Reclaiming Dementia:
Transforming the Lives of People with Dementia

Submission on the National Dementia Strategy
August 2012

The Alzheimer Society of Ireland
Temple Road, Blackrock, Co Dublin
T: 01 207 3800
E: info@alzheimer.ie
W: www.alzheimer.ie

Alzheimer National Helpline: 1800 341 341
# Table of Contents

<table>
<thead>
<tr>
<th>Executive Summary</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>5</td>
</tr>
<tr>
<td><strong>Section 1:</strong> The Essential Elements of the National Dementia Strategy</td>
<td>7</td>
</tr>
<tr>
<td>Element 1: Clinical and Policy Leadership in Dementia</td>
<td>8</td>
</tr>
<tr>
<td>Element 2: Values and Principles</td>
<td>8</td>
</tr>
<tr>
<td>Element 3: Developing Capacity to Involve People with Dementia and their Carers</td>
<td>9</td>
</tr>
<tr>
<td>Element 4: “Reclaiming Dementia” - Social and Community Model</td>
<td>9</td>
</tr>
<tr>
<td>Element 5: Promoting an Integrated Dementia Care Pathway Approach</td>
<td>10</td>
</tr>
<tr>
<td>Element 6: Dementia Education, Public Awareness and Dementia Friendly Approach</td>
<td>11</td>
</tr>
<tr>
<td>Element 7: Dementia Research</td>
<td>12</td>
</tr>
<tr>
<td>Element 8: Delivering Solutions through Actions: 7 Key Priorities</td>
<td>12</td>
</tr>
<tr>
<td><strong>Section 2:</strong> Delivering Solutions through Actions: 7 Key Priorities</td>
<td>14</td>
</tr>
<tr>
<td>Getting a diagnosis, disclosure and early interventions supports and services</td>
<td>14</td>
</tr>
<tr>
<td>Living well in the community: appropriate and timely information, supports and services</td>
<td>17</td>
</tr>
<tr>
<td>Care in the acute hospital setting</td>
<td>20</td>
</tr>
<tr>
<td>Life in residential care</td>
<td>22</td>
</tr>
<tr>
<td>Dementia palliative care and end of life care</td>
<td>25</td>
</tr>
<tr>
<td>People with younger onset dementia</td>
<td>28</td>
</tr>
<tr>
<td>Addressing stigma and maintaining stakeholder awareness and education</td>
<td>30</td>
</tr>
<tr>
<td><strong>Section 3:</strong> Developing and Implementing the Strategy</td>
<td>33</td>
</tr>
<tr>
<td><strong>Appendices</strong></td>
<td></td>
</tr>
<tr>
<td>Appendix 1: The Alzheimer Society of Ireland Consultation Plan Methodologies and Profiles of Participants</td>
<td>36</td>
</tr>
<tr>
<td>Appendix 2: Findings from the Alzheimer Society of Ireland National Survey of Stakeholders</td>
<td>39</td>
</tr>
<tr>
<td>Appendix 3: Hearing the Voice of the Person with Dementia</td>
<td>43</td>
</tr>
<tr>
<td>Appendix 4: Background to The Alzheimer Society of Ireland</td>
<td>47</td>
</tr>
</tbody>
</table>
Executive Summary

Introduction
Last year represented a pivotal moment for the 42,000 people living with dementia and their 50,000 carers when the Government announced its commitment, under the Programme for Government, to the development of a National Dementia Strategy by 2013. The Alzheimer Society of Ireland welcomes the opportunity to make a submission to the Department of Health in relation to developing a strategy to transform the lives of people with dementia and those who care for them.

A number of perspectives were involved in the emergence of this submission including the multiple perspectives gathered during the course of an extensive internal consultation process, three decades of organisational development, service delivery and advocacy and the informed perspectives of dementia care, international best practice and research evidence.

The Essential Elements of the National Dementia Strategy
The Alzheimer Society of Ireland believes there are a number of essential elements in the development of the National Dementia Strategy in order to transform the lives of the significant and growing numbers of people living with dementia now and in the future. We believe that the National Dementia Strategy combined with the National Positive Ageing Strategy and the National Carers’ Strategy will lead us to the point where we have world class services and supports for those living with dementia.

The Alzheimer Society of Ireland also believes that the National Dementia Strategy needs to reclaim and rethink dementia from a number of perspectives. This rethink needs to make dementia a priority as it is one of the most significant public health issues and societal challenges facing us in the 21st century; the reclaiming of dementia needs us as a society and as communities to “own” dementia, requiring a whole community response.

The essential elements in developing the National Dementia Strategy are:

**Element 1: Clinical and Policy Leadership in Dementia**
Clinical and policy leadership of dementia in the Strategy must come from the Department of Health and the Health Service Executive through the development of a clinical directorate and the appointment of a Clinical Director in dementia. The directorate will have dedicated resources to oversee the implementation of the National Dementia Strategy as well as ensuring that dementia permeates across all of the other clinical care programmes.

**Element 2: Values and Principles**
A comprehensive set of values and principles must be enshrined into the National Dementia Strategy including social solidarity, social sustainability, active citizenship, respect and putting the person at the centre.

**Element 3: Developing Capacity to Involve People with Dementia and their Carers**
People with dementia and their carers must be involved in the decisions that affect their lives and given recognition that they are the experts in the lived experience of dementia and included as partners in the care pathway and policy development.
Element 4:  “Reclaiming Dementia” - Social and Community Model
There is a need to “reclaim dementia” through the emergence of a new social and community model that focuses on abilities, possibilities and personhood and one where dementia is viewed as a social issue, owned by our community and requiring a community response.

Element 5:  Promoting an Integrated Dementia Care Pathway Approach
A system of integrated dementia care pathways supported by a case manager mechanism must be created, which enables service providers and supports for people with dementia to work in a joined up and consistent way.

Element 6:  Dementia Education, Public Awareness and Dementia Friendly Approach
Dementia education and awareness needs to permeate every aspect of health care and mainstream service provision to enable them to be “dementia friendly” and respond appropriately.

Element 7:  Dementia Research
There is a need for commitment to invest in a world class research agenda across all the disciplines including basic and clinical sciences, health services, health systems and health policy research. Establishing a baseline to monitor the prevalence and incidence of dementia in order to understand the current parameters, enable evidenced based decision making and plan for now and the future. The significant role that people with dementia and their carers play in dementia research should be recognised.

Element 8:  Delivering Solutions through Actions: 7 Key Priorities
There are 7 key priority areas where opportunities exist to intervene to transform people’s lives through a series of direct, concrete, efficient and cost effective “solutions through action”.

<table>
<thead>
<tr>
<th>7 Key Priorities</th>
<th>Summary of Proposed Solutions and Actions</th>
</tr>
</thead>
</table>
| 1. Getting a diagnosis, disclosure and early interventions supports and services | • Well informed and trained GPs, primary care teams and healthcare professionals  
• Clear referral pathways and implementation of a clinical framework for diagnosis and management of dementia  
• Develop a nationwide Early Intervention Support Programme to provide services and supports for both the carer and the person with dementia |
| 2. Living well in the community: appropriate and timely information, supports and services | • Develop a one-stop-shop for information and supports including dementia advisors  
• Define the service/care pathway with case management  
• Dementia Clinical Nurse Specialists in community and hospital settings  
• Develop dementia specific community services by using a Dementia Friendly Communities model  
• Promote assistive technology |
| 3. Care in the acute hospital setting | • Enhanced community and clinical outreach services to prevent hospital admission  
• Fast track protocols for people through A&E  
• Develop the role of specialist dementia nurses to support change and improvements  
• Develop Dementia Friendly Hospitals through an education programme |
| 4. | Life in residential care | - Support the role of the family carer throughout the transition phase  
- Alternatives models of residential care developed such as supported living  
- Dementia education for the residential care workforce  
- Revision of rates provided for the Nursing Home Support Scheme  
- Specialist residential care options for people who are under 65 |
|---|---|---|
| 5. | Dementia palliative care and end of life care | - Recognition that end of life care needs skilled expertise and interventions  
- Build capacity in services to respond to the needs of people with advanced dementia and at end of life  
- Dementia palliative care education element for all healthcare professionals  
- A commitment to supporting further research in the area |
| 6. | People with younger onset dementia | - Develop small number of specialist centres for diagnosis and clinical management  
- Develop tailor-made and age appropriate services  
- Develop community based nurse led case management services  
- Removal of the age discrimination barriers in terms of access to services  
- Locate people within the appropriate health service structure |
| 7. | Addressing stigma and maintaining stakeholder awareness and education | - Targeted awareness and education programmes  
- New discourse that recognises people can and do live well with dementia  
- Develop dementia champions in the stakeholder groups  
- Ensure that the principles of the NDS relate to existing disability policy  
- People with dementia are supported to be self advocates |

**Developing and Implementing the Strategy**

Clear and transparent processes are needed in order to develop and implement a robust National Dementia Strategy for Ireland. As the leading advocacy organisation in dementia The Alzheimer Society of Ireland plans to play a pivotal, strategic and operational role in the development and implementation of the National Dementia Strategy.

The Alzheimer Society of Ireland believes that while the Department of Health should take the lead in developing the Strategy there should be “a whole of Government” approach taken that recognises dementia as a priority. An implementation plan and a structure to support it must be a core part of the Strategy. The central motivation of the implementation plan will be to ensure that the potential described in the National Dementia Strategy for improved services and support for people affected by dementia can be realised.

**For further information please contact:**
The Alzheimer Society of Ireland  
Temple Road, Blackrock, Co Dublin  
**T:** 01 207 3800  
**E:** info@alzheimer.ie  
**W:** www.alzheimer.ie
Introduction

Last year represented a pivotal moment for the 42,000 people living with dementia and their 50,000 carers when the Government announced its commitment, under the Programme for Government, to the development of a National Dementia Strategy by 2013. The Alzheimer Society of Ireland (ASI) welcomes the opportunity to make a submission to the Department of Health in relation to developing a strategy to transform the lives of people with dementia and those who care for them.

Development of the Submission – Multiple Perspectives
A number of perspectives were involved in the emergence of this response from the ASI to the development of the National Dementia Strategy (NDS).

Consultation with Internal Stakeholders
This submission is informed by an extensive organisational consultation process among all our stakeholder groups including people with dementia, carers, families, staff, branch members, board members and volunteers throughout the country. (See Appendix 1 for a detailed breakdown of the consultation methodologies and the profile of those who engaged). The submission is unique in that it has had the benefit of capturing the perspectives of people living with dementia.

Organisational Perspectives
The submission is based on 30 years of organisational experience of delivering services and advocating for the person with dementia and their carer. Over the last three decades, the ASI has grown and developed a range of dementia specific services and supports for people with dementia and their carers. There is a wealth of knowledge, expertise and experience among our professional staff, trained volunteers and those with the lived experiences.

Advocating at all levels for the person with dementia and their carer is a core element of the organisation’s work, in particular ensuring that the voice of the person with dementia and those who care for them is heard in the political and policy arenas. Inherent in all of the work we do is on-going public and stakeholder education and awareness raising. This work aims to reduce stigma, ensure that the wide stakeholder groupings are informed and engaged and enable those living with dementia to talk openly about their diagnosis and experiences.

International Best Practice and Evidence
Current perspectives on dementia are also at the heart of our submission. Dementia is a major public health issue. We believe that people with dementia should be placed at the centre of policy making and service provision as equal partners in their care; that they must be respected, valued and viewed as active citizens with abilities and as full holders of human rights. Based on the seminal writings of Tom Kitwood¹, we believe that preserving the “personhood” of the person with dementia must be at the heart of the NDS.

¹ Dementia Reconsidered: The person comes first, Kitwood (1997)
This submission adds to and complements the comprehensive evidence base published earlier this year “Creating Excellence in Dementia Care – A Research Review for Ireland’s National Dementia Strategy” (2012). This review not only provides the most up-to-date and comprehensive data and evidence on the current dementia landscape in Ireland but it also very importantly signposts the international evidence and best practice models that have emerged in countries where dementia strategies exist. These learning and best practice models are central to informing policy makers in Ireland as to how best the Irish dementia strategy can adopt and adapt some of the world class models of excellence from across the world.

