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A National Dementia Strategy for Ireland:

Signposting the Possibilities A Clinician's Perspective

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Section 1 - Setting the context

Why we need a plan

Irish people are now living longer and healthier lives than ever before. This increased longevity can be attributed to diverse factors such as improvements in nutrition, housing and healthcare advances. However, an ageing population brings an associated increase in age-related health problems. Among the most important and devastating of these conditions is dementia. In fact, it is hard to imagine a disease that has more profound and wide-ranging effects on individuals, their families, carers and society generally.

Dementia includes a variety of disorders including Alzheimer's Disease, Vascular Dementia, Dementia with Lewy Bodies, Fronto-temporal Dementia and other more unusual or mixed conditions. This paper uses the general term 'dementia'.

Dementia is a severe, multi-systemic and ultimately fatal brain disease affecting on average 1 in 20 people over age 65, increasing with advancing age to affect 1 in 5 people over age 80. Overall, 1 in 10 people with dementia are under age 65.

Estimates suggest that the number of people with dementia in Ireland is expected to rise from current levels of approximately 42,000 to over 100,000 by 2036 (O'Shea, 2007). However, a number of factors, including ageist attitudes in society generally and among healthcare professionals, therapeutic pessimism and the lack of a coherent voice for people with dementia combined, has meant that for many years dementia has been kept off the national agenda. If such a disorder existed in any other cohort of the population, there would surely be far more significant efforts made at a public health level to improve prevention, early detection and treatment.

Therefore, considering the vast numbers of people currently living with dementia and the projected numbers arising in the coming decades, combined with the huge personal, clinical and societal implications means that a national dementia strategy is urgently needed in Ireland (O'Connell, 2011; Cahill, 2010). In 2010, the Programme for Government gave a commitment to developing a National Dementia Strategy.

Such a strategy must be comprehensive and adequately funded and resourced. The National Dementia Strategy ideally should address dementia at all stages, from prevention and early detection right through to treatment and support for established dementia, research into future treatments and palliative care. This paper explores, from a clinician's point of view, the policy context in relation to an emerging National Dementia Strategy as well as signposting the possibilities regarding the content of the forthcoming strategy.

Background work

A number of seminal documents have emerged on the dementia policy landscape in the last two decades. These documents formally signal the principles that should be enshrined in dementia care and the service responses that are needed in order to meet the needs of both the person with dementia and their carer. In setting the background context, this section summarises key points from three important Irish policy documents relating to dementia. The first two are policy documents written by Professor Eamon O'Shea in 1999 and 2007, the latter having been commissioned by The Alzheimer Society of Ireland. The third document is a Government policy document for mental health, Vision for Change (2006).

An Action Plan for Dementia (O'Shea, 1999)

The Action Plan for Dementia presented the key points in relation to the existing level of service provision for dementia and proposed future targets and concluded with 33 recommendations. The core principles and main targets of this document are outlined below.

Core Principles in the Action Plan for Dementia

1.	Person centred models of care which respect the preferences and rights of the person with dementia
2.	Comprehensive provision
3.	Bias towards home care solutions
4.	Care requirements to determine funding
5.	Needs-based provision
6.	Evidence-based practice linked to national quality and outcome targets

Main targets outlined in Action Plan for Dementia

1.	Increased public awareness about dementia
2.	Increase in early diagnosis through enhanced training and education for Primary Care Workers, especially for General Practitioners
3.	Development of a care management model of integrated care
4.	Expansion of dedicated community-based services, e.g., Day Care services, Occupational Therapists, Community Psychiatric Nurses
5.	Expansion of dedicated Old Age Psychiatry services
6.	Development of new and expanded psychosocial approaches to complement existing medical and neurological models of service delivery in the community and residential care units
7.	Development of small-scale, appropriately assigned, special residential care units
8.	Development of new services for people with early onset dementia including people with Down Syndrome

An Action Plan for Dementia: Old Age Psychiatry Services

Regarding Old Age Psychiatry (see recommendations below), this paper reflected the policy of the Irish Division of the Royal College of Psychiatrists, as it existed at the time, and this policy has since been superseded by the principles contained within 'Vision for Change' (2006). However, the principle of primary and community care services dealing with the majority of dementia cases, with Old Age Psychiatry becoming involved when there are problems with behavioural or psychiatric symptoms, is in keeping with the general principles of Vision for Change.

