Developing a National Dementia Strategy for Ireland: An Overview of The Research Review

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Acknowledgements
Overview

- Background
- Dementia Research Review
- Core Activities
- Key Actions
Dementia in Ireland Today

- Most recent estimates suggest 37,900 people with dementia in Ireland (Diaz, 2008)

- Great stigma associated with diagnosis of dementia (ASI, 2006; Cahill et al., 2008)

- Financial, emotional and social cost of dementia is high in Ireland (O’Shea, 2007).

- Public knowledge improving but attitudes in Ireland remain largely negative, pessimistic and nihilistic

- PwD are one of the most vulnerable and invisible groups in Irish society today

- The predicted change in age structure of the population – particularly in the old old, - will significantly influence future dementia prevalence rates
Actual and Projected Population of Older People in Ireland by Age Group, 2006-2041 (MOF2) (Source: CSO, 2008)
Government Policy

- Stated objective of government policy for people with dementia is to facilitate their continued living at home for as long as possible and practicable.

(The Years Ahead, 1988; Shaping a Healthier Future, 1994; A Review of the Years Ahead, 1997; Action Plan on Dementia, 1999; A National Health Strategy, 2001; Dementia Manifesto, 2007; HSE Report on Dementia, 2007)
Caregiver Burden across 5 European Countries at three points in time (ENABLE, 2004)

<table>
<thead>
<tr>
<th>Country</th>
<th>At the beginning</th>
<th>After 1 month</th>
<th>After 3 months</th>
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<tbody>
<tr>
<td>England</td>
<td>22</td>
<td>20</td>
<td>20.5</td>
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<tr>
<td>Finland</td>
<td>21</td>
<td>19</td>
<td>20</td>
</tr>
<tr>
<td>Ireland</td>
<td>23</td>
<td>26</td>
<td>23</td>
</tr>
<tr>
<td>Lithuania</td>
<td>31</td>
<td>26</td>
<td>23</td>
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<tr>
<td>Norway</td>
<td>12</td>
<td>17</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>24.5</td>
<td>24</td>
<td>23</td>
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## Recent Developments in Ireland

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<tbody>
<tr>
<td>Apr 2010</td>
<td>Ministerial announcement of Government commitment to Dementia Strategy</td>
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<tr>
<td>May 2010</td>
<td>Prime Time Investigates + Front Line programme</td>
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<td>May 2010</td>
<td>Roundtable meeting of AP-funded dementia stakeholders</td>
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<tr>
<td>Jun 2010</td>
<td>Dementia research review – AP Grant application</td>
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<tr>
<td>Oct 2010</td>
<td>Funding received from AP</td>
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<tr>
<td>Mar 2011</td>
<td>Dementia Strategy in Programme for Government</td>
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<td>June 2011</td>
<td>Departmental announcement of formal work on Dementia Strategy to commence by end 2011</td>
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Phase 1: Research review

- Establishment of Multi-Disciplinary Dementia Advisory Committee to guide research review (Phase 1)
  - Appoint Chairperson(s) and Research Fellow
  - Generate an evidence-based report resulting in key recommendations for dementia services in Ireland. Report to be submitted to the Department of Health (December 2011) who will take control of Phase 2 of the project
  - Host a major National Conference in Dublin (January 2012) with invited international guest speakers with experience of developing National Dementia Strategies
Core actions agreed to inform new Departmental Strategy

1. Generate new data on dementia prevalence rates and Projections up to 2041

2. Calculate new data for Ireland on the main economic costs of care

3. Generate information on community and residential care services based on extensive review of dementia care system

4. Identify lessons to be learned from national dementia strategies elsewhere
1. Prevalence

- Literature reviewed on Dementia Prevalence rates globally and within Europe – 35 million and 7.7 million respectively

- New prevalence data generated for Ireland based on Census 2006 data and applying both the EuroDem and EuroCode age/gender dementia specific prevalence rates

- New Estimates of dementia prevalence at local (HSE LHO area and county) level in Ireland have been calculated