Submission Format
The submission is divided into three sections:
- **Section 1:** The Essential Elements of the National Dementia Strategy
- **Section 2:** Delivering Solutions through Actions: 7 Key Priorities
- **Section 3:** Developing and Implementing the Strategy

---

2 Creating Excellence in Dementia Care, A Research Review for Ireland’s National Dementia Strategy, Cahill, O’Shea, Pierce (2012)
Section 1

Essential Elements in Developing the National Dementia Strategy

Introduction
The Alzheimer Society of Ireland believes there are a number of essential elements in the development of the NDS in order to transform the lives of the significant and growing numbers of people living with dementia now and in the future.

A “whole of government approach” is required, with integration across a wide range of policy areas as well as a radical shift in our understanding of dementia. The ASI believes that the NDS needs to reclaim and rethink dementia from a number of perspectives. This rethink needs to give dementia priority as one of the most significant public health issues and societal challenges facing us in the 21st century; the reclaiming of dementia needs us a society and as communities to “own” dementia, requiring a whole community response. The current responses are neither sustainable nor desirable for the future and this has been confirmed by our direct engagement with people with dementia and their carers.

The “dementia challenge” and the NDS offer real prospects for delivering cost effective person centred interventions that can be replicated in other areas of social policy. Dementia policy and practice can lead the way in terms of exemplar models that are based on best practice, evidence and that over time, prove to be cost effective and provide good value for money. Dementia remains a highly neglected area of policy with few dedicated resources and the NDS must recognise this as the starting point with a vision of transformation that supports people with dementia to be placed in the heart of our communities. Therefore the NDS combined with the National Positive Ageing Strategy and the Carers’ Strategy will lead us to the point where we have world class services and supports for those living with dementia and make Ireland the best place to grow old.

Essential Elements in Developing the National Dementia Strategy
The following are the essential elements needed to develop Ireland’s NDS:

Element 1: Clinical and Policy Leadership in Dementia
Element 2: Values and Principles
Element 3: Developing Capacity to Involve People with Dementia and their Carers
Element 4: “Reclaiming Dementia” - Social and Community Model
Element 5: Promoting an Integrated Dementia Care Pathway Approach
Element 6: Dementia Education, Public Awareness and Dementia Friendly Approach
Element 7: Dementia Research
Element 8: Delivering Solutions through Actions: 7 Key Priorities
1. Clinical and Policy Leadership in Dementia

Clinical and policy leadership of dementia in the Strategy must come from the Department of Health and the Health Service Executive (HSE) through the development of a clinical directorate and the appointment of a Clinical Director in dementia. The directorate will have dedicated resources to oversee the implementation of the NDS as well as ensuring that dementia permeates across all of the other clinical care programmes.

The introduction in Ireland in 2008 of the Clinical Directorate (CD) as the accepted method for the organisation of health services and the involvement of clinicians in the management of these services is one of the most significant developments to happen in the Irish health services in recent years. This model has posed both major challenges and opportunities for all clinical and medical professions. The clinical programmes in Ireland have been developed using a model similar to that used by the National Cancer Control Programme to deliver improvements across a large and complex organisation, such as the HSE. The programmes are bringing about a systematic approach to changes in how services are delivered to improve outcomes for patients. Currently in Ireland there is a real lack of any leadership in dementia care and few dedicated resources. The development of a NDS offers us a real opportunity for doing things more cost effectively and investing resources that really do maintain people at home.

The identification of a CD for dementia would provide a unique opportunity for the HSE to establish a national programme for dementia care. The clinical focus would develop the much needed responsibility and "road map" for the management of dementia in a range of areas across our health services including primary care. The National Dementia Strategy in England have successfully incorporated a National Clinical Director for Dementia – Alistair Burns whose responsibility is the promotion of improved care of dementia patients within the NHS and social care communities in the country.

The CD should specifically focus on solutions that will improve patient care and save money. There are many proven solutions and best practice models in the area of dementia. The CD led by the Clinical Director would work to identify these, examine the evidence base, adapt as necessary and implement them nationally.

The role of the Clinical Director would be to oversee the clinical implementation of the NDS and to spearhead change. The Clinical Director would play a key role in promoting quality dementia care, lead a corporate management team, plan how clinical services are to be delivered and how resources are to be employed, contribute to strategic planning, and deploy and manage consultants. The CD will only succeed if it has a visionary leader with excellent management skills who is willing to take tough and unpopular decisions and inspire their colleagues.

2. Values and Principles

A comprehensive set of values and principles must be enshrined into the NDS including social solidarity, social sustainability, active citizenship, respect and putting the person at the centre.

We believe that the values and principles set out in the NDS will determine what emerges in the future policy and practice and are central to transforming the lives of people with dementia.

a. Dementia is a societal issue and the principles of social solidarity, social sustainability, interdependency and active citizenship are essential in order to appropriately respond
b. The person with dementia and their carer each have the **right to have their voices heard** and be **placed at the centre** of the policy making process

c. A **holistic, lifecycle approach** is adopted taking in the social, emotional, physical, psychological and biographical aspects as well as **valuing** and **respecting** the person with dementia as an **active citizen with the full range of human rights**

d. A commitment to **evidenced based** policy and resource allocation decision making

e. **Equity, consistency, responsiveness** and **flexibility** in the approach to service provision

3. **Developing Capacity to Involve People with Dementia and their Carers**

*People with dementia and their carers must be involved in the decisions that affect their lives and given recognition that they are the experts in the lived experience of dementia and included as partners in the care pathway and policy development.*

People with dementia and their carers are the real experts in relation to the lived experience of dementia and they need formal recognition as care partners and primary stakeholders in dementia care. Engaging with people with dementia and their carers is an inherent part of the development and ongoing implementation of the NDS.

We appreciate that it can be a challenge to engage directly with people with dementia in particular, but it is a challenge that can be surmounted. There are many examples of international best practice. In Scotland, the government has recognised the Scottish Dementia Working Group (a peer advocacy movement run by and for people with dementia) as a key partner in the progression of their National Dementia Strategy. The Irish Strategy needs to create **structures to enable both people with dementia and their carers to have their voices heard** in relation to service and policy decisions.

4. **“Reclaiming Dementia” - Social and Community Model**

*There is a need to “reclaim dementia” through the emergence of a new social and community model that focuses on abilities, possibilities and personhood and one where dementia is viewed as a social issue, owned by our community and requiring a community response.*

Perspectives of dementia in the current discourse are highly medicalised, highly negative and highly stigmatised. Dementia is seen as a “burden” on society and often described as an “epidemic”. People with dementia themselves acknowledge that they have internalised this perception and often take the blame for the disabling impact of dementia on themselves. The ASI asserts that a new perspective on dementia is essential to giving voice to those who live with the condition.

**A social and community model of dementia needs to be developed**, where dementia is viewed as a social issue, one owned by our community and requiring a community response, and where “personhood” is held at the very core. A new discourse is required, viewing dementia as a socio-economic and political issue, and not just a medical one. The “problem” of dementia can be addressed by shifting the focus to looking at how communities and the socio-economic, attitudinal and architectural environments in which people live in can respond to their needs.
According to Nolan\(^3\) (2006) the social model of disability can provide a framework to better understand dementia in a way that many of the current frames do not. The focus in policy terms is on finding ways in which the retained abilities of the person with dementia can be enabled and supported. Reframing dementia within the disability framework and altering the responses using a social model of disability is a key way to shift the policy emphasis towards enabling, empowering and supporting rather than ‘doing things to’ and ‘caring for’ people with dementia.

5. Promoting an Integrated Care Pathway Approach

A system of integrated dementia care pathways supported by a case manager mechanism must be created, which enables service providers and supports for people with dementia to work in a joined up and consistent way.

The Irish dementia landscape is highly fragmented and inequitable in terms of access to services and supports. There are currently no defined care pathways for people with dementia in accessing services and supports. Services available are frequently inadequate, inconsistent and badly co-ordinated throughout the country. People with dementia often only come into contact with health and social services if a crisis occurs. The development of a NDS for Ireland represents a unique and important opportunity for creativity, in terms of providing a much clearer pathway, more positive outcomes and a smoother journey for the person with dementia and their families, along with better use of existing resources and cost savings for the service provider.

Integrated care pathways (ICPs) are instruments designed to map out the direction of clinical and administrative activities for all care professionals for a diagnosis specific group. Essentially, ICPs chronologically pinpoint the key steps to be taken throughout the person’s care journey (Rees, et al. 2004)\(^4\). Instead of reactive or crisis care, ICPs are designed to provide an improved service for both the person and their carer through a more proactive care planning approach.\(^5\)

The goals of ICPs are to enhance quality of care and quality of life, service user satisfaction, and system efficiency for individuals with complex needs (Kodner and Kyriacou 2000).\(^6\) Essentially, ICPs take agreed national policy and translate it into practice in a particular local context (e.g. service availability, geography and population structure). A move towards more integrated working in terms of planning and service delivery could help achieve better outcomes for those with dementia and make the best use of current resources. Case management is required if integrated care is to become a reality with the potential to have a meaningful impact on the lives of those living with dementia.

---


\(^4\) Joint working in community mental health teams: implementation of an integrated care pathway Health and Social Care in the Community, Rees et al (2004)


The current Genio Initiative has potential to demonstrate elements of ICP models in practice. The Genio models are presenting an alternative “activity-led” response to the needs of people with dementia. They involve a consortium of stakeholder groups that have designed appropriate supports and services that respond to the particular needs of an area. Therefore, the configuration, the matrix of supports and delivery mechanisms vary from one local area to another based on capacity and resources. The learning from Genio and the scaling up of these integrated models, based on the outcomes of the evaluation, will be central to informing the NDS.

The forthcoming development by the HSE of the Single Assessment Tool (SAT) for Older People will form a core part of supporting the development of an ICP approach. Through the SAT the person and their primary carer will undergo a needs assessment. If there were to be an ICP approach in place this will trigger an integrated response to meeting their needs and identifying what locally based supports and services are available to the person and their family.

6. Dementia Education, Public Awareness and Dementia Friendly Approach

*Dementia education and awareness needs to permeate every aspect of health care and mainstream service provision to enable them to be “dementia friendly” and respond appropriately.*

Dementia should belong to the community and our communities need to be ‘dementia ready’; capable of responding to and supporting the person to live well with dementia and making dementia part of everyday life. The ASI asserts that communities are the solution to ‘normalising’ dementia by changing how dementia is conceptualised and reconstructing it with new meanings.

**Dementia Friendly Communities are at the heart of bringing about the social, attitudinal and environmental changes needed to transform the lived experience of dementia.** The concept of dementia friendly environments in areas used by people with dementia has emerged. An example would be a “dementia friendly hospital” where the whole hospital has the capacity, skill, knowledge and expertise to respond to the needs of the person with dementia. Staff are the key to dementia-friendly care and must be supported to think creatively in resolving issues.

At every stage of dementia, from pre-diagnosis to end-of-life care, services accessed by people with dementia and their carers needs to have an intrinsic appreciation of what dementia means, how it affects everyday life, and what can be done to make services more user friendly and appropriate. This includes recognising the right of people with dementia to access services on an equal basis with others and to receive the assistance they require to do so – the right to “reasonable accommodation” under the Equal Status Act 2000.

Improving customer service roles to encompass helping people with dementia who may be disorientated, confused or upset, simplifying signage to help people with dementia find their way, supporting people with financial transactions and providing appropriate toilet facilities are just a few simple but important issues businesses can take to become more welcoming for people with dementia and to meet the obligation to provide “reasonable accommodation” for people with disabilities.