Key recommendations from Action Plan for Dementia for Old Age Psychiatry services

- The provision of one consultant in Old Age Psychiatry per 10,000 people age 65 years and over, each being provided with an appropriate multi-disciplinary team and psychiatric facilities including a day hospital, acute and long-stay psychiatric beds together with good access to non-psychiatric day and residential care.
- The development of day hospitals within each Psychiatry of Old Age service for people with dementia who have associated behavioural problems or psychiatric symptoms.
- The recommendation that there be an adoption of 1 in 4,500 elderly populations for community psychiatric nursing services within the framework of an expanded Old Age Psychiatry service.
- Close cooperation was encouraged between Geriatric Medicine and Psychiatry of Old Age services.

Partly because of the lack of implementation of the recommendations of Action Plan for Dementia, O'Shea produced a document in 2007 for The Alzheimer Society of Ireland.

Implementing Policy for Dementia Care in Ireland – The Time for Action is Now (O'Shea E, 2007)

Implementing Policy for Dementia Care in Ireland provides a timely review of dementia care, highlighting the need for increased funding and coordination of services, for the purposes of early diagnosis, treatment and care, both in the community and in residential settings.

Table 1 (from O'Shea, 2007)

Year	Persons with dementia
2006	37,746
2011	42,441
2016	49,153
2021	58,044
2026	70,115
2031	85,847
2036	103,998

Some of the key points highlighted in this paper include:

- 50,000 carers in Ireland look after someone with dementia, with the median daily provision of care provided by these carers being 10 hours.
- The total cost for implementing an Action Plan for Dementia (O'Shea, 1999) in 2007 would be €73 million, made over a 3 year period, to bridge the gap between need and existing provision for people with dementia.
- The 2006 baseline estimate for the cost of dementia care in Ireland was just under €400 million: 6% is attributable to community care services, with nearly one third (33%) of the burden of care attributable to residential care.
- The annual per capita cost of dementia care in Ireland in 2004 was estimated at just under €10,000, somewhere intermediate between the countries with the highest cost of care (Finland: €19,458) and the lowest (France: €5,981)
- In 2007, there were 1,300 highly dependent people with dementia living at home and, with a Home Care Package costed at €350 per week, their needs could be met at an annual cost of €23 million.

O'Shea's paper concludes that dementia should be made a national health priority, beginning with the full and accelerated implementation of the 1999 Action Plan for Dementia (O'Shea, 1999). There is a need for a strategy that relates to people at all stages of dementia and their carers, with emphasis placed on primary care and community care solutions. Families are acknowledged as providing the bulk of care for people with dementia and they should be afforded the appropriate support.

Vision for Change (2006)

Many of the general principles contained within Vision for Change (2006), the main Government policy on the future development of mental health services in Ireland, can be related either directly or indirectly to dementia care. Such principles include early intervention, accessibility of services, a population health approach and use of the bio psychosocial model. Specifically regarding dementia, Vision for Change states that any person aged 65 years or over, with secondary behavioural and affective problems arising from experience of dementia, has the right to be cared for by mental health services for older people.

Vision for Change also recommends that primary health care teams should play a major role in assessment and screening for mental illness in older people and should work in a coordinated and integrated manner with the specialist teams to provide high quality care, particularly care that is home-based. This principle is particularly applicable to dementia diagnosis and management.

Vision for Change recommends appropriate linkages with voluntary agencies (such as The Alzheimer Society of Ireland) and highlights that carers and families should receive appropriate recognition and support including education, respite and crisis response when required.

Finally, Vision for Change recommends that older people with mental health problems should have access to nursing homes on the same basis as the rest of the population.

Section 2 - Principles that may govern the new plan for Ireland

Key principles should include an increased emphasis on prevention, early diagnosis and access to the best available treatments and social supports.

Prevention

At present, individuals presenting to healthcare professionals even in early stages of dementia may already have substantial cognitive and functional impairments, reflecting significant underlying brain disease. Furthermore, currently available dementia treatments (Acetylcholinesterase Inhibitors and Memantine) are not disease modifying or curative. Therefore, a National Dementia Strategy should incorporate principles of dementia prevention.

