



THE ALZHEIMER
SOCIETY *of* IRELAND

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

October 2019



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, with while the remainder live in nursing homes, they 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 economic sense. Dementia places significant costs on society: The total direct and informal care costs for dementia are estimated at €2 billion per annum in Ireland¹. Internationally, it has been estimated that the total health and social care costs for dementia exceed cancer, stroke and heart disease combined, making it Ireland's most expensive disease².

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

General Election Manifesto 2019

The Alzheimer Society of Ireland (ASI) 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 implementation of the National Dementia Strategy (NDS) and its priority actions.
2. Ensure every person with dementia has access to dementia appropriate care in their home and community through the statutory home care scheme.
3. Integrate dementia into the Chronic Disease Management Programme.

¹ Connolly, S., Gillespie, P., O'Shea, E., Cahill, S. & Pierce, M. (2014). Estimating the economic and social costs of dementia in Ireland. *Dementia*, 13(1), 5-22.

²Luengo-Fernandez, R., Leal, J., Grey, A. (2015). UK research spend in 2008 and 2012: comparing stroke, cancer, coronary heart disease and dementia *BMJ Open*.

Action
1. Commit to the continued implementation of the National Dementia Strategy.

As our population ages the number of people with dementia will increase. The number of people with dementia in Ireland is estimated to be 55,266³, and by 2036, the number of people with dementia in the country will have doubled to 115,426. In response to ongoing calls for Government action, in December 2014, the Government published Ireland’s first ever NDS⁴. 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 areas⁵. To make this a reality, the NDS must be implemented and must be positioned as a political priority in any Programme for Government.

Funding To-Date

The 2018 report *Mid-Term Review of the Implementation of the National Dementia Strategy*, acknowledges the need for a dedicated budget for dementia service development. While acknowledging the initial resources provided to dementia care by Atlantic (€12.5 million), and the Department (€15 million) it should be understood in the context that persons with dementia who attend day care services will have directly funded some of their costs of care by €10 million between 2014 and 2018, and fundraising from voluntary sources to the ASI alone will have provided approximately €14 million over the same period.

It is of concern that Atlantic funding has now come to an end, and ASI believe it is crucial that additional Government funding is provided to meet urgent need in a sustainable way. **The incoming Government must build on past initiatives 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, outlined further below, to tackle the condition.

The NDS Review acknowledges that significant resources will be required to implement the diagnostic and post-diagnostic supports pathways being developed by the NDO. Reliance on Dormant Account funding is simply not sufficient or sustainable in the long-term and dedicated and committed long-term funding is necessary. The pace of investment and implementation is frustrating for people living with dementia and their families, as they are forced to deal with insufficient services and supports.

Mapping of Need

A report entitled, *Dementia Specific Services in the Community: Mapping Public and Voluntary Services*, has been collaboratively developed by the HSE and ASI. This Mapping data identifies gaps in existing dementia service provision and shows that investment in crucial elements of the NDS has

³ O’Shea, E., Cahill, S., and Pierce, M., (2018) *Developing and Implementing Dementia Policy in Ireland*. National University of Ireland Galway.

⁴ Several countries including England, Scotland, France, Norway, the Netherlands, Sweden and Australia have now well-developed strategies, some indeed are on their second and third iterations.

⁵ 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.

been insufficient overall. The ASI calls on Government to expand and develop community supports and local service gaps thereby addressing acute gaps highlighted in the Mapping report. The NDS Review acknowledges that addressing these service gaps will require a strategic approach to dementia service development at a regional level, and potentially additional resources in terms of infrastructure, funding and staffing if community-based services are to be developed in a way that meets the needs of people with dementia and their families.

The Mapping data presents an opportunity for the systematic development of new services in line with identified local need. By drawing on the evidence of the Mapping exercise to develop services at a local and national level, we can direct time, energy and resources into a constructive model of dementia care and dementia service development that is coherent and geographically consistent and equitable across the country.