Community healthcare services, community groups, community and voluntary groups, local and national media, and technology like social media and apps etc need to pull together as one to reach as wide and
diverse an audience as possible with the message that dementia belongs in the community. Realistic, but also positive, coverage of dementia that informs people, rather than terrifies them, will prove that people can live well with dementia. In this way, the ‘myths’ of dementia are dispelled and the perceptions of dementia altered, thus reducing the fear and resultant stigma of a diagnosis of dementia.

At the heart of all awareness campaigning must be people with experience of dementia, whether they are currently living with it, caring for someone with it, or have done in the past. We need to find meaningful ways to dialogue with people with dementia and give them the opportunity to advocate for themselves and realise their potential as active citizens.

7. Dementia Research

There is a need for commitment to invest in a world class research agenda across all the disciplines including basic and clinical sciences, health services, health systems and health policy research. Establishing a baseline to monitor the prevalence and incidence of dementia in order to understand the current parameters, enable evidenced based decision making and plan for now and the future. The significant role that people with dementia and their carers play in dementia research should be recognised.

Investment in dementia research in all its guises is an essential element of any NDS. Research evidence should underpin all of the Strategy’s actions. Irish-led research can also contribute to the broad European and indeed global dementia efforts. The research efforts must span across the basic and clinical sciences, health services, health systems and health policy research. We need research to monitor the course of dementia as a public health issue looking for changes in prevalence and incidence. Significantly more research is needed to better understand the causes of dementia and how and when lifestyle factors influence the risk for developing it. All investment in research needs to strike a balance between research into treatment, care and cure on the one hand and pharmacological and psychosocial intervention approaches on the other.

Therefore, the NDS must recognise the need to support world class research into both medical treatments for dementia and the delivery of care for people with dementia. People with dementia and their carers have a major role to play in dementia research by sharing their expert knowledge of living with dementia with professional researchers, giving voice to the priorities for dementia research and by becoming research subjects themselves.

8. Delivering Solutions through Actions: 7 Key Priorities

There are 7 key priority areas where opportunities exist to intervene to transform people’s lives through a series of direct, concrete, efficient and cost effective “solutions through action”. Below, is a list of the key priority areas presented in summary format along with the proposed solutions and actions. A full and detailed discussion of the issues and proposed solutions is contained in Section 2.
<table>
<thead>
<tr>
<th>7 Key Priorities</th>
<th>Summary of Proposed Solutions and Actions</th>
</tr>
</thead>
</table>
| 1. Getting a diagnosis, disclosure and early interventions supports and services | - Well informed and trained GPs, primary care teams and healthcare professionals  
- Clear referral pathways and implementation of a clinical framework for diagnosis and management of dementia  
- Develop a nationwide Early Intervention Support Programme to provide services and supports for both the carer and the person with dementia |
| 2. Living well in the community: appropriate and timely information, supports and services | - Develop a one-stop-shop for information and supports including dementia advisors  
- Define the service/care pathway with case management  
- Dementia Clinical Nurse Specialists in community and hospital settings  
- Develop dementia specific community services by using a Dementia Friendly Communities model  
- Promote assistive technology |
| 3. Care in the acute hospital setting | - Enhanced community and clinical outreach services to prevent hospital admission  
- Fast track protocols for people through A&E and acute care  
- Develop the role of specialist dementia nurses to support significant change and improvements  
- Develop Dementia Friendly Hospitals through an education programme |
| 4. Life in residential care | - Support the role of the family carer throughout the transition phase  
- Alternative models of residential care developed such as supported living  
- Dementia education for the residential care workforce  
- Revision of rates provided for the Nursing Home Support Scheme  
- Specialist residential care options for people who are under 65 |
| 5. Dementia palliative care and end of life care | - Recognition that end of life care needs skilled expertise and interventions  
- Build capacity in services to respond to the needs of people with advanced dementia and at end of life  
- Dementia palliative care education element for all healthcare professionals  
- A commitment to supporting further research in the area |
| 6. People with younger onset dementia | - Develop small number of specialist centres for diagnosis and clinical management  
- Develop tailor-made and age appropriate services  
- Develop community based nurse led case management services  
- Removal of the age discrimination barriers in terms of access to services  
- Locate people within the appropriate health service structure |
| 7. Addressing stigma and maintaining stakeholder awareness and education | - Targeted awareness and education programmes  
- New discourse that recognises people can and do live well with dementia  
- Develop dementia champions in the stakeholder groups  
- Ensure that the principles of the NDS relate to existing disability policy  
- People with dementia are supported to be self advocates |
Section 2

Delivering Solutions through Actions: 7 Key Priorities

Introduction
In this section of the submission we set out the 7 key priority areas that are essential for consideration by the Department of Health in developing the NDS. These are the areas in which the implementation of the elements identified in the previous section will impact directly and concretely on the lives of people with dementia.

7 Key Priority Areas:

1. Getting a diagnosis, disclosure and early intervention supports and services
2. Living well in the community: information, supports and services
3. Care in the acute hospital setting
4. Life in residential care
5. Dementia palliative care and end of life care
6. People with younger onset dementia
7. Addressing stigma and maintaining stakeholder awareness and education

Key Priority 1: Getting a diagnosis, disclosure and early intervention supports and services

The Issues:
It is clear that the process of seeking help and getting a diagnosis varies hugely from person to person and from one General Practitioner (GP) to the next. For some, it was a very fraught time and often a protracted process extending over many years. “Doctors should inform the family sooner. They seemed scared to tell us what we already felt we knew” (Family Carer). For others, it was a relatively straightforward process. “A supportive team in hospital gave the diagnosis” (Family Carer). It is therefore difficult to generalise yet, there are some commonalities.

Getting a diagnosis
Early diagnosis is the exception rather than the rule. There is still a very real lack of awareness and information about the early signs and symptoms of dementia, which creates a real barrier to early diagnosis. Although people may suspect that there is something wrong with themselves or with their loved one, they do not know where to go with their concerns “I kept monitoring it myself - I knew something was not quite right here” (Person with Dementia). A consistent experience that we hear through The Alzheimer Society of Ireland National Helpline service is that people think the symptoms are a normal part of ageing, or that someone is just being moodier than usual. People tell us that if they had understood the signs and symptoms of dementia earlier they would have pursued more information from their GP sooner.

Experience consistently indicates that the first and most important step to getting the right treatment and care (including at the end of life) is to have a formal diagnosis that is appropriately disclosed to the
person and their family. The GP is recognised as one of the critical health care professionals that the person with dementia and their carer engages with right throughout the journey. One of the most crucial roles that a GP plays is making the diagnosis either in their own practice or through a referral to a specialist. However, experience on the ground indicates that a GP can often be dismissive of the symptoms, refuse to believe that anything is wrong and misdiagnose people as having depression, for example.

The GP is the key person in referring on for a specialist assessment (i.e. by a consultant). Our experience would indicate that families find it very difficult to gain access to further expertise if the GP is not willing to refer them onwards. Families often have to be very insistent and pro-active to get a diagnosis and/or get a referral to a consultant.

There is a gap in the education and training of GPs in terms of having the necessary skills to diagnose dementia and to be able to refer them to a specialist. However, we found, through research that we conducted with Millward Brown Lansdowne, that there is a real desire amongst GPs themselves for more training and information about dementia, how to recognise the signs and symptoms and how to refer people appropriately onwards either to a further diagnostic process or to the relevant service providers. This finding was also reflected in the Creating Excellence in Dementia Care Report, 2012. 7

**Diagnostic process**
The diagnostic process is often stressful and extremely complex. People with dementia do not present with the same signs and symptoms each time and often particularly in the earlier stages of dementia, or with atypical dementias, these signs and symptoms can be difficult to identify. The process of getting a diagnosis (i.e. the tests that people are put through) is extremely stressful for the person and adds significantly to their anxiety. The value of the person’s own insights is very often dismissed and their “story” is not listened to in terms of their lived experience of the symptoms. The process of getting a diagnosis was described by the people with dementia we spoke to as “shocking” and “devastating” but also as a “relief”. At least now there was an explanation for what was going and they could seek appropriate help.

At present there are a number of memory clinics throughout the country. From our experience those who have attended the memory clinics often report a positive experience regarding getting a diagnosis. The nature and type of memory clinic depends on local capacity and resources. They may offer a range of services and have differing configurations in their staffing structures. Therefore, there is a need to explore further the role and function of memory clinics in terms of promoting best practice in getting a timely diagnosis and providing integrated supports and services to the person with dementia and their family.

**Disclosure of diagnosis**
The lack of appropriate disclosure of the diagnosis is identified as a major challenge to gaining access to treatment, appropriate supports and planning for the future. During the consultation process, in particular, people spoke about the harshness with which the news was often delivered, with no offer of

---

7 Creating Excellence in Dementia Care, A Research Review for Ireland’s National Dementia Strategy, Chapter 4, Cahill, O’Shea, Pierce (2012)
information, advice or where to go for further support. “I was told straight out about my wife’s diagnosis of Alzheimer’s. I was advised by the consultant to research the condition myself because he said there was too much to tell about the condition and he would not have time to tell me” (Family Carer). Others talked about how they were given “no hope” and this was really hard to deal with. “I was told to go home, not to worry and forget about it” (Person with Dementia).

The fact that a diagnosis of dementia is frequently not disclosed to the person is a critical issue in dementia care. People are unable to make informed choices about their future, exercise their rights, or participate as full partners in their own care when they are not aware of their diagnosis and prognosis. Irish disclosure rates rank poorly with other jurisdictions. This is clearly linked to the lateness of diagnosis, but also to stigma and to GPs’ lack of skill or confidence, their misperceptions about dementia and the effect of diagnosis. People with dementia are often told that they have “memory problems” or “a mild cognitive impairment”.

Early intervention supports and services
There is an urgent need to develop early intervention supports as currently there are almost none for people post diagnosis. There is significant evidence of the economic and social benefits that early intervention supports can yield at this stage. Investment in the person at the early stages of the disease trajectory may well yield significant savings in future years with interventions focusing on retaining functioning and people in the community for much longer.

For people diagnosed in the early stage of dementia there is a major gap in services and supports for both the person with dementia and their family. People are unsure where to seek help or support and who they can talk to in their community. People with dementia and their loved ones spoke about their experience of giving up activities they liked to do “I was told to stop everything, told to stop doing the things I liked” (Person with Dementia). This situation is often also compounded by the loss of confidence that people feel “you lose confidence” (Person with Dementia) and “I thought at the beginning that this was the end of the line for me” (Person with Dementia).

The overall impact of this absence of support and services is the isolation and withdrawal of both the person with dementia and their family from their routine and their community. As a result there is a serious and significant impact on their health and well being.

The Solutions:
Training and education for Health Care Professionals (HCP)
Working in conjunction with the Irish College of General Practitioners and the Health Service Executive (HSE) to ensure that there are well informed and appropriately trained GPs and Primary Care Teams (PCTs) which are essential to ensuring timely diagnosis, appropriate disclosure and ongoing care/support throughout the whole journey

---

8 Creating Excellence in Dementia Care, A Research Review for Ireland’s National Dementia Strategy, Chapter 4, Cahill, O’Shea, Pierce (2012)
9 An Economic Perspective of Dementia Care in Ireland: Maximising Benefits and Maintaining Cost Efficiency, Trepel, Department of Economics, University of Limerick (2011)
A programme of education and training to assist the GP and the PCT in their work in providing timely diagnosis and ongoing support and care in the community

National clinical framework for diagnosis

- Develop national clinical guidelines, protocols and a clear referral pathway which incorporates the guiding principles of the upcoming capacity legislation, enshrines the right to diagnosis, makes disclosure the norm not the exception and places an intrinsic value on the personal history and lived experience of the person and their family
- Provides for the opportunity for a person to receive their diagnosis through home assessments
- Guidelines on the provision of information about the condition and signposting to appropriate supports and services when a diagnosis is confirmed
- Explore the potential role and function of memory clinics in Ireland in terms of delivering timely diagnosis and post diagnostic supports and services

Early intervention - information and support services

- Develop a range of core information products for people with dementia at the early stages that are accessible and meet their identified needs including information about their condition, managing symptoms and living well, financial and legal planning and planning for future care. These products should be developed in partnership with people with dementia and dementia experts and made available free of charge.
- Peer and advocacy support groups for people with dementia and their families to enable them to have their voice heard in public discourses in relation to dementia and influence the decisions that impact their lives
- Develop and deliver a nationwide Early Intervention Support Programme to develop a suite of early intervention supports to include: timely information for both the person with dementia and for their family/carers, peer support and advocacy, counselling supports, planning for the future (legal, financial and care issues), family carer training, more specific therapies for the person with dementia such as cognitive stimulation therapy, cognitive rehabilitation therapy and general therapies such as music therapy, exercises and group activities.
- Develop and deliver psychotherapeutic interventions including support groups and individual counselling services for carers and people living with dementia

Key Priority 2: Living well in the community: information, supports and services

The Issues:
The stark reality of life for people with dementia is that they tend to withdraw following a diagnosis and as the dementia progresses they have little, to no, meaningful opportunity to engage in community life. Dementia remains a highly stigmatised and hidden condition. People with dementia and their carers are extremely socially excluded, marginalised and are an invisible group in society. “Dementia is a very lonely condition for both the patient and the carer, the stigma is huge and this needs to be tackled” (Family Carer).