Emerging evidence suggests that the different types of dementia are caused by a combination of both genetic and environmental factors. Depending on the type of dementia, genetic factors have varying levels of input. Many lifestyle, environmental and health factors (both physical and psychological) are clearly identified risk factors for the development of dementia and they include cigarette smoking, obesity, diabetes, hypertension, social isolation, inactivity and head trauma. Therefore, public health measures aimed at increased awareness of dementia and its risk factors, combined with screening and treatment programmes for conditions such as diabetes and hypertension are likely to have both direct and indirect benefits on the prevention of dementia. In fact, there is recent evidence from the US (Rocca et al, 2011) demonstrating a fall in the prevalence of dementia. This fall may be due to increasingly aggressive management of vascular and other risk factors, and the authors advise cautious optimism.

Early detection

Although dementia is as yet an incurable, progressive and ultimately life limiting disease, early detection is vital in order to optimise available treatments and to help the person with dementia and their family to plan for future healthcare and also to make plans around legal and financial affairs. Primary care, in the form of General Practitioners and Primary Healthcare teams, have a vital role to play in the early detection of dementia. Research in Ireland suggests strongly that General Practitioners feel under-skilled in the diagnosis and treatment of dementia and are keen on training and guidance in this area (Cahill et al, 2006 and 2008).

Therefore, General Practitioners and Primary Healthcare teams should be sufficiently trained in terms of clinical assessment skills and access to key diagnostics such as blood tests and neuroimaging, to enable diagnosis of most cases of dementia that arise. In patients where the diagnosis is in doubt, or where there are significant complications with medical problems or psychiatric aspects, then Primary Healthcare teams should have clear and seamless links with well-resourced secondary and tertiary levels of care, in the form of adequately resourced Old Age Psychiatry, Geriatric Medicine and Memory/Cognitive Disorders Clinics.

Access to best available treatments

A range of symptomatic medication treatments exist that may help to ameliorate at least in the short term some of the cognitive, behavioural and psychological aspects of dementia. However, access to treatment may be limited by a lack of training and awareness amongst healthcare professionals. Furthermore, all available medications must be used with caution in people with dementia, as there is a potential to worsen both the dementia and general health problems. Non medication-based treatments such as psychotherapy and social supports should also be universally available.

Section 3 - Hearing the voice of the person with dementia

This paper has focussed so far on a predominantly medical model, emphasising the important status of dementia as a disease that warrants early diagnosis, prevention and treatment measures. It is also vital that the voice of the person with dementia is heard in the process of healthcare planning. Hearing the voice of the person with dementia is not simply a vague concept without practical implications. Giving a voice to people with dementia would have undoubtedly powerful impacts on public perceptions and knowledge regarding dementia, arguably more powerful than any discussions initiated by clinicians or healthcare planners.

Furthermore, the person with dementia will most likely have different priorities from the clinician or healthcare planner, being perhaps less interested in future gene therapies or prevention strategies and more interested in developing everyday supports for themselves and their families, such as adequate home-care, respite care and access to long-term care.

The National Dementia Summit (The Alzheimer Society of Ireland, 2011) was an important meeting, aimed at hearing the voice of people with dementia, along with their families and carers. Focus groups were used to discuss different themes and the findings were ultimately communicated to politicians in Dail Eireann. The themes explored included the following:

1. Getting a dementia diagnosis
2. Adjusting to a diagnosis; information and support (including services)
3. Living well with dementia
4. Awareness of dementia and public perceptions
5. Political messages
6. Younger onset dementia

For each theme, a number of key issues were developed, leading ultimately to a number of proposed solutions and published in a report 'Getting on with Life: Our action plan for living with dementia'. The themes, key issues and proposed solutions are summarised in Appendix 5 of the National Dementia Summit Report (The Alzheimer Society of Ireland, 2011).

Section 4 - International dementia strategies

There are a number of existing dementia strategies at different stages of development and delivery in many European countries. Simply having a national strategy is an essential first step for the development of services, whatever the specific national priorities.