The NDS recognises that a social and clinical response is required and that dementia cuts across many areas of provision. It emphasises the need for a ‘whole community response’ to dementia, with health and social care services as only one part of the package of supports that people with dementia need. Communities are key to ensuring that staying at home with dementia is a feasible option, and the following services are vital to securing this:

Dementia Advisers

At ASI we regularly hear from those with dementia and their carers about the lack of support they received following their diagnosis. Community-based Dementia Advisers (DAs) are a valuable early intervention for people living with dementia, their family and carers and help promote dementia awareness in their communities. DAs play a pivotal role in efficient dementia care in the community by sign-posting families to relevant services and supports available. Their role is to work with individuals and their families, giving information and support in a timely manner, directing people to appropriate agencies and supporting them throughout their journey. The ASI’s DA service has recently been independently evaluated, commissioned by the NDO in 2018⁶. The main advantageous characteristics reported of the service included support, reassurance, local knowledge and the link to national organisations.

While Budget 2020 provides for 10 DAs in addition to the existing 9 posts, the details of these positions are not yet clear, and we do not know, for example, if these are part- or full-time posts. Data from the Mapping project indicates significant gaps in DAs services across all counties, showing that there were a total of 12 counties and parts of counties, which did not have a DA service. DA investment should be sustained and developed further over time. The ASI’s awareness initiatives, specifically Dementia Inclusive Community projects along with the HSE’s Dementia Understand Together campaign, have resulted in increased demand for DAs and there is currently a waiting list for DA services in many areas. ASI is seeking to ensure continued investment in the DA service to provide a full time service across all 26 counties.

⁶ Coffey, A., Cornally, N., Hegarty, J., O’Caoimh, R., O’Reilly, P., O’Loughlin, C., Drennan, J., Clarke, C., Hartigan, I (2018). *Evaluation of The Alzheimer Society of Ireland Dementia Adviser Service*. Available at [file:///C:/Users/brock/Downloads/Dementia%20Advisor%20Evaluation%20Report%20Sept%2018%20\(4\).pdf](file:///C:/Users/brock/Downloads/Dementia%20Advisor%20Evaluation%20Report%20Sept%2018%20(4).pdf)

Dementia Key Workers

Dementia Key Workers (DKWs) are of paramount importance to coordinating the care of each person with dementia and promoting a collaborative management plan for individual dementia care. DKWs differ from the role of a DA in that the former monitors and coordinates individual cases/caseload through the health and social care system, whereas the DA is concerned with signposting and advisory services. While a need for the DKW role has been identified in the NDS, this role has yet to be implemented and funded. This role would help to co-ordinate individual care plans and assist people to navigate complex care pathways, and would be critical in supporting and facilitating an integrated approach to dementia care.

Dementia Inclusive Communities

Dementia Inclusive Communities (DICs) is a vital component of the NDS, and in 2018, the ASI in partnership with the HSE, NDO, Healthy Ireland and Genio sought to develop and implement the Community Activation component. Unfortunately, this investment has relied on Dormant Accounts funding, an unsustainable source of funding. The mission of DICs is to grow a social movement to create understanding and inclusive communities where people with dementia and their families are respected, supported and connected. Community Activation is an element of the Dementia Understand Together campaign aimed at creating awareness of dementia and associated risk factors, encouraging businesses and organisations to sign up to support the campaign, and setting out clear signposting and pathways through HSE and health services, and community supports.

The Mapping report indicates that majority of the 44 dementia friendly activities reported were located in Dublin. The low number of dementia friendly activities identified in the Mapping project highlights the patchy and inequitable availability of DIC resources, and the need for substantive investment to meet the needs of people with dementia in all counties. Coordinators are required to develop Dementia Inclusive Communities to ensure social understanding and supports enable people with dementia to live well and compliment any existing health and social service provision. To-date dormant accounts investment in the existing Coordinator has already created 250 community champions and 40 partner organisations who are at the heart of this campaign. These champions heighten awareness of dementia through information meetings and community talks, and have inspired other community members to be involved. Over 40 organisations are partnering with the campaign, taking a variety of actions to raise awareness, be inclusive and support a person with dementia. For the continued roll-out of the Community Activation and to ensure its longevity and sustainability, investing in DICs is critical.

