



THE ALZHEIMER
SOCIETY *of* IRELAND

Making Dementia a Political Priority

The Alzheimer Society of Ireland Submission to Political Parties on their General Election Manifestos

April 2015



Election 2016: Make Dementia a Political Priority

The Alzheimer Society of Ireland is asking all parties and public representatives to commit to making dementia a political priority and to pledge their support for the following actions:

1. Commit to the implementation of the National Dementia Strategy.
2. Provide ring-fenced funding for dementia.
3. Develop a follow-up strategy for dementia based on the review of the current strategy.
4. Ensure every person with dementia that requires home care has access to dementia specific care in their home.
5. Ensure that everyone with dementia has access to a timely diagnosis and appropriate post-diagnosis support including, but not limited to, a dementia adviser as a minimum standard of follow-up support.

Planning Effectively for the Growing Number of People with Dementia

Actions	Timeframe
1. Commit to the implementation of the National Dementia Strategy.	Immediately
2. Provide ring-fenced funding for dementia.	First year of Government
3. Develop a follow-up strategy for dementia based on the review of the current strategy.	End of second year

As our population ages the number of people with dementia will increase. In response to ongoing calls for Government action, in December 2014, the Government published Ireland's first ever National Dementia Strategy¹ (NDS). When implemented, the strategy has the potential to change the lives of people living with dementia in Ireland with the implementation of its six priority areas². To make this a reality, the NDS must be implemented and must be positioned as a political priority in any Programme for Government.

Implementation would be a first step in bringing about systemic change, that is changing societal attitudes to dementia and influencing frontline practice within large systems including Primary and Community Care, Mental Health, Hospital and Long-Term Care. It will mean improved rates of diagnosis³ and improved pathways to enable people to access care.

¹ Several countries including England, France, Norway, the Netherlands, Sweden and Australia have now well developed strategies, some indeed are on their second and third iterations.

² These six areas include: Better Awareness and Understanding of Dementia; Timely Diagnosis and Intervention; Integrated Services, Supports and Care for People with Dementia and their Carers; Training and Education; Research and Information Systems; Leadership.

³ The rate of dementia diagnosis in Ireland is unknown as we do not have a dementia register and a national prevalence study has never been undertaken. However, like many European countries dementia is largely invisible and undiagnosed (Cahill et al, 2012).

The National Dementia Strategy states that the Department of Health will conduct a mid-term review of progress in 2016. The findings from this mid-term review must then be utilised to develop a revised dementia strategy. This makes absolute political sense. Cahill et al (2012) highlight the fact that dementia continues to lag behind other chronic diseases in terms of budget allocation in most countries and in the share of resources devoted to research on the topic, particularly relative to the disease burden. The review of the National Dementia Strategy should be accompanied by ring-fenced funding for dementia as the initial joint investment by Atlantic Philanthropies and the Government has a limited lifespan. Longer-term thinking and investment is required.

Dementia-Specific Care at Home

Actions	Timeframe
4. Ensure every person with dementia that requires home care has access to dementia specific care in their home.	First one hundred days

Dementia-specific home care consists of person-centred, consistent and continuous care, dementia trained staff and partnership with the person with dementia and their family carer, while promoting independence and inclusion.

We strongly believe that the recent problems experienced in relation to delayed hospital discharge and issues accessing the Nursing Home Support Scheme could be addressed through the development of an appropriate community care response. The current lack of support and provision for people with dementia in the community must be addressed; **ensuring people can live well in the community** and making this a priority issue.

The majority of people with dementia, over 63%, live in the community. The majority wish to continue to live at home as a first option⁴. Our current health and social care system depends largely on family carers who provide the main bulk of care; its estimated value to the State is in the region of €807 million per annum. Government must support carers to ensure that they can continue to care. Carers have indicated that there are indirect costs to Government associated with stress related to care-giving, especially when providing care without adequate supports. These include costs related to carer's personal health, employment and wider social engagement.

Research has found that the two strongest predictors of admission to care homes are whether the older person has dementia and whether or not their family carer is coping (Jacobs et al, 2009⁵). There is evidence that specialist home care services for people with dementia can reduce the likelihood of requiring or delaying entry into long-term care (Riordan and Bennett, 1998⁶; Andrew et al 2000⁷). In our experience providing services for over 30 years in the community, we have found that dementia-specific home care⁸ is a critical component to ensuring that people with dementia can live in the community. The Alzheimer Society of Ireland (ASI) plays a large role in the delivery of

⁴ Quince, Chris (2011) *Support, Stay, Save: Care and support of people with dementia in their own homes*. Alzheimer's Society, UK.

⁵ Jacobs et al. (2009) Modernising Social care Services for Older People. *Ageing and Society*, 29(4): 497-538.