Dementia Strategy in England

The aim of the UK strategy for England (Department of Health, UK, 2009) is to ensure that significant improvements are made to dementia services in three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care.

A consultation process was conducted, involving over 50 stakeholder groups, attended by over 4,000 individuals, and approximately 600 responses to the consultation document were received. The final document outlines 17 key strategy objectives relating to the development of a Dementia Strategy for England, as outlined in table below.

Strategy objectives for 'Living Well with Dementia: A National Dementia Strategy, Department of Health, UK (2009)

Objective 1: Improving public and professional awareness and understanding of dementia
Objective 2: Good quality early diagnosis and intervention for all
Objective 3: Good quality information for those who are diagnosed with dementia and their carers
Objective 4: Enabling easy access to care, support and advice following diagnosis
Objective 5: Development of structured peer support and learning networks
Objective 6: Improved community personal support services
Objective 7: Implementing the Carers' Strategy
Objective 8: Improved quality of care for people with dementia in General Hospitals
Objective 9: Improved intermediate care for people with dementia
Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers
Objective 11: Living well with dementia in care homes
Objective 12: Improved end of life care for people with dementia
Objective 13: An informed and effective workforce for people with dementia
Objective 14: A joint commissioning strategy for dementia
Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers
Objective 16: A clear picture of research evidence and needs
Objective 17: Effective national and regional support for implementation of the Strategy

Dementia Strategy in Northern Ireland

The Department of Health, Social Services and Public Safety in Northern Ireland (DHSSPS) has also published strategy on dementia services, 'Improving Dementia Services in Northern Ireland - A Regional Strategy' (Consultation on Improving Dementia Services in Northern Ireland, 2010).

The key messages in the Northern Ireland Dementia Strategy

Prevention - there is scope to prevent or delay the onset of dementia - mainly through a healthy lifestyle approach and reduction in cardiovascular risk factors;
Raising awareness and addressing stigma associated with the condition;
Access to early diagnosis , enhancing existing memory services to agreed standards to provide assessment, diagnosis, information and support;
Staged approach to care and support as the condition progresses, with the aim of maintaining daily living and independence as far as possible;
Improving staff awareness and skills to respond appropriately to people's needs;
Redesign of services to provide care and support, as far as possible, in people's own homes and avoid admission to hospital or care home.

Dementia Strategy in Scotland

The Scottish National Dementia Strategy identifies 8 'Action Areas', with top priority being given to:

1. The development of post-diagnostic support services
2. Improved general hospital care

Other key areas for action include:

3. Training to improve staff skills and knowledge in both health and social care settings
4. The development and implementation of dementia specific care standards
5. Targets for the reduction in the inappropriate use of antipsychotic drugs
6. Integration of health and social care for people with dementia at a local level
7. Improved data collection and information management for planning purposes
8. Action to support dementia research

The French Alzheimer Plan

The French Government launched its plan in 2008, with €1.6 billion pledged to the five-year programme. The plan consists of three main areas, with 11 main aims derived from these.

- A. Improve the quality of life of people with dementia and carers
 - Improve support and respite for carers
 - Reinforce the coordination between all key actors
 - Make home care a real option for people with dementia and their carers
 - Improve access to diagnosis and ensure a continuous chain of care
 - Improve residential care

- Develop skills sets and vocational training for all care professionals
- B. Develop our understanding of the disease for future action
- Make an unprecedented research effort
 - Set up epidemiological monitoring
- C. Mobilise society for the fight against dementia
- Provide information and increase awareness amongst the general public
 - Promote an ethical debate and approach
 - Make Alzheimer's disease a European priority

Dementia Strategy in the Netherlands

The National Dementia Programme of 2004 - 2008 has now ended and led on to the Dementia Care Plan. The Dementia Care Plan has three main objectives:

Objective 1: The creation of a coordinated range of care options throughout the Netherlands that can meet the client's needs and wishes.

Objective 2: People with dementia and their carers have sufficient access to guidance and support.

Objective 3: Measuring the quality of dementia care annually.