Accessing information
Lack of information about the condition, medication available and the next steps people need to take following a diagnosis are major challenges. “We have worked with families who have left an
appointment where a diagnosis was confirmed and they then called our Helpline using their own initiative to say my dad was told he has Alzheimer’s, what is Alzheimer’s? Will he get better? Who can we talk to about this?” (Staff Member).

There is very little accessible and easy to read information available for the person with dementia that covers essential areas such as understanding dementia, how to manage the symptoms and live well, financial and legal planning and decision making. Although their families may have been presented with information about dementia, people with dementia often are not, or the information is not presented in an appropriate way for them to take it on board. The people with dementia who participated in the consultation expressed huge frustration about this situation as they found it even more disempowering. “If you just told me in the beginning to just do this and this – I would have been happy” (Person with Dementia).

Although information and support services for family carers exist (information products, support groups and training) they are not available at a level that meets their needs and it is a common experience for the family to be provided with the appropriate information too late. “In fairness there is no easy way to receive the diagnosis. It is very important that an information pack or leaflet should be available for relatives so they can access local services and supports at time of diagnosis” (Family Carer).

Information is not provided proactively – rather people have to seek it out. This was regularly described to us throughout the consultation as an “overwhelming” or “daunting” prospect. Most people do not know who to ask or what to ask for. They describe being sent to several places with differing responses and levels of service. No one service, or professional, has responsibility for meeting and providing the full range of information needs that people have.

People with dementia and their families have consistently expressed a preference for printed materials so they can read it a number of times and come back to it at different intervals. Others have expressed a preference for audio visual and on-line materials in addition to printed materials. There is also a need to provide one-to-one delivery of information, which is then supplemented by written materials.

Accessing services and supports

Families are unsure about where to seek help or support, who to talk to in terms of services / entitlements or where to go for timely information. “A diagnosis should be accompanied by the availability of someone to answer the questions that you have - either immediately or when you have come to terms with the diagnosis” (Family Carer).

There are massive gaps in provision and a complete lack of availability in some cases in relation to services and supports for people living in the community. The lack of any signposting and referral mechanisms for people who need a service and the complexity for carers in terms of navigating the system is a very real issue. It should be noted that navigating the system for a person with dementia is almost out of the question due to the inaccessibility and complexity. “Receiving a diagnosis of dementia is a traumatic thing and it is also frightening. Having then to try to search out vital information in a number of different places....online, from the HSE, from the hospitals, from the GP...makes the trauma so much worse” (Family Carer). The search for information and gaining access to services is exhausting and a repetitive one for families.
Access to services is entirely inequitable and is often based on where the person lives, how well they can navigate the system and advocate for themselves and whether or not they have access to public or privately funded services. There is also a need to rethink the range and type of services that are provided. Families want to support the person to live at home and see flexible and responsive home based services as being crucial. “I think they (the HSE) take total advantage of the goodwill and desire to do the right thing of family members” (Family Carer).

Staying connected in the community
A striking aspect of the consultation with people with dementia was the overwhelming desire of people to stay positive and remain involved in their community. People also spoke about the very conscious decision they had taken following their diagnosis to bring a positive attitude to their situation in order to maintain their well being “I stay positive because I made a decision to keep a positive attitude” and “it’s up to yourself to keep fit.” However, the immense impact this condition has on people’s lives and the constant changing nature of dementia was also highlighted “it is hard at times because of the things you can no longer do. You definitely feel different” (Person with Dementia).

Assistive technology
There is growing evidence to support the use of assistive technology to help maintain independence and to support people with dementia to remain at home for longer. In line with this growing evidence base, The Alzheimer Society of Ireland has been involved in a European based Telecare project: INDEPENDENT. The project sets out to develop and pilot an integrated set of telecare packages which includes: pendant alarms, flood detectors, property exit sensors, smoke detectors, temperature extreme sensors, bed occupancy sensors, bogus caller/panic buttons, fall detectors and gas detectors.

The Solutions:
Development and delivery of information
- The development of core information packages for people with dementia and their carers to be received on diagnosis. These packages need to be supported by further information products that are topic specific and reflect the lived experience of dementia as the condition progresses, through to end of life. The material must be accessible and be developed in partnership with people with dementia, their families and appropriate experts. The information needs to be dementia specific, supplemented with details of locally based services and supports and available free of charge.

- A one-stop-shop for the provision of timely information, counselling and supports for the person and their family from pre-diagnosis to the end of life stages. Central to the one-stop-shop model is the inclusion of the appointment of a regionalised network of highly trained/skilled dementia advisors who are community based and available to provide information/support and guidance to the person and their family throughout the journey and particularly at transition points.

- The development of a one-stop-shop model should also incorporate a variety of ways to access information including dementia advisors operating a mobile information service and drop-in centre, a Helpline service which provides an out of hours service and online supports.

Services and supports
- Develop the role of the Dementia Clinical Nurse Specialist in the hospital and community settings to provide clinical expertise to the broad range of HCP, people with dementia and families to build their capacity in responding to the needs of the person with dementia.
Structured family carer training and family support groups, at every stage of the journey from post diagnosis support groups to bereavement support groups to provide the knowledge and skills that the family will need to support the person with dementia to live well

Establish a National Network for Carers and a Working Group for People Living with Dementia (based on the model established in Scotland by the Scottish Dementia Working Group) in order to provide a platform for campaigning, lobbying, education and awareness raising around dementia

Develop standards for community based dementia care based on international best practice and evidence. Currently, the area of residential care has standards that are regulated by HIQA. There are no such standards supported by legislation /regulations that apply to the area of community care, particularly home care.

Develop an integrated care pathway that uses a case management approach for both the HCP and the person and their family to provide clarity on the appropriate and relevant services and supports available to the person

**Staying connected in the community**

Maintain and increase the level of dementia specific services available in the community which incorporate best practice models of dementia care. Dementia specific care services need to move beyond the traditional provision of weekday services to providing care at night and at the weekend

- Respite - new models such as home respite – e.g. Home from Home
- Develop and increase the social outlets available for people with dementia and their carers through the development of more Social Clubs and Alzheimer Cafe’s across the country
- Support the development of dementia specific family mediation/conflict resolution services and counselling support services for families to enable them to resolve issues and address crisis situations

Support the development of Dementia Friendly Communities to adapt our neighbourhoods and mainstream services to ensure they provide supportive living spaces for people with dementia to remain engaged and included

**Assistive technology**

- Assistive technology should form an intrinsic part of home care packages to improve the persons quality of life and enable the person to continue to live independently in their own home
- Develop an online database of assistive technology to help people navigate the growing range of products available

**Key Priority 3: Care in the acute hospital setting**

**The Issues:**

People with dementia often end up A&E departments or as in-patients in hospitals, settings that are far from ideal given their unique and complex needs. As with other patients in the acute hospital setting this is very often due to co-morbidities. From our knowledge and consultation, this tends to be a time of crisis in the person’s life. The transition to the acute hospital setting has been described as very traumatic and the stay in hospital is a difficult time for the person, their family and the staff in the hospital. There is a very clear need to improve the quality of care for people with dementia in hospitals.
Unplanned and unnecessary hospital admissions
In the UK, 42% of people over the age of 70 being admitted to acute care are people with dementia and these admissions are often unplanned and unnecessary.\(^\text{10}\) We find a similar situation when the Irish situation is examined. There is a clear need to avoid unnecessary hospitalisation and to enable a pathway out of hospital for the person with dementia.

Length of stay in hospital
People with dementia stay far longer in hospital than other patients who go in for the same procedure.\(^\text{11}\) The longer people with dementia are in hospital, the worse the impact on the symptoms of dementia and the individual’s physical health; discharge to residential care becomes more likely and antipsychotic drugs are more likely to be prescribed. Hospital stays can often have a negative and exacerbating effect on the person’s symptoms of dementia, with many people becoming more confused and less independent than before their admission.

Challenges to hospital staff
Acute hospital care staff have identified working with people with dementia as challenging. Common issues that occur include a lack of understanding or recognition of the symptoms of dementia; a lack of person-centred care; managing difficult or unpredictable behaviour; communication difficulties; lack of time to provide one-to-one care; and ensuring patient safety. Hospital staff struggle to meet the person’s needs and very often resort to using inappropriate pharmacological interventions in the form of anti-psychotic medication to manage behavioural and psychological symptoms.

Cost of acute care for people with dementia
In patient care is not only expensive but has a range of negative outcomes for the person. The recently published report “Creating Excellence in Dementia Care” 2012 reported that the total cost for dementia care in acute hospitals came to just over €21 million per annum.\(^\text{12}\) In-patient care can also lead to reduced independence and earlier admission to long-term residential care, with further cost implications. There is an enormous saving to be made if hospital admissions can be prevented for the person with dementia or if their length of stay can be reduced.

The Solutions:
Avoiding unplanned or unnecessary hospital admissions
- Reduce hospital admissions by providing enhanced community services and shifting investment and funding from inappropriate acute care into alternative services that are provided in the community
- Reconfigure services in the community to provide better access to care services at appropriate and anticipatory times for people in order to avoid a crisis hospital admission
- Reduce the numbers of people with dementia being transferred from the residential care setting to acute care through the provision of more proactive outreach specialist clinical support

---

\(^{10}\) Counting the cost - Caring for People with Dementia on Hospital Wards, Alzheimer’s Society UK (2009)

\(^{11}\) Counting the cost - Caring for People with Dementia on Hospital Wards, Alzheimer’s Society UK (2009)

\(^{12}\) Creating Excellence in Dementia Care, A Research Review for Ireland’s National Dementia Strategy, Chapter 3, Cahill, O’Shea, Pierce (2012)
Reducing the length of stay in hospitals for people with dementia
- Each person with dementia is given an individual care plan on admission to acute care with an integrated care pathway to accelerate their return back to the community
- When hospital admission is deemed necessary, protocols are put in place to fast track the person through A&E and promote a timely discharge
- People with dementia must be involved as far as possible in their day-to-day care and treatment decisions, in accordance with incoming capacity legislation
- The vital role of carers in providing information about the person’s situation, wishes and preferences must be recognised in all care and treatment decisions

Providing a person centred service within a hospital setting
- Involve people with dementia and families in their care to improve delivery of person centred care
- The person with dementia has access to an appropriately trained and supervised advocate during their stay in hospital
- The approach to care for people with dementia in hospitals is one based on dignity and respect for the individual and their human rights

Improving dementia awareness and training for hospital staff
- Commission the role of specialist dementia nurses to support significant changes and improvements in the standards of care for people with dementia and their families while in hospital through specialist advice on care delivery, information, training and support
- Dementia specific training for staff that addresses their concerns within the context of person-centred care for people with dementia and empowers and informs the staff
- Carry out a review of the use of anti psychotic medication in the acute setting, raise awareness of the issues that relate to the prescribing and develop clinical guidelines for doctors regarding their appropriate usage
- Develop the concept of Dementia Friendly Hospitals where a whole-hospital approach is taken that includes training and education in dementia for all personnel, provision of specialist dementia nurses and dementia friendly design principles are incorporated into the environmental designs

Key Priority 4: Life in residential care

The Issues:
Many people with dementia live in residential care, particularly, when their dementia progresses. This experience is challenging practically, emotionally and financially for both the person with dementia and their family carers. Given the key role that residential care facilities play in the provision of dementia care there is a compelling need to address the issues through the NDS.

