



THE ALZHEIMER  
SOCIETY *of* IRELAND

**Submission to SAGE on the Long Term Care Forum**

***February 2015***



## **1. Introduction**

There is a significant and rising number of people currently living with dementia in Ireland; approximately 48,000 individuals<sup>1</sup>. If current trends continue this will increase to 68,216 people by 2021 and to 132,000 people by 2041 (Cahill, S. & Pierce, M, 2013<sup>2</sup>). There is not a community in Ireland unaffected by dementia as the vast majority of people live at home (63%<sup>3</sup>).

Although the main proportion of people who have dementia are over 65 years, as age is the main risk factor, there is a significant group aged under 65, an estimated 4,000 people, many of whom are in their 30's and 40's.

The ASI is the leading dementia specific service provider and dementia advocacy organisation 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 family 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.

A national non-profit organisation, The ASI is person centred, rights-based and grassroots led with the voice of the person with dementia and their carer at its core.

The ASI also operates the Alzheimer National Helpline offering information and support to anyone affected by dementia at 1800 341 341.

## **2. Long-term care and dementia**

The Alzheimer Society of Ireland (ASI) welcomes the opportunity to input into the Forum on Long-Term Care.

ASI welcomes the wider definition of long term care proposed in the consultation call, which broadens the discussion beyond nursing home care and recognises the support within one's home and wider community as part of a long-term care model . Given that 63% of people with dementia live in the community, it is imperative that long term care supports and services are available to ensure that people can live well in their place of choice on a long-term basis.

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<sup>1</sup> Department of Health (2014) National Dementia Strategy. Download from: <http://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>

Pierce, M. Cahill, S and O'Shea, E. (2014) Prevalence and Projections of Dementia in Ireland, 2011-2-46 [http://www.genio.ie/system/files/publications/Dementia\\_Prevalence\\_2011\\_2046.pdf](http://www.genio.ie/system/files/publications/Dementia_Prevalence_2011_2046.pdf)

<sup>3</sup> Ibid.

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. There is also a commitment within the National Dementia Strategy (2014) to support people with dementia to live at home. Despite these policy commitments, in recent years we have not seen an investment in community care to meet the growing demand. This lack of resources and supports for people in their homes means that long-term care is now almost synonymous with nursing home care.

The people with dementia and their family members who the ASI regularly works with, express a desire for dementia specific care, when it is needed, to be delivered at home. Sustaining people with dementia at home also makes rational economic sense. For example, European analysis of average costs in dementia care deduced that *institutional long-term care* costs €4,491 per month compared to €2,491 for aggregate costs from *home care*; in relative terms suggesting a 1.8 (min-max: 1.4 - 2.4\*) difference across all countries (Wübker et al. 2014). Yet, in the absence of the required level of community support, people with dementia can be placed in long-term residential care prematurely (Cahill et al.,: 82). However, families and people with dementia acknowledge that there are times when residential care is the most appropriate care option but express a first option for long term care at home. The following submission will be structured according to a human rights based approach to long term care. It will approach long term care in the context of meeting the needs of people with dementia and their carers in an appropriate and timely way in the right setting by the right professional.

### **3. A human rights approach to long-term care**

The ASI maintains that a human rights based approach to dementia care is the best means to provide a continuum of support and care based on choice.

The following submission is structured according to a human rights-based approach (known as the “PANEL” approach, endorsed by the United Nations). It emphasises the rights of everyone to:

- Participate in decisions which affect their human rights.
- Accountability of those responsible for the respect, protection and fulfilment of human rights.

- Non-discrimination and equality.
- Empowerment to know their rights and exercise them.
- Legality in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements.

### ***3.1 Participation***

As a starting point, people with dementia and their carers have the right to be provided with accessible information and the support they require in order to enable them to exercise their right to participate in decisions which affect them. People with dementia and their carers also have the right to full participation in care needs assessment, planning, deciding and arranging care, support and treatment, including advanced decision making. People with dementia and their carers, therefore, have a right to be consulted and included in discussions about long term care in Ireland.

The Assisted Decision Making (Capacity) Act 2015 provides a modern statutory framework supporting decision-making by adults who have difficulty in making decisions unaided. This legislation will have a significant impact on the lives of people with dementia as it places their will and preferences central to decision making. This means that a person's choice to remain living at home must be managed in compliance with the Capacity legislation.

### ***3.2 Accountability***

Accountability in long term care refers to the need for leadership and funding to ensure that people with dementia have access to a range of long-term care options. The consequences of an underdeveloped and fragmented community care system are that significant and, in the long-term, unsustainable care falls disproportionately on family carers (Cahill et al, 2013: 90).