Dementia Registry

There is some commitment to improving and increasing the evidence we have on dementia in Ireland. In May 2018 a project, funded by Dormant Accounts via the Department of Health and the National Dementia Office (HSE), commenced to develop a model for a National Dementia Registry in Ireland. This follows on from the 2016 report, *A National Dementia Registry for Ireland*, commissioned by the ASI, which provided much needed information on the feasibility of developing a dementia registry. The NDO is currently funding the development and testing of the registry model through Dormant Accounts of €200,000. However, the implementation of the registry will need to be further resourced and it is not clear how it will be resourced. Reliance on Dormant Accounts funding is not sustainable or appropriate, considering the importance of this registry, which will be

key to providing comprehensive data to facilitate planning of services, and will support service providers, clinicians and researchers.

Sláintecare

The 2017 Sláintecare Report acknowledges that *“Under the current health and social care system, people with dementia and their carers face serious barriers in equity of access and outcomes from the point of diagnosis to end of life”*. However, it is of concern that Sláintecare does not include dementia as an issue to be addressed in its proposals for increased emphasis on health promotion and proposed suggestions on tackling health inequalities. The Health Reform Alliance, of which the ASI is a founding and current executive member brings together voices to call for reform of Ireland’s health and social care system, seeking health and social care that treats everyone equally, and that is focused on the needs of all social groups in society.

Dementia-Appropriate Care at Home

Actions
2. Ensure every person with dementia has access to dementia specific care in their home and community through the statutory home care scheme

Budget 2020 provides an increase of one million home help hours from the 18 million home help hours currently provided to 19 million hours. Notwithstanding, appropriate care at home for people with dementia is crucial and requires further Government response. Communities are key to ensuring that staying at home with dementia is a feasible option. The majority wish to continue to live at home as a first option. The ASI plays a large role in the delivery of dementia-appropriate 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, and in our experience providing services for over 30 years in the community, we have found that dementia-appropriate home care⁷ is a critical component to ensuring that people with dementia can live in the community.

The development of a statutory home care scheme is currently being negotiated, and is expected to be in place within 2 years. The ASI has supported and contributed to the consultation process, and called for dementia-appropriate home care, consisting 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. In addition, ASI has also contributed to home care discussions through its membership of the Home Care Coalition. We are concerned that since this consultation closed in October 2017, there has been no further opportunity to input, as promised, and no update about where this process is at and relevant developments. Additionally, there are concerns that delays around the implementation of Sláintecare might delay development and establishment of the scheme. **Developing this new statutory scheme must be prioritised and every effort must be made to progress this matter without delay and within the 2021 deadline.**

⁷ 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, 1998⁷).

The NDS included funding of €22.1m for the delivery of Intensive Home Care Packages (IHCPs) for people with dementia. These packages have been linked to delayed discharge, implemented initially to solve problems in the acute hospital system. NDS funding for the delivery of home care for people with dementia has come to an end, and an evaluation of the IHCP initiative has been completed in 2019. The evaluation shows that IHCPs are more feasible for supporting people with dementia, at home for significant periods of time and indicate:

- IHCPs represent a valuable addition to home care as part of a continuum of care based on need, ranging from low levels of support to the relatively high levels seen in the IHCPs. If we want to support older people to remain at home as their needs increase, significant hours of care, as provided by the IHCP are required, but they are effective in keeping the person at home.
- The provision of IHCPs for people with complex needs, such as dementia, has been effective in a variety of circumstances; in urban and rural settings; for people with maximum and high dependency levels; for people with little or no family or informal care; and for people who were at the end of life.
- The average weekly cost of the IHCPs was €925 for dementia-IHCPs. At this rate, all IHCPs, even the most expensive, were more cost effective than acute care.