⁶ Riordan and Bennet (1998) An Evaluation of an Augmented Domiciliary Service to Older People with Dementia and their Carers. *Ageing and Mental Health* 2(2): 137-143.

⁷ Andrew et al (2000) Outcome of Referral to Social Services Departments for People with Cognitive Impairment. *International Journal of Geriatric Psychiatry* 15: 404-414.

⁸ There are specific practices associated with dementia specific home care that ensure a flexible and responsive approach to care provision that meets the person's needs in a more meaningful way with improved outcomes for them. For example, ensuring that a person is linked with the same care worker can avoid a person with dementia being unnecessarily confused by a succession of formal carers coming into their home. This type of support also enables carers to care for longer (Riordan and Bennet, 1998⁸).

dementia-specific home care whereby a trained dementia care worker is assigned to a person with dementia in the community for a designated number of hours per week.

People with dementia can have complex and changing needs. Therefore, in addition to dementia-specific care, there needs to be a focused and co-ordinated approach to dementia care that can bring the range of supports⁹ needed by people with dementia and their carers together. Timely diagnosis and appropriate care pathways are key actions in the National Dementia Strategy. A multi-disciplinary case-management approach to dementia makes sense and has the potential to ensure an adequate response to dementia at a primary care level and in the community.

Timely Diagnosis and Post-Diagnosis Support

Actions	Timeframe
5. Ensure that everyone with dementia has access to a timely diagnosis and appropriate post-diagnosis support including, but not limited to, a dementia adviser as a minimum standard of follow-up support.	First year of Government

With the right information and support, people can live well with dementia. Timely diagnosis is identified internationally as best practice however a shockingly large proportion of people remain undiagnosed. Cahill et al (2012)¹⁰ state that across most European countries, including Ireland, dementia remains largely invisible and under-diagnosed (Bamford et al., 2004; Carpenter and Dave, 2004; Leifer, 2003; Lopponen et al., 2003; Wilkins et al., 2007). This finding is across all care settings from the community, to acute care and in nursing homes. Rates of diagnosis in Ireland are likely to be comparative to rates in the UK where it is estimated that less than half of those with dementia have a diagnosis (Alzheimer’s society UK¹¹). Without a diagnosis a person cannot get the information they need, access timely supports and interventions, or make decisions about their future care. We believe that it is every person’s right to receive a proper and timely assessment.

We regularly hear from those with dementia and from their carers about the lack of support they received following their diagnosis. Community-based dementia advisers are a valuable early intervention for people living with dementia, their family and carers and help promote dementia awareness in their communities. They also provide dementia training and education, information and referrals, and assist with home management strategies. Since July 2014, ASI has funded seven dementia advisers who cover specific parts of the country. But this is nowhere near enough. We need a comprehensive dementia adviser network in each region that serves as an access point and capacity builder across the various services.

⁹ The National Dementia Strategy (2014: 25) recognises that public health nurses, community mental health nurses and intellectual disability nurses, home helps, occupational therapists, social workers, physiotherapists, speech and language therapists, pharmacists, day care services, a range of respite services (including in home and residential, elective and emergency), meals-on-wheels and home care packages all have an important part to play in supporting people with dementia to remain viably and safely in their own homes for longer.

¹⁰ Op.cit.

¹¹ Download here: <http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200346>

Why Dementia Requires Government Action

Improving dementia services is an essential part of political and social reform in Ireland. The quality of dementia services has a major impact on us all. Over 63% of people with dementia live in the community, and people living in nursing homes are also part of the community; it is therefore a **major constituency issue and it must be a political priority**. The Programme for Government must include a specific reference to Government action and investment on dementia.

Strategic action and investment in dementia makes political sense. Strategic action and investment in dementia must be a part of any Programme for Government.

Dementia itself is an umbrella term which describes a range of progressive conditions which cause changes to the brain. These changes can affect memory, thinking, language and a person's ability to perform everyday tasks. Each individual's experience of dementia is different, dependent on the type of dementia they have, the stage of dementia they are in and factors relating to their personality, their social and psychological responses, their support networks and the physical environment in which they live. Dementia has a physical, psychological, social and economic impact not only on the person affected, but also their carers, families and broader society. Dementia is **one of the most serious social challenges facing the world today** (WHO, 2012¹²).

Much is happening across the globe to address dementia. For instance around Europe considerable progress is being made in mobilising joint action on dementia and in the development of a European Initiative on Dementia (European Commission, 2009 in Cahill et al, 2012: 21¹³). In 2012, the World Health Organisation and Alzheimer's Disease International jointly issued a report explaining that dementia must be treated as a global public health priority because dementia affects more than 35 million people worldwide and this number is expected to almost double every 20 years as populations undergo rapid and nearly universal ageing. Since then, dementia has been positioned as a priority issue on the global stage with the G8 (now G7) Dementia Summit held in London in 2013¹⁴ and subsequent establishment of the World Dementia Envoy and World Dementia Council.

