Reframing Dementia - An Irish perspective

Eamon O'Shea
Dementia in Ireland Today

- Dementia an ageing problem
- Great stigma still associated with diagnosis of dementia
- Financial, emotional and social cost of dementia is high
- Public knowledge improving, but attitudes remain largely negative pessimistic and nihilistic
- People with dementia 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
- Need for clinical, economic and social discourse
Actual and Projected Population of Older People in Ireland by Age Group, 2006-2041 (MOF2) (Source: CSO, 2008)
Actual number and projected growth in the number of people with dementia in Ireland by age group, 2006-2041 (M0F2) (n)

<table>
<thead>
<tr>
<th>Age groups</th>
<th>2006</th>
<th>2011</th>
<th>2016</th>
<th>2021</th>
<th>2026</th>
<th>2031</th>
<th>2036</th>
<th>2041</th>
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</thead>
<tbody>
<tr>
<td>30-59</td>
<td>2,576</td>
<td>2,803</td>
<td>2,967</td>
<td>2,982</td>
<td>2,930</td>
<td>2,869</td>
<td>2,791</td>
<td>2,686</td>
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<tr>
<td>60-64</td>
<td>983</td>
<td>1,193</td>
<td>1,303</td>
<td>1,449</td>
<td>1,592</td>
<td>1,696</td>
<td>1,853</td>
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<tr>
<td>65-69</td>
<td>2,258</td>
<td>2,734</td>
<td>3,334</td>
<td>3,649</td>
<td>4,069</td>
<td>4,488</td>
<td>4,842</td>
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<td>70-74</td>
<td>4,130</td>
<td>4,542</td>
<td>5,575</td>
<td>6,868</td>
<td>7,576</td>
<td>8,495</td>
<td>9,397</td>
<td>10,141</td>
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<tr>
<td>75-79</td>
<td>6,716</td>
<td>7,378</td>
<td>8,328</td>
<td>10,421</td>
<td>12,992</td>
<td>14,467</td>
<td>16,323</td>
<td>18,178</td>
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<tr>
<td>80-84</td>
<td>10,096</td>
<td>10,924</td>
<td>12,504</td>
<td>14,543</td>
<td>18,632</td>
<td>23,568</td>
<td>26,554</td>
<td>30,301</td>
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<td>85+</td>
<td>14,688</td>
<td>18,319</td>
<td>22,392</td>
<td>27,581</td>
<td>34,131</td>
<td>44,464</td>
<td>58,441</td>
<td>71,946</td>
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<tr>
<td>Total</td>
<td>41,447</td>
<td>47,893</td>
<td>56,404</td>
<td>67,493</td>
<td>81,922</td>
<td>100,047</td>
<td>120,201</td>
<td>140,580</td>
</tr>
</tbody>
</table>

Main costs of dementia

- New burden of illness estimate has been produced for dementia in Ireland: 1.7 billion

- 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 >50% and residential care

- Primary care and community care low in comparison

- Irish burden has been analysed in comparative context- burden significant relative to other diseases
Current Realities

- Lack of focus on prevention
- Diagnosis - poor – stigma, instruments, resources, pathways
- Most people unaware they have disease
- Too few memory clinics
- Primary care – knowledge, information, pathways
- Community care – fragmented and incomplete
- General hospital care – awareness, training, education
- Residential care – focus on instrumental care - weak on personhood and quality of life
- Palliative care - poor
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)
A National Dementia Strategy for Ireland

“We will develop a national Alzheimer’s and other dementias strategy by 2013 to increase awareness, ensure early diagnosis and intervention, and development of enhanced community based services. This strategy will be implemented over five years” (p. 38)

(Programme for Government 2011-2016)
Other Countries

- **Living Well with Dementia (England)**: comprehensive, address continuum of care from diagnosis to death, (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 ring-fenced 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

- **European**: Emerging European themes: origins of ND disease; disease mechanisms and models; disease definitions and diagnosis; developing therapies, preventive strategies and interventions; health care and social care
Genio Initiative

- Developing and testing new service models within local communities
- Funding from AP and HSE
- Four initiatives being funded
- Innovation in primary and community care
- Focus on people with dementia and communities within which they live
- Consortia include: carers and individuals with dementia/representative older people; community groups with a focus on older people; organisations/community groups with a focus on carers and families; voluntary/not-for-profit organisations with a focus on dementia; GP(s) and other primary health care providers such as public health nurses, home helps etc.; providers of ‘mainstream’ services for older people, for example, HSE day centres; and other mainstream voluntary and community groups and initiatives.
Current Policy Frames

- Individual
- Biological
- Residential
- Risk
- Deficits
- Exclusion
Counter Policy Frames

- Collective
- Social
- Home
- Capabilities
- Assets
- Inclusion
Practice Implications: Collective

- Making dementia public
- Knowledge for people with dementia
- Knowledge for health professionals
- Combating ageism and prejudice
- Policy and planning
- Prioritising dementia
Practice Implications: Social

- Maintaining identity
- Enabling relationships
- Securing attachments to people and places
- Challenging communities
- Sustaining care relationships
- Replicating good practice
Practice Implications: Home

- Self and identity
- Biography and personality
- Care services
- Autonomy and empowerment
- Giving and receiving
- Funding models
Capabilities

- Stages of the disease
- Younger people with dementia
- Relationships
- Physicality
- Personhood explained
- Partial equilibrium
Assets

- Person with dementia as active citizen
- Being, doing and failures
- Whole families and communities
- Networks, friendships, dignity, respect
- Memory and relationships
- Power of now
Inclusion

- Citizenship
- Rights
- Home
- Visibility
- Acceptance
- Protection
- Resource allocation
Conclusion

- Dementia is the most important ageing question
- Mobilising intellectual resources in support of liberating dementia strategy
- Creating awareness and understanding
- Agreeing key priorities
- The practice of personhood
The Challenge

- Do we have the vision, courage and capacity to imagine and initiate a new paradigm for people with dementia?
- Like dementia itself, only time will tell!