There is a need for greater investment in IHCPs, and IHCPs should be included in the statutory home care scheme. This is a crucial component of care for people with dementia as it meets their complex and changing needs. To date, the protracted pace of investment and implementation of home care and community-based support is of serious concern.

There is strong evidence that innovative, low level, flexible strategies to support people with dementia at home, particularly those in early to mid-stages, can be hugely impactful in keeping people living well in their community. ASI's 2019 policy position paper, *Dementia and Loneliness*⁸, emphasises how public support and social provisions play a germane role in enabling families to manage living life with dementia. By the same token, however, the difficulties of securing these supports were a source of anxiety, frustration, and loneliness for people with dementia. Living with dementia means there is a longer care continuum, requiring low levels of social care and support in the earlier stages and requiring high levels of care in the latter stages.

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. 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 (Knapp et al, 2016⁹). Adequate support of carers is crucial in supporting the person with dementia, as highlighted in the De-Stress study (Brennan et al., 2017)¹⁰, which was part-funded by the ASI. The 2017 De-Stress study of carer well-being indicates that 76% of carers experienced mild to severe levels of burden, defined as stress associated with caring. Stress related to care-giving can directly impact on the carer's personal health, employment and wider social engagement. Family carers need to be viewed and included as partners in the care of the person with dementia, working with formal care providers.

⁸ Dementia and Loneliness (2019) Published by The Alzheimer Society of Ireland https://alzheimer.ie/wp-content/uploads/2019/01/ASI_PP_DementiaLoneliness.pdf

⁹ Knapp, M., Chua, K., Broadbent, M., (2016) *Predictors of care home and hospital admissions and their costs for older people with Alzheimer's disease*. BMJ Open 2016;6: e013591.

¹⁰ Brennan, S. Lawlor, B. Pertl, M. O'Sullivan, M. Begley, E. O'Connell, C. (2017) *De-Stress: A Study to assess the health and wellbeing of spousal carers of people with dementia in Ireland*. Trinity College Dublin/Alzheimer Society of Ireland.

Dementia in the Chronic Disease Management Programme

Actions
3. Integrate dementia into the Chronic Disease Management Programme

The NDS states that dementia policy, service delivery and development should be guided by the principles of Chronic Disease Management Programme as set out by the Department of Health (2014). Ireland's chronic disease policy framework addresses the challenges of chronic disease so as to reduce the burden for individuals, their carers and the health system. The Framework for Management of Chronic Disease, which underlines the importance of intersectoral activities for risk factors and prevention, addresses the management of chronic disease at different levels through a reorientation towards primary care and the provision of integrated health services that are focused on prevention and a better quality of life. Currently however, dementia does not form part of the Chronic Disease Management Programme.

ASI is exploring the case for inclusion of dementia in the chronic disease framework, and this body of evidence will be completed in early 2020. Evidence from other jurisdictions shows that incentivisation and resourcing of chronic disease management can lead to health promotion, proactive care and better outcome measures. Categorising dementia as a chronic illness could improve access to and quality of GP care for people with dementia. For example, one of the current challenges in dementia care is that GPs are unable to give appropriate time and attention to proactively manage dementia. But as a chronic disease, this issue could be addressed as people with dementia would receive better planned and structured care at a primary level.

ASI is seeking the inclusion of dementia in Chronic Disease Management Programme as a means of improving quality of integrated and planned care in an appropriate setting, supporting people with dementia and their carers and reducing cost burden. ASI is of the view that a strategic approach to dementia care within the health care system needs to include an integrated and multi-disciplinary response by community services, primary care and secondary care to support people with dementia and their carers. Home care support and Dementia Advisers (DAs), as mentioned below, need to be allied closely with primary, secondary and long-term care and have a strong working relationship within HSE structures, whilst a 'whole community' approach mobilises support and understanding for dementia care.

