are sustained, that waiting lists are cleared and that each service user with dementia receives a minimum package of service as outlined. The Alzheimer Society of Ireland is calling on government to respond to the needs of these vulnerable groups and protect basic levels of service to them by:

- 1 Protecting current community services provided by the Alzheimer Society of Ireland nationally** – funding requirement (€14.61m – i.e. HSE €12.25m and CE €2.36m). This will help sustain the basic level provision of 4 hrs day care service per week / 2 days day care service per week, plus carer support groups, social clubs for carers and persons with dementia and the Alzheimer National Helpline to current service users.
- 2 Extending current levels of services to the 1,000 people on waiting lists nationally** – funding requirement €4.6m. This could be achieved quickly and cost effectively by The Alzheimer Society of Ireland if funding was made available.
- 3 Ensuring the 4,400 younger people with dementia**, who currently have little or no support structures or services, have a regional Case Management Service (i.e. 4 x case managers) to assist post-diagnosis in accessing entitlements, services and information – funding requirement €350k.
- 4 Promoting risk reduction** and prevention of dementia in the general public, through public health campaigning in order to delay the onset of dementia – funding requirement €250k.

Therefore, the total package of funding needed by the Alzheimer Society of Ireland in 2011 is €19.81m.

The Alzheimer Society of Ireland

The Alzheimer Society of Ireland fully recognises the challenges of the current economic situation and its impact on the state and its citizens. However, we are acutely aware of the increasing numbers of people affected by dementia, their growing health and social care needs and the cost to the state if waiting lists are not cleared.

The Alzheimer Society of Ireland is the **national leader in providing dementia-specific supports and services**, comprising a network of 16 branches, 3,500 volunteers, 700 staff and **115 specialist services** – such as home care, day care, overnight respite, family carer training, support groups and the National Alzheimer Helpline.

By the end of 2010, the Alzheimer Society of Ireland will have provided an estimated **800,000 hours of community-based care** despite absorbing **€850k cuts** in HSE funding and a projected decrease in fundraising income. The 'cuts' were absorbed by implementing pay reductions throughout the organisation (based on the public sector pay cut model). Given the national context, this action was the most appropriate way to absorb the reduced state contribution. However, if further cuts are extended in 2011 the organisation will not be able to maintain the integrity of the service. **It will mean direct cuts to services and job losses and ultimately costing the state more.**

For every €18,500 cut from existing HSE funding levels, four service users and their carers will lose their service AND one job will be lost.

The average number of hours provided to users of the Alzheimer Society's **home care service is 4 hours per service user per week**. Users of our day care services receive an average of **two days day care service per week**. Waiting lists for Alzheimer Society of Ireland services have increased by 33% (to 1,000) in the last year and this trend is expected to continue. For every person affected by dementia there is significant impact on one family carer and up to three family members.

Carers are reaching crisis point. A recent national survey of family carers found that two in three carers are caring alone for more than 12 hours per day, and 3 in 4 reported feeling stressed and overwhelmed on a regular basis. In addition, almost 45% of family carers have had to stop, or significantly reduce their hours of work, in order to care for their loved one. (Survey carried out by the Alzheimer Society of Ireland April 2010.)

The waiting list – the cost of doing nothing

There are 1,000 people on waiting lists nationally, an increase of 33 % on last year. For an additional investment of €4.6m the organisation has the capability of clearing that waiting list in a very short timeframe. What will happen if this waiting list is not addressed in the next year? We estimate that approximately one third of the carers will no longer be able to care, due to excessive carer burden, and the 300 people with dementia being cared for by them would be admitted to long term care or will

experience repeated admissions to A&E/acute care. Apart from the fact that both acute care and/or long-term care are inappropriate for this group at the moderate stages of the condition, there is also the massive costs of meeting their needs if the family carer is absent. **We calculate that it would cost the state in the region of €12m* in 2011 to provide residential care services. So the costs of doing nothing are extremely high for this group currently on our waiting lists.**

* Based on average cost of €40k p.a. for a nursing home bed (Nursing Home Ireland)



Summary of essential investment required in 2011

Core service developments

Funding 2011

Providing current levels of care to service users:

Maintaining the current level of Alzheimer Society of Ireland services to existing service users with dementia and their families (i.e. providing 4 hours home care/ 2 days of day care per week, carer support groups, social clubs, National Helpline etc.).

(CE) **€2,360,000**

(HSE) **€12,250,000**

A further **€4.6m** is needed to extend the current level of service to clear waiting lists (i.e. to provide 4 hours home care × 731 or 2 days of day care per week × 263 on Alzheimer Society waiting lists).