Learning from other Countries' Strategies

It is clear that there is a commonality to all of the plans, with each country prioritising different areas. Broadly, the commonalities focus on disease prevention, timely diagnosis, early intervention, public awareness, improving quality of life for the person with dementia and their carer, developing services and care pathways, training and education for health care professionals and research. Common to all the plans is the commitment to having people with dementia and their carers involved in decision making as well as emphasizing the central role that families and communities play in supporting people to lead a good quality of life.

Cahill et al (2012) highlight the fact that dementia continues to lag behind other chronic diseases in terms of budget allocation in most countries and in the share of resources devoted to research on the topic, particularly relative to the disease burden. Developing a National Dementia Strategy is, however, an important first step in generating additional resources for dementia.

Section 5: The Irish National Dementia Strategy: What could, should and must be included in the plan

As indicated, there are various priorities emerging in the dementia plans across Europe. Some of them are very comprehensive in nature, for example the English strategy with its 17 objectives, and others are really focused into key areas. For example, the Scottish plan has 8 proposed areas of work but has prioritised two, diagnosis and acute care. Given the current economic context, it probably makes sense for Irish policy makers to follow the model of the Scottish plan, where a very clear set of issues are addressed with a prioritisation given to two key areas over the five year period of the plan.

In terms of what 'should' be in the plan, the content might look something like:

- Putting in place a national dementia **screening** strategy for everyone over age 65
- Developing an **individualised care-plan** for each person diagnosed with dementia using case managers. Such a care plan would be comprehensive and individualised for each person. The care plan would cover all aspects of dementia care, such as dealing with diagnosis, legal and financial aspects, accessing services and best available treatments. The care plan could also serve as a '**health-passport**', thus ensuring that all healthcare professionals and other agencies that come into contact with the individual would be aware of the individual's diagnosis, treatments and specific needs. This would be especially relevant for example when a person with dementia is admitted to acute hospital.
- Dementia care incorporated into all aspects of **national health policy**
- Dementia **education and training** for all healthcare professionals
- Specific training on detection, diagnosis and treatment of dementia for **Primary Care** workers
- Adequately resourced **specialist services** such as Old Age Psychiatry and Geriatric Medicine throughout Ireland
- Adequately resourced and accessible **Memory/Cognitive Disorders Clinics** throughout Ireland
- An increased emphasis on adequate resourcing of **home-care solutions** when feasible, with increased provision for home-care packages
- A range of social supports, care services and a **clear pathway** are put in place right across the spectrum of the disease with appropriate opportunities for planning for the future and timely information is provided at the relevant stages both for the person with dementia and their carer.
- **Best practice standards** in respite and long-term care
- Increased emphasis on **prevention measures**
- Increased funding for **research** on future treatments
- Increased emphasis on **evidence based approaches** to the best use of currently available medication and non-medication treatments
- Increased emphasis on **palliative care** in end-stage dementia

However, while the wish list is laudable, the reality of the situation is that the Irish Government will have to prioritise and move towards what is possible to achieve within the timeframe, the resource mix and the capacity of a rapidly changing healthcare system to deliver the services needed. Therefore, writing from the clinician's perspective, it is suggested that the following key areas should form part of the Irish National Dementia Strategy.

1. Early detection and diagnosis to include **clinical training for General Practitioners** and an enhancement of the availability of dementia specialists within primary care
2. **Dementia awareness**, education and training for all healthcare professionals and service providers
3. Individualised **care planning** to become a standard feature of dementia care

Section 6: How to evaluate outputs and outcomes of the plan?

Ideally, evaluation of outputs and outcomes should follow on from the aspirations outlined in Section 5 above, i.e. it should be possible to evaluate the impact of any strategy implemented, in terms of its impact on people with dementia, carers, families and also in terms of a cost-effectiveness analysis. Comparisons for all outputs and outcomes should also be made between Irish regions and for Ireland in comparison with other countries.

Evaluation and Measurement

Any new approaches introduced in a dementia strategy should be evaluated and measured in order to assess their impact on people with dementia, their carers and family members. Only with evaluation and measurement can the efficacy of new approaches be adequately assessed.