Transition to residential care
Many carers face the experience of placing their relative in a residential care setting. However, throughout the consultation process people with dementia had a strong reluctance to entering residential care “I don’t want to be in a home. People get forgotten, nobody visits you” (Person with Dementia). Many of those we consulted with indicated that this transition is a particularly difficult time for the person with dementia and their carer. It is vital that residential care is able to provide a good quality of life for people with dementia. People with dementia in residential care are still a part of the
community and they should not be isolated as a result of an admission to residential care. "It gets to a stage where people need to be cared for by professionals, we could not provide the quality of care my mother now receives in the nursing home. Also I think she was bored at home whereas there's always something going on in the nursing home" (Family Carer).

Dementia specific residential care
A large majority of people with dementia in Ireland living in residential care, are cared for within generic care facilities for older people most of which are not purpose-built for dementia and do not cater for the complex, challenging and unique needs of people with dementia. Significant concern was expressed about the lack of availability of good quality dementia specific residential care facilities. Carers expressed that they were ‘getting the door closed in their face’ (Family Carer) when the diagnosis of dementia was brought up in conversation with the residential care provider. People with dementia had strong feelings on how residential care facilities should be operated “care homes need to look after people properly and provide a decent service” (Person with Dementia).

There is a distinct feeling the residential care service providers do not want to provide a place for people with dementia as they are perceived as difficult to manage with very high dependency levels. “My loved one has been removed from 3 private nursing homes in the last 12 months because they cannot cope with her aggressive behaviour when dressing her” (Family Carer).

New models of supported living and residential care
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 options available in this situation. The majority of people with dementia living in residential care are in generic settings, which in most cases struggle to meet the complex and often unique care needs of people with dementia. Alternative options are urgently needed to address the very serious issues that the current model creates for people with dementia, their families and for HCP working in residential care settings.

Staff training and education
The importance of people with dementia being cared for by trained staff, who have an understanding of dementia and the relevant skills needed for dementia care, cannot be underestimated. There is a significant lack of dementia training amongst nursing and care staff. Dementia care training and support focusing on the person-centred approach must be provided to all staff who work in residential care facilities. In the absence of appropriate training, many staff employed in residential care facilities find the work very stressful and challenging.

Nursing Home Support Scheme
It is reasonable to conclude that since 2009, the Nursing Home Support Scheme - Fair Deal - has been accessed by many people with dementia and their families. The majority of people with dementia in Ireland who reside in residential care live in private nursing homes. However, traditionally public beds were best placed to care for people with complex and/or chronic health problems as they had access to more intensive nursing care and a wider range of HCP and services. For a person with dementia, whose

13 Creating Excellence in Dementia Care, A Research Review for Ireland’s National Dementia Strategy, Chapter 7 Cahill, O’Shea, Pierce (2012)
condition is progressive and whose care needs intensify, having access to appropriate care responses through to end of life is a key factor in identifying appropriate residential 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 residential care facilities to have residents with lower support needs. This would suggest as we have outlined above that this has led to those with high support needs, such as people with dementia, experiencing real difficulty accessing residential care.
2. Additional costs are placed on 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.

People with younger onset dementia
People with younger onset dementia can apply to the Nursing Home Support Scheme, however there is no consideration given to the unique set of circumstances that often present when someone develops dementia at a young age. The current Nursing Home Support Scheme states that if a person is successful in their application they must identify a residential care facility from the list provided that has availability and who can meet their needs. There is no dementia specific residential care option for younger people with dementia in Ireland.

This cohort of people have unique care needs due to their age and often the type of dementia they develop. This has led to people who are under 65 either being told there are no facilities that can accommodate them or moving to one only to be told after a period of time that the nursing home cannot meet their needs and that they need to move on. The impact on both the person with dementia and their family is highly detrimental.

The Solutions:

Transition to residential care
Carers often want to continue to have a caring and familial role in their relative’s life and this should be promoted through good relationships with residential care facilities, informed and supportive staff, accessibility of the facility, and the provision of information and education about dementia and dementia care

Enhance the resourcing of, and access to, community based services for people with dementia and their carers, so that admission to residential care is a proactively planned choice rather than being crisis-driven

Recognition that people with dementia and their carers need guidance and support in order to navigate the residential care system

Community based practitioners (GPs, Public Health Nurses, Social Workers) should adopt a persuasive, proactive and preventative approach to people with dementia and their families through the prompt and gradual input of appropriate support both prior and post admission to residential care

Relevant service providers and agencies need to provide information, education and emotional support to carers at the various stages of the transition process

The person with dementia needs to have access to an appropriately trained and supervised advocate to support them to have their voice heard
New models of supported dementia specific community and residential care

- Develop alternatives to residential care for people with dementia who can no longer remain at home but who do not need high dependency care, including supported housing in local communities.
- The replication of Specialist Care Units, such as those developed in Mount Carmel, Clonakilty (public) and Moore Hall Lodge, Louth (private) around the country. These units adopted the Teaghlach Model of care and have proven very successful in meeting the needs of people with dementia.
- Access to dementia palliative care interventions in all residential care settings to ensure quality of life throughout the trajectory of the condition (see Priority 5).

Staff training and education

- Dementia education, training and on-going support for all staff working in residential care settings is essential to ensure quality care is provided.
- The continued roll out of the National Dementia Education Programme (NDEP) which is designed to deliver a suite of education programmes to nursing and support staff working with people with dementia in acute, residential and community care.
- Management of residential care facilities need to ensure the provision of dementia specific training for their staff in order to promote the provision of quality care which upholds the dignity and respect of the person with dementia.

Nursing Home Support Scheme

- An enhanced rate is introduced to the Nursing Home Support Scheme to meet the costs of providing care for people with complex needs. This will help to ensure people with dementia are not excluded from residential care due to the cost of providing specialist care.
- Funding should be available up to the same level as residential care costs to provide meaningful options to people with dementia to remain at home for as long as that is possible.

People with younger onset dementia

- Specialist residential care options for people with dementia who are under 65, which can meet their care needs through the course of the condition, should be identified and developed. Specialisms should be developed within mental health and neurological services.
- The financial assessment of the Nursing Home Support Scheme should make provision for the situation where the person requiring residential care has young dependents.

Key Priority 5: Dementia palliative care and end of life care

The Issues:
End of life care poses many challenges for the person, their family, service providers and HCP alike. However, the process of starting to name “dementia palliative care” has already begun in the dementia discourse. Through a Feasibility Study on Dementia Palliative Care (DPC) undertaken by The Alzheimer Society of Ireland and The Irish Hospice Foundation there was clear agreement for the need to build understanding, knowledge, skills and sectoral capacity in order to respond to the specific needs of
people with dementia in terms of palliative care. There is also a shared eagerness and willingness among both expert groups to engage and learn from each other to deliver a DPC agenda.

Applying palliative care principles to dementia care
DPC reflects the qualities of person-focused dementia care and the holistic focus of palliative care. Both models share a person-centred philosophy and a set of underlying principles that focuses on quality of life, whole-person care, a respect for autonomy, and care of the person and their family.

However, the very nature of dementia as a progressive organic brain disorder is challenging in terms of the application of palliative care principles in the care of the person with dementia. The duration and unpredictable nature of the disease trajectory is a very real issue. Unlike in other disease areas, it is difficult to predict when the person with dementia is actually dying and the duration of the dying phase maybe much more protracted. In addition, the best opportunity to start having these conversations, for all the obvious reasons is soon after diagnosis. Families and people with dementia acknowledge that this is a difficult process that requires timely information and support from HCP in order to facilitate these discussions.

Dementia is relatively unique in that, the earlier the DPC intervention takes place in the disease trajectory; the more appropriate it is given the nature of the condition. The ability of the person with dementia to have their voice heard at the more advanced stages of dementia is hugely challenging. Furthermore, the issue of whether people with dementia die with, or from, dementia is contended.

Understanding of DPC
There is limited knowledge of what is good DPC in practice. The skill set, education and training needs of a broad range of HCP working in this area is not yet developed. From our knowledge, it is clear that the GP is the one HCP that plays a consistent role in the end of life care process.

We also know that families and people with dementia need good quality and timely information so that they can understand what is happening and to ensure that they are empowered to take decisions that are meaningful and appropriate. “Extra support for family carers for people with dementia at the time of death/palliative care” (Family Carer). The challenge is for services providers to accept and introduce the palliative care principles appropriately throughout the disease trajectory.

Services
It has already been highlighted that there is a multiplicity of sectors and service providers involved in the care of the person with dementia throughout the illness. There are many ‘transitions’ to services—acute care, residential care, respite care, community care—at key times when DPC interventions can come into play. DPC must be located in the mainstream services and supports for people with dementia and led by dementia experts with support from the palliative care specialists.

The Feasibility Project identified that people with dementia should be diverted away from the acute hospital setting, including A&E, and these facilities should only be used in cases where there is a real

---

14 A comprehensive report is soon to be published by the Alzheimer Society of Ireland and The Irish Hospice Foundation providing in-depth detail, discussion and a set of recommendations entitled “Building Consensus for the Future: Report of the Feasibility Study on Dementia Palliative Care: Building Consensus and Signposting the Future.” Download at www.alzheimer.ie/research
need for hospital admission, based on a comprehensive assessment, with systems and protocols in place to ensure the proper response.

Residential care facilities play a critical role, particularly, for people with more advanced dementia. Throughout the Feasibility Project, residential care service providers indicated their strong desire to respond to the DPC needs of their residents but also identified that there are capacity and resource issues at play. Service providers in these settings are also key to helping and supporting families to plan and to come to terms with what the future holds.

Education and training
There is limited awareness, skills and knowledge at present across the disciplines and services in relation to DPC. It is essential that DPC interventions are approached using mixed learning methods and resources to build the knowledge and skills base in the area. This needs to take place at all the different levels of education and training across the total spectrum of the HCP.

Research
There is a dearth of research in the area of DPC and there is a need for significantly more research in this area that informs the understanding of the dynamics, parameters and elements for further building a concept and paradigm for DPC. There is also a clear need for research to take place to understand the policy, services, education and training responses required in this area. In addition to this, we need to research and map what is currently happening in Ireland around existing and developing DPC initiatives.

Policy and advocacy
There is a need to recognise from a policy perspective that dementia is a life-limiting condition which requires an appropriate multi-disciplinary service response. As such, dementia policy needs to recognise that end of life and palliative care are a central part of the dementia journey and that capacity building is needed to grow the expertise and skills among key HCP.