- New projections on dementia prevalence rates in Ireland up to 2041 have been calculated based on CSO 2008 data and using two different methodologies
2. Main costs of dementia

- New burden of illness estimate has been produced for dementia in Ireland

- A variety of national and international sources have been used to put together unit cost data for the first time

- Main cost drivers of burden have been identified: informal care, residential care, primary care, community care, acute care and drugs

- Irish burden has been analysed in comparative context
3. Service review

Engagement with Services

- Primary care
- Community care – Generic and dementia-specific
- Secondary care
- General hospital care
- Residential care
- Palliative care
One Example
General hospital services

- Prevalence: Up to 25% of hospital patients are PwD, figures vary widely across hospital wards (Sampson *et al.*, 2009; Mukadam and Sampson, 2010)

- Detection and assessment: significant under-detection before and following admission; assessment in hospital not often considered; dementia may be known but not recorded or communicated (Afzal *et al.*, 2010; Bentley and Meyer, 2004; Hickey *et al.*, 1997; Sampson *et al.*, 2009)

- Patient Outcomes: length of stay longer; higher mortality after admission; less likely to return home on discharge from hospital (Alzheimer’s Society, 2009; ESRI, 2010; MacNeill and Lichtenburg, 1997)

- Hospital environment: causes distress/confusion; PwD paint bleak picture of their experiences; staff have a significant impact (Cowdell, 2010; Nolan, 2006)

- Behaviours that challenge a significant issue (Borbasi, 2009; McGlade, 2009)

- Limited staff knowledge and understanding is a major constraint to best practice
4. Review of Dementia Strategies

- What is the overall approach taken in other National Strategies?
- What principles and key concepts underpin these strategies?
- What areas are prioritised and why?
- What research evidence informs these Strategies?
- What models of Service Reform have been recommended?
- What examples of Best Practice can be gleaned from NDS?
- Which country’s Strategy has most application to Ireland?
- What can we in Ireland learn from NDS?
4. National Dementia Strategies:

- *Living Well with Dementia (England)*: comprehensive, address continuum of care from diagnosis to death, focus on 3 areas – (i) public and professional understandings; (ii) early diagnosis, (iii) treatment and support; (iv) quality care in community, hospital and residential settings

- **France**: ambitious: making dementia a European priority, commitment to resources, detailed implementation plan; focuses on a broad range of areas including raising awareness of dementia

- *Making the Most of the Good Days (Norway)*: Focus on 3 areas – Day care, Developing and adapting Nursing Homes; Increased knowledge and skills for all

- **Scotland**: key services delivery areas – Improved post-diagnostic information and support; Improved care in general hospital settings, including alternatives to admission

- **Australia/Canada**: Incorporate a focus on prevention - research, risk reduction, delaying onset of dementia
Approaches to raising awareness

- Gaining an understanding of knowledge of and attitudes to dementia - though literature reviews, representative surveys and qualitative research (e.g. France, Wales)

- Improving understanding of dementia among the general public - though evidence-based national, local, targeted awareness campaigns (e.g. England, Wales, Scotland)

- Promoting and supporting help-seeking – through information campaign (e.g. England)

- Involvement of people with dementia in community activities (e.g. Scotland)
Summary: Arising from the Research Review

- New dementia prevalence data and projections on future prevalence rates generated for Ireland

- New burden of illness estimates for dementia generated for Ireland

- New information on existing service provision and deficits at regional and national levels for PwD

- Best Practice emerging from other National Dementia Strategies identified
Conclusion

- Dementia has remained a hugely neglected, underfunded and under-prioritised issue in Ireland

- The evidence is convincing and conclusive that the baseline profile of services for people with dementia in Ireland is very low

- We need a careful crafted National Dementia Strategy based on up-to-date research evidence, as provided by the review, and the involvement of all stakeholder groups in Phase 2

- We need coalition of interests to advocate for prioritisation of dementia in public resource allocation process
Acknowledgements

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Vanessa Moore: Research Assistant
References


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