Examples of evaluation and measurement:

- Incidence and prevalence rates for dementia (to assess impact of prevention strategies, as in the Rocca et al 2011 study)
- Patient and family satisfaction surveys (qualitative)
- Surveys of healthcare professionals and carers working with people with dementia (qualitative)
- Database on numbers of people diagnosed with dementia, numbers who have had specialist assessment and diagnosis, numbers on dementia medications (quantitative)
- Life expectancy for people with dementia (quantitative)
- Levels of acute hospitalisation for people with dementia (quantitative)
- Levels of respite care available for people with dementia
- Levels of long-term care for people with dementia
- Regional variations in patient experiences, clinical practice and available services
- Cost-benefit analysis to examine economic implications for investment in dementia care (and to highlight the economic benefits of adequately planned dementia care)

Section 7 – Conclusion

What do we want for Ireland?

Dementia policy in Ireland has historically been patchy and relatively under-resourced. It has remained on the margins for many years but the commitment in the Programme for Government has added a new impetus for the need to move towards a more co-ordinated and appropriately resourced strategy that needs to translate into a clear and workable implementation plan. To this end, focusing on a small number of key priority areas is a sensible approach and one that allows change to happen that leads to improved quality of life for the person with dementia and their family.

Recent evidence

This year, a research report entitled ‘Creating Excellence in Dementia Care: A Research review of Ireland’s National Dementia Strategy’ (Cahill et al 2012) provides an up to date evidence base to inform the development of a new strategy. It provides contemporary data to support the proposed new strategy and guidelines as to the future direction of public policy for dementia in Ireland. The key elements that have been identified for the new strategy include (in summary):

- Emphasis on primary prevention
- Enhanced public awareness
- Early diagnosis
- Case management models of integrated care
- Expansion of flexible community services
- Developing psychosocial approaches
- Developing appropriately designed residential units
- Greater leadership of dementia in acute care
- Expansion of palliative care services
- Developing services for younger people with dementia
- Enhanced information systems

Final Remarks

There is now compelling and extensive research and evidence both nationally and internationally for the development of an Irish Dementia Strategy. In addition, hearing the voice of the person with dementia and their carer is an essential prerequisite to the development of the strategy. Other clinical stakeholders must be engaged in the process. There is a real appetite for change and a momentum building to transform the lived experience of dementia and make dementia a part of our everyday lives.

Glossary of terms

Acetylcholinesterase Inhibitors: A group of drugs used in the treatment of dementia (Donepezil, Galantamine and Rivastigmine). These drugs act by increasing the levels of acetylcholine, a brain chemical involved in memory and other cognitive functions. They can lead to short and medium term improvements in memory and thinking and in the behavioural and psychological aspects of dementia.

Alzheimer's Dementia: The commonest type of dementia, accounting for approximately two thirds of cases. Memory and language are primarily affected in the early stages, with a gradual progression to involve different aspects of thinking, psychological symptoms and behavioural changes.

Cognitive impairment: A general term used to describe the wide range of changes seen in people with dementia, including deterioration in memory, language, orientation, thinking and judgement.

Dementia: A brain disorder that leads to general cognitive decline, psychological changes, behavioural and personality changes and progression to involve functional impairment and physical deterioration.

Dementia with Lewy Bodies: A specific type of dementia characterised by parkinson's-like symptoms (e.g. tremor, reduced mobility), visual hallucinations (seeing things that are not actually present) and fluctuating cognition (i.e. changes in the levels of confusion). It accounts for 5-15% of dementia cases.

Frontotemporal Dementia: A specific type of dementia characterized by changes in personality, judgement and behaviour in the earlier stages, with a gradual progression to involve other aspects of thinking. It accounts for less than 5% of dementia cases.

Functional impairment: The loss of abilities to do both everyday tasks (e.g. care for self) and more complex tasks (e.g. reading) due to a disorder such as dementia.

Memantine: A drug used in the treatment of all types of dementia, at all stages. It works by reducing the toxic effects of Glutamate, a chemical in the brain. Memantine can help by reducing the levels of behavioural disturbance in dementia.

Neuroimaging: The use of brain scans such as CT and MRI. In dementia assessment, scanning is usually used to identify blood vessel changes, recent stroke, tumours and excess fluid in the brain.

Vascular Dementia: A specific type of dementia that follows after significant blood vessel damage or stroke. It accounts for 15-25% of cases of dementia and is sometimes mixed with other types of dementia, mainly Alzheimer's.

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