The Solutions:
Recognition of DPC as a speciality
- Recognition by the NDS that DPC is an area that requires skilled expertise and that interventions have relevance right throughout the disease trajectory
- Build capacity in the broad range of mainstream and dementia specific services (community/primary care/hospital/residential care) in order to introduce a palliative care approach in dementia to include planning for the future (care, legal and financial) and expressing end of life care preferences

Services
- In conjunction with the relevant clinical care programmes, a review should be undertaken of the selected sites with existing good DPC practices to examine the interdisciplinary/multi-disciplinary partnerships that takes place both in acute and residential care settings, in order to disseminate them as models of good practice for shared learning
- Engagement with the residential care sector in order to identify ways to build capacity and begin to resource DPC interventions in residential care settings
- Provide support to the acute hospitals via the proposed clinical care programme and the introduction of DPC interventions, the Irish Hospice Foundation Hospice Friendly Hospitals
Education and training
- Evaluation of the existing training and education materials in order to establish a baseline to determine how to advocate for the inclusion of DPC in the training of HCP and to strengthen the educational components on ‘dementia’, ‘palliative care’ and ‘dementia palliative care’ at all levels of HCP education and training
- Introduce education and training for GPs, PCT and all other relevant HPC regarding DPC

Research
- Formulation of a research agenda that spans policy, services, education and training and promotes DPC as a unique element within these spheres
- A commitment to supporting further research in DPC to build the paradigm and to understand the policy and practice issues
- Research and develop a range of guidance documents/good practice guidelines/decision making trees for HCP dealing with the specific aspects of end of life care for example PEG feeding, nutrition, hydration and communication etc
- Dissemination of the research findings across a range of stakeholder groups

Policy and advocacy
- The NDS gives full policy recognition to DPC as an area that requires skilled expertise and that these interventions have relevance right throughout the illness trajectory

Key Priority 6: People with younger onset dementia

The Issues:
People diagnosed with dementia at a younger age (under 65) present a unique set of needs and challenges. This cohort represents a significant proportion of the overall numbers of people living with dementia. Currently in Ireland it is estimated that 3,583 of the 41,740 people living with dementia (approximately 8.6% of the total population) are diagnosed with younger onset dementia. Obtaining a diagnosis and accessing age appropriate services are two of the key issues for people.

Typically, people who are diagnosed with younger onset dementia are in very different circumstances in life to older people with dementia. Services and interventions tend to be geared towards people aged 65 years and over. This means it is often very difficult for younger people and their families to access support, especially in the early stages. Also activities in a range of settings (residential care and day facilities) are often planned with much older and physically frailer people in mind. Dementia is so strongly associated with older people; younger people can feel extra stigma and discrimination.

Profile of people with younger onset dementia
The profile of this minority grouping of people with dementia is quite different to the majority of people with the condition. They are still of working age, most likely to be in employment, generating an income for the family and/or involved in child rearing. They are most likely to be a parent of dependent
(teenage) children and have significant financial commitments. In addition, young members of families impacted by younger onset dementia are often propelled into a caring role for their parent without the support to deal with the psychological impact on them and their family. There was a real sense throughout our consultation that this group is not acknowledged, often ignored or forgotten by the health care service. “The family of a person under 65 years with a diagnosis of dementia will spend many hours fighting a system that leaves them anxious, frustrated and very depressed” (Family Carer).

Getting a diagnosis
The difficulties of getting a diagnosis are really significant for those who are younger and outside the typical profile of those with dementia. Many GPs will see very few younger persons with dementia during their working life, and therefore tend to misdiagnose the symptoms as some form of depression and treat it accordingly. The person and their carer have to be extremely persistent and insistent to get a referral to a specialist consultant. Getting a timely diagnosis is of utmost importance to the person with dementia as it affects the person’s ability to actively arrange their family life and participate in the management of their own care for as long as they are still able to do so.

Appropriate supports and services
There is a complete dearth of appropriate information and suitable supports and services. “Having a diagnosis under 65 means you don't fit into any box in the health service, it’s not considered a disability and under 65s are not covered by elder persons services” (Family Carer). The existing services are totally unsuitable for the person and there is a need for tailor-made personalised services that are designed to meet the person’s specific requirements.

Community services play an important role in facilitating people with younger onset dementia to stay in the family home for as long as possible. However, besides the general lack of places, existing community services are far from adequately equipped to provide the services needed by younger people with dementia. Existing services primarily cater for older people with dementia and tend to lack sufficient stimulus for younger people. People with younger dementia who attend day care centres often put considerable demands on staff, mainly due to their greater level of activity, strength and, at times, challenging behaviour which is often due to the frustration they experience by being placed in an environment that does not meet their needs. Younger people with dementia have their own unique set of needs which are not met through generic older person services (e.g. medical card, information, financial planning, family counselling and specific legal advice e.g. on employment rights etc).

Access to residential care
There is an urgent need to improve residential care facilities that are available and appropriate for younger people with dementia as there are an insufficient number available. Families of people with younger onset dementia frequently find it more difficult to source appropriate facilities due to the admission criteria of existing residential care facilities.

Clarifying Departmental responsibilities
Younger onset dementia does not easily fall under the responsibility of any one section within the HSE and Department of Health. It is largely dealt with as an adjunct to dementia more generally and is therefore closely associated with services for older people. However, the care provisions which are needed in response to younger onset dementia differ significantly from those needed for older people
with dementia. Questions arise as to whether dealing with younger onset dementia is best served in the context of developing services for older people.

The Solutions:
Getting a diagnosis
- Through the proposed dementia clinical care programme, develop a small number of specialist centres with a multi-disciplinary team to support the diagnosis and clinical management of younger onset dementia

Appropriate supports and services
- Develop tailor-made service responses to include in-home respite/community services to help the person to remain involved in their community and live at home
- Develop a younger dementia community based, nurse led case management services
- Counselling and emotional support for the person with the diagnosis, their spouse and children, needs to be made available at every stage of the dementia journey
- Establish specific support groups for younger people with dementia and their families

Access to residential care
- Remove age discrimination to gain access to services including the Nursing Home Support Scheme
- Improve access to appropriate respite facilities for younger people with dementia by setting up at least one dedicated respite facility
- Review access criteria for existing residential care facilities

Clarifying Departmental responsibilities
- The HSE needs to appropriately locate people with younger onset dementia within its structures to ensure delivery of specific services that are supported by a dedicated budget
- Review the benefit criteria of the HSE to include the direct provision of, or financial support towards residential care for younger people with dementia
- Younger onset dementia is acknowledged as a specific needs group with appropriate care packages and financial supports to be drawn up to reflect the special circumstances
- Urgent consideration needs to be given by the HSE to create the necessary structures to overcome the current fragmentation of responsibilities between services for older people, disability services and mental health services, and facilitate the effective development of comprehensive dementia care for younger people, independent of age.

Key Priority 7: Addressing stigma and maintaining stakeholder awareness and education

The Issues:
Stigma, regardless of its origins, creates fear, shame, social isolation, discrimination and perceptions of negativity. The stigma associated with dementia, is an entirely socially constructed phenomenon and has a significant impact on the way people with dementia live their lives. Stigma assigns the person with dementia to a ‘new social group’ associated with devaluation, mistreatment, social exclusion and loss of status. In order to reduce the stigma associated with dementia and its consequences, dementia needs to be ‘normalised’ and seen as part of everyday life.
Awareness about dementia
There is a need to create a safe space to enable an open debate to happen and in turn demolish the current understanding and reconstruct new meanings associated with 'dementia'. Enabling the voice of the person with dementia is core to addressing stigma as is the need to move towards a new social order where people with dementia are part of the “norm”. Creating awareness and education among the range of stakeholders is important to addressing stigma and the associated social isolation. “TV and radio alone will not work without community involvement at local level” (Family Carer).

We also need to acknowledge the powerful role that the media and popular discourse play in creating the stigma and fear that is often associated with dementia amongst those directly impacted and the general public. As a result there is a strong need to work proactively with media sources to present a different picture and a different discourse that encourages and acknowledges that people can live well with dementia. This will play an important role in reframing dementia and the language adjustment that needs to take place across the public sphere (in a top down approach) to help diffuse the day to day stigma in the community.

Creating a social model of dementia
A social model of disability is an approach being suggested as a potential framework to better understand dementia and challenge stigma. It shifts the focus away from the individual and looks at how societal structures and societal responses create the stigmatisation. “People should be encouraged to maintain their independence as long as possible; continue with their hobbies, and their clubs should have a greater awareness of the condition; integrate people with dementia into society rather than keeping them on the periphery” (Family Carer). The ‘stigma of dementia’ resides not with the individual but in the broader socio-economic, attitudinal and architectural environments.

Adopting a rights-based approach
Dementia is often not framed within a disability rights model, leaving the person and their carers unaware of and excluded from the frameworks which exist to protect the rights of people with disabilities. For example, there is no recorded case of a person with dementia taking a case to the Equality Tribunal on the grounds of disability discrimination, despite it being one of the most prevalent disabilities.

The imminent introduction of modern capacity legislation in line with the UN Convention on the Rights of People with Disabilities, offers an opportunity to tackle stigma through the education of professionals, the general public, people with dementia and their carers about the presumption of capacity and the right to be supported to exercise capacity.

Political and stakeholder awareness
Maintaining political and other stakeholder awareness ensures that there is an ongoing focus on dementia as a social, political and economic issue. Keeping levels of awareness raised is crucial to engaging a broad range of stakeholder groups including clinicians, allied HCPs, community based personnel e.g. the Gardai, emergency workers and service providers in the private and public spheres. “While Government has a responsibility to provide essential services, I believe families and local communities also have vital roles to play” (Family Carer).
The Solutions:

Awareness about dementia
- Develop targeted and specific awareness and educational programmes at key stakeholder groups in particular GPs, PCT and specific allied HCPs
- Create public awareness campaigns that focus on maintaining a healthy brain, building your cognitive reserves, risk reduction strategies and early interventions
- Create new frameworks that challenge the current perceptions of living with dementia and continually work on raising awareness among the political and other stakeholders. The message needs to be one of hope with a focus on the fact that there is a life after diagnosis and that people can and do live well with dementia.

Creating a social model of dementia
- Utilise the Dementia Friendly Communities framework to create awareness in the mainstream community services and supports (Gardai, shop workers, bank and post office personnel, etc)
- Develop dementia champions within each of the stakeholder groupings to work as agents of change within their group as well as in the wider public

Rights-based approach
- Develop the capacity of and support for people with dementia to become self advocates
- Ensure that the principles of the NDS are directly informed by those of the UN Convention on the Rights of People with Disabilities and that the NDS complements existing disability policy, the National Disability Strategy, Vision for Change and the HSE Report on Congregated Settings etc.
- Collaboration with the Human Rights and Equality Body to improve awareness of dementia within the disability rights context
- Public and professional education on the new capacity legislation and the obligation to support people with dementia to exercise their capacity

Political and stakeholder awareness
- The NDS, future policy documents on dementia and information materials that are produced by the Government focuses on the new language of living well with dementia and the empowerment of the person with dementia and their families
Section 3

Developing and Implementing the Strategy

Introduction
Ireland’s first National Dementia Strategy will clearly signpost the future direction of dementia care and provide the framework for the development of dementia services for the next 5 years. Clear and transparent processes are needed in order to develop and implement a robust NDS for Ireland. As the leading advocacy organisation in dementia The Alzheimer Society of Ireland plans to play a pivotal, strategic and operational role in the development and implementation of the National Dementia Strategy.

Responsibility for developing the Strategy
The ASI believes that while the Department of Health should take the lead in developing the NDS there should be “a whole of Government” approach taken that recognises dementia as a priority. The mechanisms to achieve this are already in place via the Cabinet Committee on Social Inclusion and the Senior Officials Group on Social Inclusion. The Office for Older People should have a clearly mandated role both in the process of developing and implementing the plan. This approach would ensure that not only the health and social care needs are addressed but the broader community, environmental and equality issues are tackled in the strategy.

In addition, the Implementation Group, supporting the development of the Strategy will need to be comprehensive in nature, have capacity to seek nominations from a range of sources (both within Government and amongst the other stakeholder groupings) and a Terms of Reference that will enable them to take into account the multiple facets and range of issues that pertain to the lived experience of dementia. The Implementation Group through the course of its deliberations will also need access to specific expert advice as the process unfolds.