What is Dementia

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:

- Dementia affects 50 million people worldwide, with a new case of dementia occurring somewhere in the world every 3 seconds.
- Approximately 50 million people worldwide have dementia.
- Dementia is now the 7th leading cause of death.
- Dementia can also affect individuals under the age of 65 (young onset dementia).

Key Facts on Dementia

- There are 55,266¹¹ people currently living with dementia in Ireland.
- If current trends continue this number is expected to rise to 115,426 by 2036¹².
- It's estimated that 7,752¹³ people develop dementia each year.
- The majority of people living with dementia are women - 30,359 women and 17,385¹⁴ men.
- A significant proportion of people with dementia are aged under 65, an estimated 4,066¹⁵ people, many of whom are in their 30's and 40's.
- Nearly two thirds (63%¹⁶) of people with dementia live at home in the community.
- There are 50,000¹⁷ 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%¹⁸ of hospital admissions are people with dementia; 63%¹⁹ of people in long-term care have dementia.
- The annual cost of dementia is in the region of €1.69²⁰ billion per annum. It has been estimated that the total health and social care costs for dementia exceed stroke, cancer and heart disease combined, making it Ireland's most expensive disease.
- The average annual cost per person with dementia is €40,500²¹.
- The Mapping report shows that the ASI provides 68% of dementia-specific services in communities across Ireland. A total of 314 dementia-specific community-based services

¹¹ O'Shea, E., Cahill, S., and Pierce, M., (2018) *Developing and Implementing Dementia Policy in Ireland*. National University of Ireland Galway.

¹² Pierce, M. Cahill, S. and O'Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland*.

¹³ O'Shea, E., Cahill, S., and Pierce, M., (2018) *Developing and Implementing Dementia Policy in Ireland*. National University of Ireland Galway.

¹⁴ Pierce, M. Cahill, S. and O'Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland*.

¹⁵ Pierce, M. Cahill, S. and O'Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland*.

¹⁶ Pierce, M. Cahill, S. and O'Shea, E. (2014) *Prevalence and Projections of Dementia in Ireland*.

¹⁷ Cahill, S. O'Shea, E. and Pierce, M. (2012) *Excellence in Dementia Care*. TCD and NUIG.

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ Connolly, S., Gillespie, P., O'Shea, E., Cahill, S. and Pierce, M., 2014. Estimating the economic and social costs of dementia in Ireland. *Dementia* (London, England), 13(1), pp. 5-22.

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

were identified across the Republic of Ireland in the Mapping project.

- The Mapping report clearly demonstrates that there is significant geographical inequity in relation to dementia service provision, which presents unique challenges in terms of accessing and providing services within rural communities.

Global Developments

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* and the launch of the *2nd Joint Action on Dementia in 2016*. The Global Action Plan on the Public Health Response to Dementia 2017-2025 was adopted by WHO Member States at the 70th World Health Assembly in May 2017. The plan follows 10 years of advocacy for a global response to dementia by Alzheimer's Disease International and people living with dementia worldwide. Seven key areas of the plan include dementia treatment and research, improving awareness, dementia friendliness, risk reduction, information and care and support.

In 2017 the Global Dementia Observatory (GDO) was launched by WHO. This data and knowledge exchange platform offers easy access to key dementia data from Member States across the domains of policies, service delivery, and information and research. The GDO supports countries in measuring progress on dementia actions outlined in the Global Action Plan and assists them in strengthening policies, service planning and health and social care systems for dementia.

The Organisation for Economic Cooperation and Development (OECD) Health Division has an ongoing programme of work to support countries in developing long-term care systems that can meet the needs of their populations now and in the future. The OECD is striving to help countries develop better policies to improve the lives of people living with dementia. It is working to develop comparable measures of the quality of care that people with dementia receive, and these measures are currently being piloted with OECD countries.

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 people on the journey of dementia are valued and supported.

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.

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	1.09%
	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%