€4,600,000

Investing **€350k** for a **pilot community intervention** specifically for early interventions for younger people with dementia (i.e. those who are under 65) who currently have no services – 4 × specialist case managers.

€350,000

Total revenue required for core service provision:

€19,560,000

Project specific development

Investing **€250k** in a **prevention and risk reduction** public awareness and education campaign to create understanding of reducing the risk of developing dementia.*

€250,000

Total required funding

Total investment required for 2011

€19,810,000

* Delaying onset by 5 years means a 50% reduction in new cases per annum which would result in significant savings in health care spending. (Alzheimer's Australia, Delaying the Onset of AD, 2004)

Impact of dementia 2010



Impact of dementia 2026



By investing in the Alzheimer Society of Ireland, the state is getting proportionally more for its spend and excellent value for money.

The investment from the state to provide services (currently 69% costs) in turn, enables the organisation to lever significant additional resources from philanthropy organisations, grant making bodies, EU and direct fundraising. After sustained effort in 2010, this additional funding is expected to reach €4.5m (i.e. 23% returns on state investment). The Alzheimer Society will strive to sustain this level

of additional funding in 2011; however we believe this to be a highly optimistic outlook given the current economic climate and constraints.

In addition, we attract over 3,000 fundraising and awareness volunteers to work on our behalf throughout the country. Another 500 volunteers actively commit time to care provision in our professionally led services. If the state's funding is reduced, it will in turn reduce our capacity to lever additional funds and bring down the added value of volunteer time in care provision and fundraising. An erosion of either will ultimately cost the state.

Background information

Dementia

Dementia is an umbrella term for a group of conditions that cause brain cells to die; Alzheimer's disease is the most common form of dementia. It is a condition that has a life changing physical, emotional and mental impact on the affected person and their primary carer and family. It is characterised by progressive (and almost always) irreversible decline in mental functioning. The progression of dementia can often be a slow, gradual process and as a result the person can often live independently and with dignity in the community, with the support of appropriate, person-centred services. Dementia is largely, but not exclusively, a condition of older age; it is not a part of normal ageing.

Some key statistics

- Currently there are approximately **44,000 people with dementia** in Ireland; in 2026 there will be 70,115; in 2036 there will be 103,998.
- **Every year 4,000 people** approximately develop Alzheimer's disease or dementia.
- There are **50,000 carers** of people with dementia symptoms; the numbers of lives impacted upon by dementia is several multiples of this when you consider the effect on the wider family.
- Approximately **1 in 10 people with dementia are under 65 years** and are therefore unable to access any appropriate supports and services. Currently dementia services are funded through, and designed as, older persons' services.
- The baseline cost of dementia in Ireland is estimated at €400m; estimates suggest that the **family care contribution to this cost is 57%** (76% if family care is valued using substitution labour costs); in sharp contrast, only 6% of the cost of dementia is attributable to community care services.
- Demographic trends, health and social care cost and disease burden mean that dementia must become a health priority like cancer and heart care.

The Alzheimer Society of Ireland

The Alzheimer Society of Ireland was set up in 1982 by family carers to meet the support and service needs of family caregivers and the person with the condition. Our vision is to promote a world free of Alzheimer's disease/dementia and ensure that those with the condition and their carers occupy their rightful place in society, are respected, understood and enjoy fulfilling lives. The mission of the Alzheimer Society of Ireland is to advocate the rights and meet the needs of people with Alzheimer's/dementia and their carers. The core values of the organisation are to always be person-centred, rights-based, grassroots and learning-led.

The main supports and services provided by the Alzheimer Society of Ireland include:

- Dementia specific day care (incl. transport)
- Dementia specific home respite care
- Overnight dementia respite care
- Social clubs for people with dementia and carers together
- Family carer training
- Carer support groups
- Public awareness raising
- Advocacy, information and advice
- National Freephone Helpline Service

Prioritising dementia – a national strategy

There are compelling economic and social arguments to recognise and **designate dementia as a National Health Priority and to develop a national strategy** without delay. A national dementia strategy would enable the formulation of a strategic and fully co-ordinated response to meet the needs of people with dementia and their carers. The Alzheimer Society believes that a **specific budget line for dementia services** is essential in order to prioritise dementia as a key public health issue.



Alzheimer National Helpline 1800 341 341

The Alzheimer Society of Ireland
Temple Road, Blackrock
Co Dublin, Ireland

Tel 01 207 3800
Email info@alzheimier.ie
Website www.alzheimer.ie