#### ***Leadership***

The Government published Ireland's first National Dementia Strategy (NDS) in December 2014. The Strategy is the blueprint for how dementia will be addressed in Ireland. It is imperative that all Government policy and practice, supports the strategic approach to dementia that the NDS outlines. The NDS states that dementia policy, service delivery and development should be guided by the principles of chronic disease management set out in the Department of Health's Policy Framework for the Management of Chronic Diseases, which includes the development of a model of shared care that is integrated across organisational boundaries; planning care that is delivered in the appropriate setting; and using multidisciplinary teams in the provision of care.

An additional key principle that underpins the NDS is a 'whole community approach' with health and social care services as only one part of the package of supports that people with dementia need. The NDS commits to an integrated and multi-disciplinary response by community services, primary care and secondary care to support people with dementia and their family carers.

Specific to long term care, the NDS under the Priority Action Area concerned with Integrated Services, Support and Care, has a clear objective that there should be a range of long-term care options designed to comply with best practice architectural principles and staffed by competent and skilled personnel trained to address the complex and unique needs and preferences of people with dementia of all ages (NDS, 2014: 24). The NDS further states that people who develop dementia in residential long-term care should be provided with the same opportunities for diagnosis, treatment and care as those in other care settings (ibid). In addition, the NDS maintains that people with dementia should be facilitated and supported to live and die well in their chosen environment including their own home or nursing home if that is their choice. Specialist palliative care should be available to all people with dementia and their families in all care settings and at home, if required, to optimise quality of life and support a comfortable and dignified death (Ibid).

There is a specific commitment within the NDS that the Health Service Executive will examine a range of appropriate long-term care options to accommodate the diverse needs of people with dementia, including those with behaviours that challenge. In planning future long-term residential care, the Health Service Executive will take appropriate account of the potential of new residential models, including housing with care, for people with dementia (ibid: 30). Long term care for people with dementia, therefore, must be developed in the context of the principles and leadership set out in the NDS.

### ***Funding***

In addition to leadership, appropriate long term care needs adequate funding. 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.

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.

Current government policy promotes the care of all older people in their own home and communities. Under the current system of services, and even with the development of Home Care Packages including additional packages under the National Dementia Strategy, there are few options open to people with dementia who require increasing levels of support. The availability of home care services are not consistent throughout the country and where they are available, they often do not meet increasing care needs as dementia progresses. The cost of privately operated home care is often prohibitive given the level of support that may be required. Long term residential care is often the only option available. This means that even where people with dementia do not necessarily need 24 hour care, but do need extra care, they move to nursing homes. The impact on the person with dementia and their families is significant and often detrimental. Inappropriate transition to long term care also results in significant cost implications for the state and so for society as a whole.

Funding for long term residential care also needs to be reconfigured to ensure that people with dementia receive appropriate care. Currently, a flat fee is paid to a nursing home as agreed with the National Treatment Fund. This approach means:

1. It is more cost effective for nursing homes to have residents with lower support needs. The ASI has received calls from concerned family members where their loved one with high support needs, experienced real difficulties accessing residential care.
2. Additional costs are placed with people with dementia and their families as the flat fee structure provides for a narrow range of services and excludes the cost of items such as incontinence wear and services such as physiotherapy and chiropody.
3. Anecdotal evidence suggests that many people with dementia are inappropriately transferred to hospital from nursing homes at different times during the course of the condition. This has a hugely detrimental impact on the person with dementia as hospitalisation itself can increase confusion and cause agitation. This situation also places enormous strain on families.

The ASI recommends that an enhanced rate is introduced to meet the costs of providing care for people with complex needs. This will help to ensure people with dementia are not excluded from nursing homes due to the cost of providing specialist care. ASI also recommends the greater development of service links between hospitals / GP services and nursing homes to allow, where

appropriate, for expert health professionals to go to nursing homes rather than residents go to hospitals.

Leadership and funding, however, is directly linked to having accurate and available data for service planning. In Ireland, there is no reliable official data on the number of people with dementia in the country, or where these people are likely to be located (Cahill et al., 2013: 127). The generation of this data should be a priority in the development of appropriate long term care options for people with dementia. The needs of people with dementia in residential care are also important, given how many people with dementia live in this setting in Ireland. Unfortunately, hard data on the numbers of people with dementia in long-stay settings is largely absent (ibid: 129).

### **3.3 Non-discrimination**

For some people with dementia and their families, the most appropriate and realistic option is a move to a supported care environment. In Ireland, there are very few care or living options available. The majority of people with dementia living in residential care are in generic nursing home settings, which in most cases struggle to meet the complex and often unique care needs of people with dementia. ASI believes alternative options are urgently needed to address the very serious issues the current model creates for people with dementia, their families and for health care professionals working in residential settings.

