



Reframing Dementia - An Irish perspective

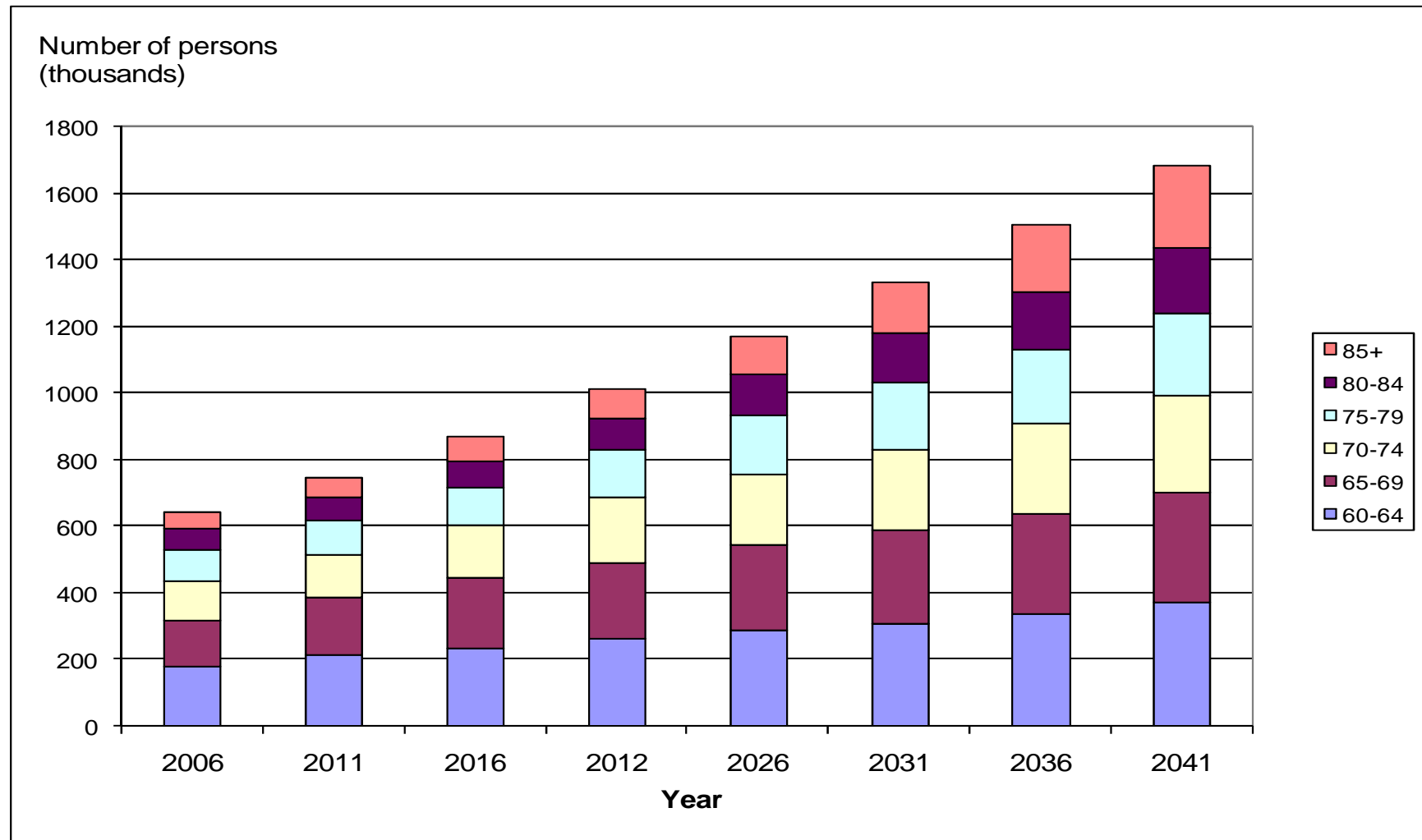
Eamon O'Shea



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 (MOF2) (n)

Age groups	2006	2011	2016	2021	2026	2031	2036	2041
30-59	2,576	2,803	2,967	2,982	2,930	2,869	2,791	2,686
60-64	983	1,193	1,303	1,449	1,592	1,696	1,853	2,024
65-69	2,258	2,734	3,334	3,649	4,069	4,488	4,842	5,304
70-74	4,130	4,542	5,575	6,868	7,576	8,495	9,397	10,141
75-79	6,716	7,378	8,328	10,421	12,992	14,467	16,323	18,178
80-84	10,096	10,924	12,504	14,543	18,632	23,568	26,554	30,301
85+	14,688	18,319	22,392	27,581	34,131	44,464	58,441	71,946
Total	41,447	47,893	56,404	67,493	81,922	100,047	120,201	140,580

Source: CSO (2008) *Population and Labour Force Projections, 2011-2041*, Stationary Office, Dublin, Table 5, p. 42; EuroCoDe (2009) estimates of age/gender-specific prevalence of dementia rates.



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!