The World Health Organisation hosted the first ever Ministerial Conference on Global Action Against Dementia in Geneva in March 2015. A Global Dementia Framework was established as part of this conference, allowing countries and organisations to promote their work and to identify other organisations, nations and regions they can collaborate with¹⁵.

At home, the publication of the National Dementia Strategy (NDS) in December 2014 was a long overdue development in dementia policy in Ireland. **The incoming Government must build on this initiative and continue to mobilise public support and public resources on dementia**, so people living in Ireland who have dementia now and in the future can benefit from the growing global momentum to tackle the condition.

¹² WHO and Alzheimer Disease International (2012) Dementia: A Public Health Priority. Downloaded from: http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf

¹³ Op. cit.

¹⁴ G8 Dementia Summit Declaration is available here: <https://www.gov.uk/government/publications/g8-dementia-summit-agreements/g8-dementia-summit-declaration>

¹⁵ The Global Dementia Framework is available here: <https://globaldementiaframework.wordpress.com/>

About The Alzheimer Society of Ireland

The Alzheimer Society of Ireland is the leading dementia specific service provider in Ireland.

We work 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 our core.

Key facts on dementia

- There are 47,744¹⁶ people currently living with dementia in Ireland.
- If current trends continue this number is expected to rise to 68,216 by 2021 and 132,828 by 2041¹⁷.
- It's estimated that 4,000¹⁸ people develop dementia each year.
- The majority of people living with dementia are women - 30,359 women and 17,385 men.
- A significant proportion of people with dementia are aged under 65, an estimated 4,066¹⁹ people, many of whom are in their 30's and 40's.
- Nearly two thirds (63%²⁰) of people with dementia live at home in the community.
- There are 50,000²¹ family carers in Ireland providing care to someone with dementia.
- People with dementia are one of the main users of health and social care services e.g. 25%²² of hospital admissions are people with dementia; 63%²³ of people in long-term care have dementia.
- The annual cost of dementia is in the region of €1.69²⁴ billion per annum.
- The average annual cost per person with dementia is €40,500²⁵.

¹⁶ Department of Health (2014) *The Irish National Dementia Strategy*. <http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>

¹⁷ Ibid.

¹⁸ Cahill, S. O'Shea, E. Pierce, M. (2012) *Excellence in Dementia Care*. TCD and NUIG.

¹⁹ Pierce, M. Cahill, S. and O'Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland*.

²⁰ Pierce, M. Cahill, S. and O'Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland*.

²¹ Cahill, S. O'Shea, E. and Pierce, M. (2012) *Excellence in Dementia Care*. TCD and NUIG.

²² Ibid.

²³ Ibid.

²⁴ Ibid.

²⁵ Ibid.

Estimated number of persons with dementia in Ireland by county and province, 2011

(Pierce, M. Cahill, S. and O'Shea E. 2014. Prevalence and Projections of Dementia in Ireland)

Province	County	Population (all ages)	Persons with dementia	% of total county/province population
Leinster	Carlow	54,612	543	0.99%
	Dublin	1,273,069	12,498	0.98%
	Kildare	210,312	1,453	0.69%
	Kilkenny	95,419	1,057	1.11%
	Laois	80,559	711	0.88%
	Longford	39,000	434	1.11%
	Louth	122,897	1,198	0.97%
	Meath	184,135	1,400	0.76%
	Offaly	76,687	790	1.03%
	Westmeath	86,164	904	1.05%
	Wexford	145,320	1,524	1.05%
	Wicklow	136,640	1,274	0.93%
	Total (Leinster)	2,504,814	23,786	0.95%
	Munster	Clare	117,196	1,282
Cork		519,032	5,425	1.05%
Kerry		145,502	1,848	1.27%
Limerick		191,809	2,013	1.05%
North Tipperary		70,322	848	1.21%
South Tipperary		88,432	1,054	1.19%
Waterford		113,795	1,276	1.12%
Total (Munster)		1,246,088	13,746	1.10%
Connacht	Galway	250,653	2,683	1.07%
	Leitrim	31,798	441	1.39%
	Mayo	130,638	1,835	1.40%
	Roscommon	64,065	893	1.39%
	Sligo	65,393	857	1.31%
	Total (Connaught)	542,547	6,709	1.24%
Ulster (part of)	Cavan	73,183	851	1.16%
	Monaghan	60,483	700	1.16%
	Donegal	161,137	1,929	1.20%
	Total (Ulster part of)	294,803	3,480	1.18%