It is estimated that 34% of all people with dementia live in residential care (NDS, 2014), a small proportion of whom (1,000 approx.) currently live in specialist care units. However, the prevalence figure for the number of people with dementia in long-term care is regarded as underestimated, supported by research evidence<sup>4</sup> from a sample of Dublin-based nursing homes which shows that 89% of residents had a cognitive impairment (Cahill et al, 2009).

The majority of people with dementia currently reside in generic residential care facilities. It is critical that residential standards for Units accommodating people with dementia take appropriate account of the needs of these residents even where the Unit in question is not formally described as specialising in dementia. It is also desirable that people with dementia in residential care facilities should be accommodated as close as possible to their home communities.

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<sup>4</sup> Accessed via <http://www.tara.tcd.ie/xmlui/bitstream/handle/2262/49754/The%20underdetection%20of%20cognitive%20impairment%203%20in%20nursing%20homes%20in%20the%20Dublin%20area.%20The%204%20need%20for%20on-going%20cognitive%20assessment.pdf?sequence=1&isAllowed=y>.

Specialist Care Units are currently a rare feature in the Irish long-term care landscape where the more traditional model of nursing home care continues to prevail<sup>5</sup>. In contrast to generic care, these units employ professionally trained staff, nurses, care attendants, household and support staff skilled in understanding some of the challenges and dilemmas that having a dementia poses to the individual and who are knowledgeable in helping residents cope with behaviours that might otherwise be considered as challenging. Specialist Care Units emphasise the importance of psychosocial stimulation and meaningful activities for improved quality of life. They demonstrate an awareness that people with dementia can become easily frightened and can get lost even in familiar surroundings. Accordingly, the design reflects an unobtrusive concern for safety and security, and where possible they use signage and cueing to help their residents negotiate the environment.

### ***Specific groups***

There are a significant number of people under age 65 diagnosed with dementia in Ireland. It is recognised that younger people with dementia (those aged less than 65) are a particularly vulnerable group whose needs and experiences are very often far more complex than those of older people with cognitive impairments (Haase, 2005). Younger people with dementia in Ireland find it particularly difficult to access residential care (ASI, 2011) and because of their age, life experiences and interests, even in circumstances where long-term residential care facilities are accessed, the environment is often far from ideal (Cahill et al., 2012). Therefore, the issue of designing residential services responsive to the unique needs of younger people with dementia in Ireland also needs to be considered.

Cahill et al (2012: 33) highlight, the Irish dementia prevalence rates exclude data on people with intellectual disability (ID) including those with Down syndrome and dementia. People with an ID have no excess risk of developing a dementia but they do face particularly issues with diagnosis, assessment and management of dementia. However, those with Down syndrome (DS) are at a heightened risk and there is a large body of research evidence which provides convincing evidence that rates of Alzheimer's type dementia are significantly higher in persons with Down syndrome compared with the general population (Stanton, 2004). The National Dementia Strategy (2014) refers to the need to ensure that available resources are deployed on the basis of need and as effectively as possible to provide services for all people with dementia, including those with an intellectual disability (NDS: 13). In addition, Cahill et al (2012: 86) maintain that people with intellectual disabilities, who develop a dementia, are a particularly disadvantaged group in Irish society at risk of being overlooked by mainstream and specialist service providers.

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<sup>5</sup> Accessed via A Guide to Specialist Care Units <http://dementia.ie/images/uploads/site-images/SCU.pdf>

It is increasingly the case that people who have one chronic condition also have another or other chronic conditions, increasing the complexity of care and support received. Co-morbidity once again means that a multi-disciplinary approach at primary care is critical. For those with dementia, this may be pre- 6 existing or may develop after the diagnosis of the dementia. In either-case, additional care and support is required to ensure effective disease management of the conditions.

### **3.4 Empowerment**

People with dementia need to access care from the point of diagnosis right through to end of life. Having real choices is an important aspect of empowerment for people living with dementia. People with dementia face limited long-term care options in Ireland. People need choices in order to exercise autonomy and self-determination. Dementia services that are fragmented and lacking co-ordination poorly serve the needs of people with dementia and carers.

People with dementia have the right to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. A continuum of care for people with dementia, in order to be empowering and uphold their human rights, must include comprehensive case management, care pathways and multi-disciplinary approaches to care.

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<sup>23</sup>) 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.

There is also positive evidence 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). 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).

People with dementia have the right to health and social care services provided by professionals and staff who have had appropriate training on dementia and human rights to ensure the highest quality of service. Dementia specific training puts a central focus on person-centred care and staff are trained to deliver a high quality, highly responsive and flexible service. This involves a focus on maintaining independence for the person with dementia and working in partnership with family carers through a relationship centred approach. For this reason, discussions about long-term care must include social care supports to move beyond a medical model of dementia care. This means viewing the person with dementia receiving long-term care in the community as a citizen with a right to actively participate in community life to the best of his/ her ability.