Implementation plan
It is essential that there is a clearly defined Implementation Plan as an integral part of the NDS. The Implementation Plan should explicitly outline the actions to be taken, the timeframe for implementing them and detail the available resources and/or reconfiguration of resources and services. It must have clear lines of accountability by naming those who are responsible for the implementing the various actions and contain a set of agreed outcomes and targets. It is imperative that a broad range of stakeholder groups are partners in the implementation of the actions emerging from the Strategy. It will require joined up thinking, new working arrangements (including commissioning of services) and systemic reform. The central motivation of the Implementation Plan will be to ensure that the potential described in the NDS for improved services and support for people affected by dementia can be realised.

The Implementation Plan will:
- Set out the priorities, actions and targets for the Strategy;
• Describe the governance arrangements to secure and monitor delivery of the Strategy, including the monitoring structure and national and regional support for implementation;
• Define a structured programme for implementation of the Strategy with measures to evaluate and report progress;
• Provide a proposed timetable for implementation
• Assign clinical ownership and leadership

**National Dementia Strategy implementation priorities**

It is essential that one of the first aims of a NDS is to identify the main priorities over specific time periods through detailed consultation with a range of stakeholders both nationally and locally in order to determine both national and local priorities. Following these consultations, priority objectives will be identified that will require focused attention to achieve urgent changes in the experiences of people with dementia and their carers. Implementation of these priority objectives will require joint planning and working between health and social care professionals and providers, the community and voluntary sectors, people with dementia and their carers.

**Implementation structure**

An implementation structure is essential to ensure effective delivery of the NDS. An Implementation Group should be established in order to monitor and measure progress of the actions and priorities in the NDS. The Implementation Group would specifically oversee the implementation of the actions and proposed next steps if necessary. It would monitor the impact of the resources that are available to implement the actions and the implications this has for decisions regarding future resource allocation. In addition it would establish a monitoring framework that is valid nationally and locally that can track changes and improvements overtime. The latter will require a commitment in the NDS to the development of a baseline for dementia.

It is recommended that the Implementation Group meets quarterly and is comprised of Principal Officers at the Department of Health, Clinical Director for Dementia, Older Person Leads in the HSE, The Alzheimer Society of Ireland and a small core operational team. Each Implementation Group member leads on particular objectives in the Strategy and would have developed detailed project plans with work streams, timelines and dates for delivery. A system of progress reporting and updating these plans would be put in place.

The tasks of the Implementation Group will include:
• Establish a consultation and awareness raising process to identify and agree the NDS priorities
• Ensure delivery of the identified priorities within the NDS, including being responsible for considering the next steps in relation to particular actions
• Set out a timetable of work with regular publicly available progress reports
• Monitor the impact of the various priorities that have a potential resource implication
• Establish a monitoring framework which is valid both nationally and locally to track change and improvement over time in respect of dementia services
• Prepare an Annual Report for the Monitoring Group to report on progress of the NDS
Leadership
A key concern of other strategies developed in Ireland and beyond has been the lack of clarity in responsibility for implementation and the lack of a systematic approach to the various strategies published. One of the key ways that a NDS can be implemented and avoid these challenges is to ensure that clear leadership is identified through the appointment of a National Clinical Directorate for Dementia. The Clinical Director will provide clinical leadership and accountability for improving dementia services.

Implementation regionally and locally
Although the NDS will set out the direction and describe where and how improvement should be pursued, translating the recommendations into delivery will need local and regional agreement and partnerships to put in place operational systems and enable effective pathways and integrated working. It is accepted that for change to be effective and sustainable it has to be locally designed and owned. Therefore it is important to recognise that local agencies will need to play a role in designing and planning local approaches although they will be supported by the national Implementation Group.

Accountability
It is essential that the responsibilities and tasks of the Implementation Group are overseen by a Monitoring Group to ensure the delivery of the agreed commitments and to monitor and track improvements in outcomes over time. It is suggested that the Implementation Group report annually on progress of the NDS to the Monitoring Group chaired by the Department of Health with a publicly available report made available. The Monitoring Group will be comprised of representatives of key stakeholders, including those from the statutory, voluntary and private sectors, regulatory bodies, as well as people with dementia and their carers.

Resources
There will be resource implications for the effective implementation of a NDS. A key objective of the Implementation Group should be to ensure that decisions on funding for future years should be made in light of learning from successful implementation plans locally and the lessons for service development nationally. The purpose of this Implementation Plan is to provide clarity and consistency on these priorities; to set out robust arrangements to support and assess the progress of the Strategy.

Communication
A communications strategy needs to be in place to ensure that information on all of the developments of the NDS are clearly available, transparent and communicated to each of the relevant stakeholders. It is recommended that the Department of Health establish a Dementia Forum which would include people with dementia, carers and representatives from of a wide range of interested parties. The aim of the Dementia Forum would be to provide guidance and information to support the work of the Implementation Group and also to receive regular reports on the progress of the implementation of the Strategy.
Appendix 1

The Alzheimer Society of Ireland Consultation Plan
Methodologies and Profiles of Participants

Rationale for consultation
It is our view that the meaningful inclusion and active participation of people with dementia, their carers, families, staff, volunteers and the wider general public is essential to inform our official response to the Department of Health’s development of the National Dementia Strategy. Participants were informed that the purpose of the consultation process was to inform our position on what should constitute the key elements of the Irish National Dementia Strategy.

Consultation process
The Alzheimer Society of Ireland put in place a comprehensive internal stakeholder consultation plan that commenced in late May 2012 and was completed in mid July 2012. In total we directly consulted with 247 people from across the organisation and incorporated a range of stakeholders.

There were **four distinct parts** to the consultation:

1. Internal consultation
2. National survey
3. Focus groups
4. Direct consultation with people with dementia

**1. Internal Consultation**
A targeted and focused consultation took place with staff and volunteers (26) from The Alzheimer Society of Ireland who came from across the country representing each of our services on the 28th June in Dublin.

**2. National Survey**
A national survey was distributed (via Survey Monkey) across the organisation to give people with dementia, carers, volunteers and staff an opportunity to have their say even if they were unable to attend a “consultation event”. As part of this survey we contacted our campaigner’s network. The campaigner’s network is comprised of people who have a signed up on our website as a “campaigner” because they have an interest in the work we do particularly around lobbying for a National Dementia Strategy. We received over 150 responses from across the country with 67% of the respondents having a direct experience of caring for a loved one with dementia.

**3. Focus Groups**
Nationwide focus groups (8) were undertaken with family carers that have links with our services, volunteers connected with The Alzheimer Society of Ireland and also members of staff.

**4. Direct consultation with people with dementia**
As this was one of the more important and challenging areas of the consultation process we will examine the methodology used for this focus group in more detail.
Direct consultation with people with dementia
It is our view that the meaningful inclusion and active participation of people with dementia is essential to inform our submission on the National Dementia Strategy to the Department of Health. We assert that it is only by gathering information from this group of people that are directly affected by the condition that the full potential of a national approach to dementia service planning can be realised. The consultation with people with dementia was based on an outreach approach and culminated in a focus group for people with dementia, alongside their key supporters where necessary (please see details in Appendix 3 which outlines the findings from the focus group).

Accessing Participants for the Consultation
Participants were sought from a number of sources including contact people have with our services, existing contact that we have with people impacted by dementia and other organisations that work directly with people with dementia (e.g. Memory Clinic, St James’s Hospital and DCU Memory Works).

Details of the Consultation
On Thursday July 19th 2012, we consulted with 5 people with dementia and 4 carers in Dublin. The aim of the consultation was discussed in detail with each of the participants in advance and information was circulated to them also. There was also direct telephone contact with the participants by the facilitator directly before the consultation.

Focus Group Details
The consultation lasted approximately 2 hours with group discussion time lasting 1 hour and the other hour an opportunity to get to know each other, explain the rationale for the consultation and to feedback the main issues identified in the group discussions. The questions asked were open ended and based on the themes used throughout the whole consultation. The focus group was facilitated by The Alzheimer Society of Ireland Advocacy team with support provided from two other members of staff that knew a number of the participants. Tea, coffee and biscuits were available on arrival and a light lunch was served after the group discussions.

The facilitator opened the focus group by explaining why the consultation was being undertaken and the particular aims for this focus group. It was then explained that there would be two groups – group 1 which would discuss the issues that impact on the person with dementia and group 2 the issues that affect carers. People were given the opportunity to choose which group they would like to participate in. All of the people with dementia chose to partake in group 1 and likewise each of the carers chose to partake in group 2 as the carers were comfortable that a member of staff would be with their loved one for the duration of the group discussion. The issues that were identified in the focus groups with people with dementia and carers are presented throughout this submission.

Focus Group – People with Dementia
For the group discussion with people with dementia it was identified that it may be difficult for some of the participants to fully get involved so the concept of a Cara Pair was introduced - Cara meaning the Irish word for friend. The Cara Pair was designed to create an opportunity for people to have some time out and 1:1 time with a member of staff. We ensured that each person with dementia was assigned a Cara. After the general group discussion time there was 5 minutes allocated for the Cara Pairs to have some time out to reflect on the issues the group had discussed. This was an opportunity for the staff
member to ask the person what they thought about what they heard or to give them the opportunity to say something they did not have the chance to say in the group. This was done to ensure that everyone had an opportunity to give their thoughts.

### Summary of Consultation

<table>
<thead>
<tr>
<th>Method</th>
<th>Date</th>
<th>Venue</th>
<th>Total no. of Participants</th>
<th>Category of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal stakeholder knowledge exchange meeting</td>
<td>June 28th 2012</td>
<td>Dublin</td>
<td>26</td>
<td>Board Branch Chairs Volunteers National Office Staff Regional Staff</td>
</tr>
<tr>
<td>National Survey</td>
<td>May – June 2012</td>
<td>Nationwide</td>
<td>151</td>
<td>Carers ASI Staff Health Care Professionals</td>
</tr>
<tr>
<td>Focus Groups</td>
<td>May – June 2012</td>
<td>Cork Ennis Dublin Dundalk Killaloe Offaly Sligo Wexford</td>
<td>54</td>
<td>35 Carers 12 Staff 7 Others (Others included Health Care Professionals, volunteers and friends)</td>
</tr>
<tr>
<td>People with Dementia Consultation</td>
<td>July 19th 2012</td>
<td>Dublin</td>
<td>16</td>
<td>5 people with dementia 4 carers 7 ASI staff</td>
</tr>
</tbody>
</table>
Appendix 2

Findings from the Alzheimer Society of Ireland National Survey of Stakeholders

Introduction
This section presents an outline of the results collected from the National Survey that was undertaken. The National Survey was drawn up using Survey Monkey and was distributed amongst our key stakeholders in the organisation including Board of Directors, Branch Committees, Staff, Carers and our Campaigners Network. It was circulated online as well as hard copy throughout the organisation and to a limited number of people not directly connected with The Alzheimer Society of Ireland. The following sections present a breakdown of some of the relevant results from the National Survey.

Section 1 - Respondents
People were asked to identify themselves using a variety of categories. The vast majority of respondents (67%) had some present or former experience of caring for a loved one with dementia. However, no person with dementia responded to the survey, this may be explained by the fact that is not a very user friendly mechanism of accessing information from people with dementia.

![Graph showing the breakdown of respondents](image-url)  
*Figure 1*
Section 2 – Getting a Diagnosis

People were asked about their experience of receiving a diagnosis and it was found that 65% of people had received a diagnosis of dementia.

Figure 2

We then went on to ask people to identify from whom they had received their diagnosis of dementia and a variety of sources were identified. The highest number of people had received their diagnosis from a Consultant Geriatrician (30%), which was closely followed by a Consultant Psychiatrist of Old Age (28%) and GPs at 27% - please see figure 3 below.

Figure 3
91% of people felt that getting a diagnosis is very important

85% of people felt that getting a diagnosis from a well-informed GP who was aware of the impact of dementia is important

90% of people responded that if they, or a loved one, were worried about their memory, having the certainty of a diagnosis is important to help them to plan ahead

Section 3 – Information and Services

98% of people either agreed or strongly agreed that having a designated person or point of contact who provides information, support and links into services following a diagnosis is helpful for the person with dementia and their family

88% of people either agreed or strongly agreed that family carers find it difficult to navigate the system to access the information and services they need to support themselves and their loved one

Section 4 – Living at Home

People were asked to identify the services that are important to them for maintaining the person with dementia to live well at home and figure 4 represents the results.