In addition to case management, long term care models must recognise the significant role of a multidisciplinary response to dementia. ASI welcomes the wider Future Health (2013) policy reform of primary care services as many of the most effective management approaches for dementia care are provided by primary level healthcare professionals from multiple disciplines (Grand et al., 2011). General Practitioners, Public Health Nurses, Occupational Therapists (OT), Speech and Language Therapists, Mental Health Nurses and other key healthcare professional play a significant and frequent role in the management of dementia care. Meeting the many medical and social needs that present with dementia is one of the most significant ways of ensuring that people continue to have a quality of life and have a sense of empowerment in living with dementia.

Empowerment matters to people with dementia receiving long term care in the community but also those in residential long term care. Cahill et al (2012) draw attention to a range of issues related to accessing long term residential care in Ireland (ibid: 123). They highlight the lack of data available on exact numbers of people with dementia in long stay settings, including data on the number and type of dementia-specific accommodation that is available. The review states that International evidence points to the wisdom of providing care to people with dementia in small-scale, homely and specialist care settings (ibid: 124) and yet Ireland has few alternatives to the nursing home model of care.

### **3.5 Legality**

Perhaps the clearest and most common example of an area where people with dementia struggle to realise their rights is in the area of access to community health services. Ireland has ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR) which recognises the right to health defined in relation to availability, access to, acceptability and quality of health facilities,

goods and services. However, the right to health and personal social services is not defined in Irish legislation. In 2011, Seanad Éireann's Public Consultation Committee invited relevant stakeholders to make submissions on the Rights of Older People. The need for a legislative right to community care came up repeatedly. The Report of the Seanad Public Consultation Committee (March 2012) reflected these concerns. The report identified two major themes emerging from across the submissions heard; the need for the rights for older people to be enshrined in a formal way and recognised and the need to support and encourage independent living at home for as long as possible. The Committee's recommendations "support fully the idea that future policies relating to older people must move away from the 'maintenance' model to the 'rights' model and that future policies should be in step with international best practice and indeed contribute to such best practice."

There also needs to be a move towards rights based legislation. For example, the Nursing Homes (Support Scheme) Act 2009 gave a statutory footing to arrangements for financial support for people entering nursing home care, known as the "Fair Deal" Scheme. The stated intention of the scheme was to provide greater clarity and equality of access to state funding for long term residential care. However, the legislation is not rights based in the sense that the Scheme is budget-capped and does not confer an actual entitlement to financial support for nursing home care. Thus, a person can fully complete the application process and meet all the criteria for eligibility but be left without a nursing home place due to lack of financial resources earmarked for the Scheme.

The Office of the Ombudsman has heavily criticised the NHSS as being poorly drafted and unclear, and disagrees with the Department of Health's interpretation that it has amended the 1970 Health Act to give the State the discretion to provide long term residential care for those who cannot afford it, in place of the original obligation to provide care. Submissions to the 2012 NHSS review also identify the detrimental effect of having a statutory footing for support for residential care but not for care in the community, with anecdotal accounts of people who would have been able to stay at home with some extra support being forced to opt for residential care, as the only option for which financial assistance was available.

It is also envisaged that the Assisted Decision Making Act (2015) will inform a cultural shift in how long term care is developed as people will have a legislative basis to express options and refuse specific types of care. If more people demand care at home then the resources, currently lacking, may need to be provided to ensure that a person's will and preferences are met and that the Act is complied with.

#### **4. Conclusion**

A continuum of care for people with dementia starts from diagnosis to end-of-life care. Long term care services and supports must be available throughout the dementia journey. This means developing timely and appropriate care pathways so that people are empowered to live well with dementia. It also means ensuring that long terms care is conceptualised as community-based care given that the majority of people with dementia express a desire to be cared for at home. Participating in decision about long term care and care panning is a critical part of ensuring that long term care respects the preferences and rights of those receiving care. Accountability means that clear leadership and funding is available for a range of choices. This implies that accurate data is available for service planning and development. In addition, to ensure that this is done in a way that meets the needs of all people with dementia, supports must be provided equitably so that where you live, your age or a comorbidity does not disadvantage a person in accessing a continuum of care. Empowering people to live well with dementia will involve strategic policy on long term care that includes dementia specific training, comprehensive case management, care pathways and multi-disciplinary approaches to care. Finally, legislation is needed to ensure that long term care is provided equally between residential and community care. Taking a PANEL human rights based approach to developing long term care for people with dementia will significantly contribute to maintaining maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life for people with dementia.

Ends.

For further information, or if you have any questions or queries about this submission please contact the ASI's Policy Officer, Mags Crean on 01 2073800 or email [margaret.crean@alzheimer.ie](mailto:margaret.crean@alzheimer.ie)