![Services that are important for people to live well at home with dementia](image-url)

*Figure 4*
85% of people strongly agreed that people with dementia should be supported to live at home for as long as possible/as long as they want to

88% of people strongly agreed that receiving dementia-specific care is vital

SECTION 5 – Awareness and Understanding of Dementia

92% of people strongly agreed that the role of the carer in maintaining a person with dementia to live well at home needs more recognition

91% of people strongly agreed that a National Dementia Strategy for Ireland is urgently needed to make sure that people living with dementia get the services and supports they need

SECTION 6 – People under 65

Please note: This section had the highest proportion of skipped questions which may demonstrate that there is still a huge lack of understanding when it comes to the issue of people affected by dementia under the age of 65. One person wrote - “For the last 4 questions - I don't know anyone under 65 with dementia so I really could not answer them”. However, for those that did respond to the questions the following was revealed:

64% strongly disagreed that dementia is a condition that only affects people over the age of 65

54% disagreed that health and social care professionals have a good understanding of the needs of people under 65 living with dementia

79% of people either strongly disagreed or disagreed that generic dementia services are age appropriate for people with dementia under the age of 65
Appendix 3

Hearing the Voice of the Person with Dementia

Rationale for the consultation
The meaningful inclusion and active participation of people with dementia is essential to inform our submission to the Department of Health for the National Dementia Strategy. We assert that it is only by gathering information from people that are directly affected by the condition that the full potential of a national approach to dementia service planning can be realised. People with dementia are also one of the more challenging stakeholders to consult with but the importance of involving them in policy development cannot be underestimated.

A focus group was organised in July 2012 to collect the views of people living with dementia. Although there were also carers present at this particular focus group (predominantly to support the person with dementia to participate) the two groups of people were divided for the group discussion. (Please note the details of the methodology used for this consultation can be found in Appendix 1). The facilitator explained that there would be two groups – group 1 which would discuss the issues that impact on the person with dementia and group 2 the issues that affect carers. People were given the opportunity to choose which group they would like to participate in. All of the people with dementia chose to partake in group 1 and likewise each of the carers chose to partake in group 2. The issues that were identified in the focus group with carers are presented throughout this submission along with the issues raised in the other focus groups held. However, this section will highlight only the issues presented to us by people with dementia.

Finding out about having dementia
Finding out that they had a diagnosis of dementia was clearly a major, life changing event for both the person and their families. We opened the group discussion by focussing on this area and people spoke about how initially they had noticed changes in their personality, mood and memory. “I kept monitoring it myself - I knew something was not quite right here.” People spoke about how they knew themselves something was wrong “there was something missing” but that they did not quite understand what was happening “it’s the frustration of not knowing.”

Although for many of those present, the actual process of getting the diagnosis was now unclear or they were unable to recall it, in many of the cases it was their loved one or their GP who actually prompted them to find out more about what was happening. One person did speak about the time they went to their GP for a check up and was referred on for a more detailed health check where a diagnosis of dementia was then given. This was described as “a shock to the system.” However, the person was subsequently told to “go home, not to worry and forget about it.” People spoke about their almost complete lack of knowledge about the symptoms of dementia and how it impacted on their daily living however, all of them expressed a desire to learn more “I can’t remember anything that I was offered or given regarding managing my dementia.”

People spoke very clearly about the shock of receiving the actual diagnosis. One person also recalled their families reaction to the diagnosis “initially there was pandemonium and panic but they got used to
The point that people were now at was very much focussed on living, staying involved and trying to do what they could. “I thought to myself – what can I do now? What do I do now? What I do now is walk around with a smile on my face because I’m still alive and I’m still happy, enjoying my life.”

One person spoke about their experience of being told to give up a sport they loved “I was told to stop everything, told to stop doing the things I liked.” This situation of people being told to give up things was often also compounded by the loss of confidence that people felt “you lose confidence” and “I thought at the beginning that this was the end of the line for me.”

Information and services
One point that people really emphasised during the consultation was the lack of information that was made available to them at the point of diagnosis and in their follow up with services. Although their families may have been presented with information, only one person could recall being given any information for themselves which they subsequently forgot about as it was not relevant for them at the time. People expressed huge frustration about this situation as they found it even more disempowering “if you just told me in the beginning to just do this and this – I would have been happy.”

People wanted to receive information about their diagnosis, appropriate services they could access and how they could plan for the future. Most of the participants did not know much about what services or support options were available to them and how they could access them. People need the right information at the right time but for people with dementia their information needs should not be ignored because of the problematic symptoms the condition brings.

More services are needed for people in the earlier stages of dementia. A number of the participants attended a service provided by The Alzheimer Society of Ireland which meets the needs of people in the earlier stages of dementia. The roles of services like the Alzheimer Cafe were also mentioned as places where people can meet other people with dementia. Many of the participants said they wanted to meet others with the condition to share their experiences and they stressed that this should not be something just for carers “get up and listen to the needs of patients and carers.”

There was a strong recognition of the role that their main family carer played in supporting them to stay involved at home and in their community and also for them to maintain a positive outlook “family carer (name) takes on a lot.”

Maintaining yourself in your home and in your community
People spoke about the importance of maintaining important roles in their lives such as one gentleman who is a grandfather. He described his grandchildren as giving him “perspective” and that he was “in awe of everything they did.” As well as roles, another point that came across strongly from people is the importance of keeping a routine “every day I go for a walk and a coffee is good. Routine is important.”

People also spoke about the importance of staying visible in their community, for instance, visiting the cafe they always went to or going to the class that they loved or even just their “need to get out”. Otherwise people felt that you risk becoming even more isolated and that a common feeling for people with dementia is that they “don’t want to be seen when you have this.”
Another important aspect for people in maintaining themselves independently in their home and in their community was their use of memory tools such as diaries and note pads that is kept with them all the time “I write everything down in my diary, it helps me remember.”

One of the most striking aspects of the group discussion was the overwhelming desire of people to stay positive and involved in their community. People really wanted to emphasise the resilient aspects of their personality which enabled them to stay positive “I am good with people, that helps.” People also spoke about the very conscious decision they had taken following their diagnosis to bring a positive attitude to their situation in order to maintain their well being “I stay positive because I made a decision to keep a positive attitude” and “it’s up to yourself to keep fit.” However, the immense impact this condition has on people’s lives and the constant changing nature of dementia was also highlighted “it is hard at times because of the things you can no longer do. You definitely feel different.”

For some of the participants who had still been working at the time of diagnosis and giving up work had quite a profound impact on them. One gentleman said in relation to his job “I miss it, the people.” Others also said that the diagnosis of dementia forced them to re-evaluate the role of work in their life “I took a step back from my working role when I received the diagnosis – I felt unsure about my ability.”

Another issue that was raised directly by the participants, as opposed to the question being asked in the group discussion, was the area of driving. Some people had already made the decision to give up driving “I drove for years but not now, I would not drive anymore”. Whereas others felt that they should not have to give up driving just because they had been diagnosed with dementia “you know something is wrong if you’re not driving properly and if you realise there’s something wrong then you know it’s time to put the keys down and stop driving.”

People emphasised the important role that family and neighbours can have. Although, two of the participants lived alone they felt they had good support from people around them “I have good neighbours that drop in for a chat and check in with me.” One person spoke very strongly about the need to discuss their diagnosis with their family, friends and neighbours because they did understand and they had received a lot of support as a result, as this person simply said “tell people you have dementia, they want to know.”

**Residential care**

Although it was not specifically addressed as a theme through the focus group the issue of residential care did come up throughout the discussion. One person in particular had strong feelings on how residential care should be operated “care homes need to look after people properly and provide a decent service.” Another person also spoke about their feelings on residential care “I don’t want to be in a home. People get forgotten, nobody visits you.”

**Conclusions**

This consultation undertaken with people with dementia was relatively small scale but it does show significant parallels with other studies and with the views of people with dementia that have been collected in other areas where dementia strategies have been developed e.g. Scotland and England. The findings demonstrate that when people are facilitated to be involved in a meaningful way, people with dementia have many thoughts and views on issues that they wish to contribute.
The differing experiences of people receiving a diagnosis of dementia were highlighted. Although, some of the participants received relatively early and swift diagnoses they felt left adrift after this process. People wanted to maintain control in their lives and they wanted to be given the information and tools to facilitate them to do this. It was also clear that people wanted a diagnosis that was delivered by someone who understood their condition and gave them the news with compassion and empathy. They wanted a person that could follow up with them after they had time to take in the meaning of their diagnosis to point them in the direction of services and information available to them. People were clear that they wanted to be part of the diagnosis process and they wanted to be facilitated to be involved in the decisions that affect them.

The lack of appropriate and timely information for people with dementia was very much identified in the group discussion. Several people reported receiving little or no information from the person who had diagnosed them or indeed any relevant follow up. As a result, people felt they were left in a very isolated and vulnerable place. The difficulty people have in getting a clear picture of the kinds of supports that are appropriate and available to them in the community may indicate that there is a necessity for people with dementia to have access to a person (e.g. case manager) who can direct them to these.

One of the strongest messages from the overall consultation was the need for people with dementia to keep living positively and continuing to do what they do. They very much want to remain as active contributors and members of their own communities. Although a diagnosis of dementia can bring a loss of confidence and a tendency to withdraw, people expressed a desire to learn more about new mechanisms they can use to maintain their well being. They wanted to be able to access services and supports that emphasise the importance of connection (in many cases with other people with dementia) and ensure that people continue to have meaningful roles to play at home and in their community. This strong desire to stay at home and be part of their community was also reflected in people’s fears regarding nursing homes and what they felt often happened to people who entered residential care.

Although, the process of involving people with dementia in consultation, particularly on policy issues, is challenging, the outcomes are essential in terms of informing the development of a National Dementia Strategy. This consultation was relatively small in scale but it presents the opportunity for ensuring that the voice of the person with dementia is truly represented in the National Dementia Strategy. This consultation has also highlighted that, when careful consideration and thought is given, to involving people with dementia they can have very powerful and meaningful contributions to make. The importance of ensuring that the voices of people with dementia are clearly heard within the development of the National Dementia Strategy cannot be over emphasised.
Appendix 4

Background to The Alzheimer Society of Ireland

The Alzheimer Society of Ireland (ASI) is a national voluntary organisation and works to meet the needs of all people with Alzheimer’s / dementia and their carers. Working in the heart of local communities, ASI provides a range of dementia-specific services and supports and advocates for the rights and needs of all people living with dementia and their families.

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 dementia. Our vision is an Ireland where no one goes through dementia alone, where policies and services respond appropriately to the person with dementia, and their carers, at the times they need support. The mission of The Alzheimer Society of Ireland is to help 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 Alzheimer Society of Ireland is the main dementia specific service provider in Ireland and provides over 120 dementia specific supports and services that include:-

- Day care (including transport)
- Home respite care
- Social clubs
- Advocacy, information and advice
- Overnight/short term respite care
- Carer support groups
- Family carer training
- Public awareness raising
- National Freephone Helpline Service

Some Key Statistics

- Currently there are approximately 42,000 people with dementia in Ireland; in 2026 there will be 70,115; in 2036 there will be 103,998
- Every year approximately 4,000 people develop Alzheimer’s disease or dementia in Ireland
- 14,266 people with dementia live in various residential care facilities throughout the country, including 537 people who are under 65. A further 644 people with dementia are thought to be reside in acute care settings and 456 people in psychiatric care settings
- There are 50,000 carers of people with dementia; the number of lives impacted 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 appropriate supports and services as currently dementia services are funded through, and designed as, older person’s 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% of family care is valued using substitution labour costs); in sharp contrast, only 6% of the cost of dementia is attributable to community care services