

# Confronting Dementia in Ireland: Creating and Reviewing the Research Evidence for a National Dementia Strategy

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The Science Gallery, Trinity College Dublin

# Acknowledgements



School  
of Social Work  
and Social Policy



Irish Centre for Social Gerontology

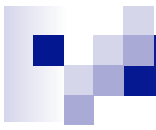


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# Overview

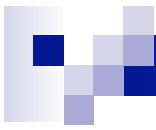
- Background
- Dementia Research Review
- Core Actions
- Methodology
- Key Findings
- Summary



Marius Bernon

# Core actions

1. Review current and future demographic trends in Ireland and provide estimates of current and future dementia prevalence rates
2. Calculate new data for Ireland on the main economic costs of care
3. Review current service availability (based on recent HSE audit) and estimate future demand for services
4. Examine best practice in dementia care locally and internationally



# Methodology

- Literature review
- Secondary analysis
- Interviews with experts
- Guidance from Dementia Advisory Committee

# 1. Prevalence

- Literature reviewed on dementia prevalence rates globally and within Europe - 35 million (Ferri *et al.*, 2005) and 7 million (Prince, 2009) respectively
- New prevalence data generated based on Census 2006 data and applying EuroCoDe age/gender dementia specific prevalence rates
- New estimates of dementia prevalence at local (HSE LHO area) 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 sets of projections

Estimated number of people with dementia by age group and gender in Ireland, 2006, as per EuroCoDe age-related dementia prevalence rates

Age groups	Total Population (Census 2006)		Persons with dementia		
	Men	Women	Men	Women	Total
30-59	869,212	850,724	1,738	851	2,589
60-64	91,561	90,166	183	811	994
65-69	70,895	72,501	1,276	1,015	2,291
70-74	56,540	62,612	1,809	2,379	4,188
75-79	40,121	52,345	2,808	3,978	6,786
80-84	24,694	40,190	3,581	6,591	10,172
85-89	11,021	22,281	2,303	6,350	8,653
90-94	3,231	8,814	943	3,913	4,856
95+	593	2,088	192	1,019	1,211
Total			14,833	26,907	41,740

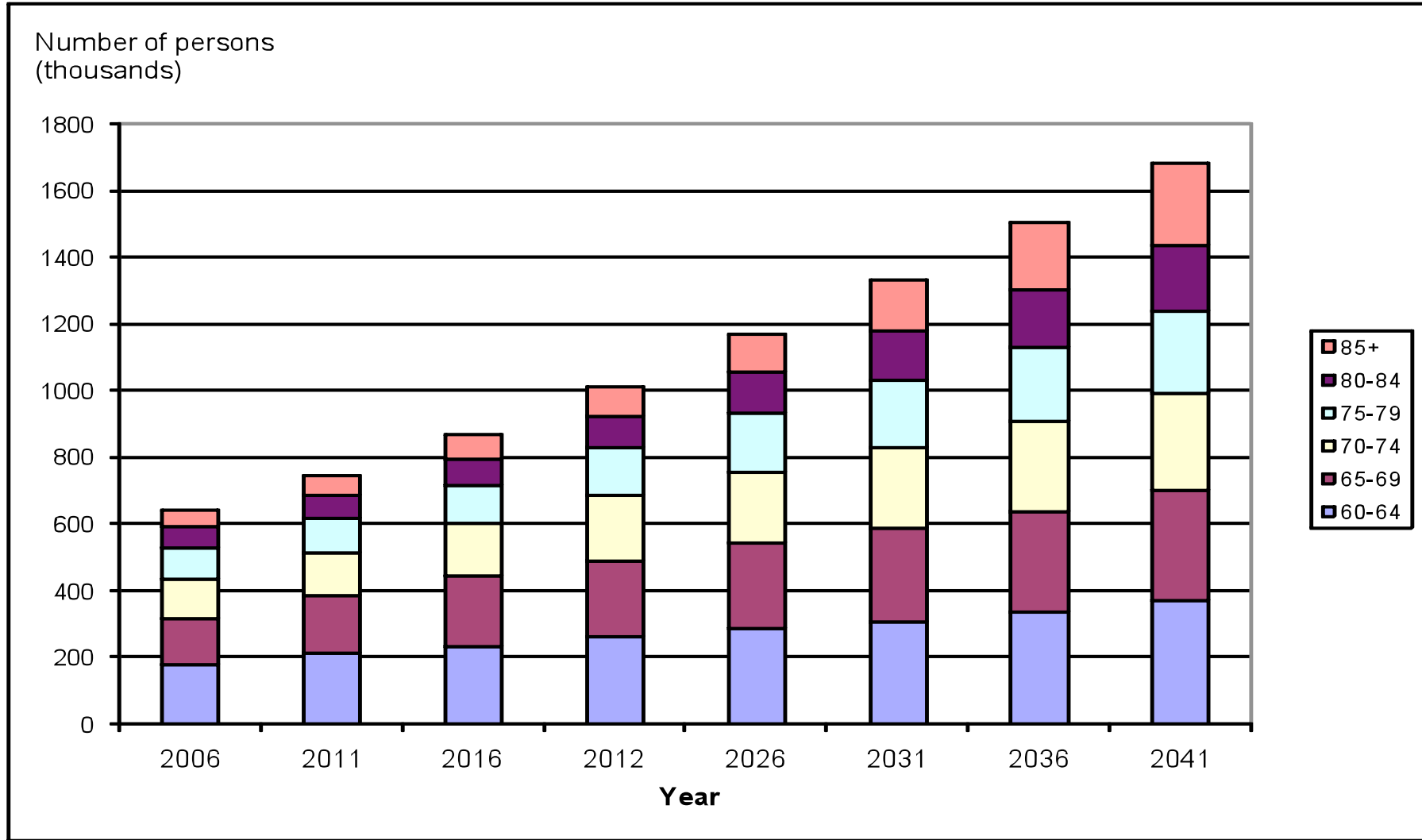




## **Prevalence of dementia in Ireland (2006) at local level (i.e. HSE Local Health Office area)**

- West (1.13%) all LHO areas have dementia prevalence rates  $> 1.00\%$ , with Roscommon highest in the country at 1.40%
- South (1.04%) with a diversity of prevalence rates
- Dublin/Mid-Leinster (0.90%) with Dublin West lowest in the country at 0.63%
- Dublin/North East (0.87%) – majority of LHO areas have dementia prevalence rates below 1.00%

# Actual and Projected Population of Older People in Ireland by Age Group, 2006-2041 (M0F2) (Source: CSO, 2008)



Actual number and projected growth in the number of people with dementia in Ireland by age group, 2006-2041 (M0F2) (n)

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



## Distribution of people with dementia across care settings in Ireland

Care Setting	Number of people with dementia	%
Community	26,104	63%
Acute Care	644	2%
Psychiatric care	456	1%
Long stay residential care	14,266	34%
All	41,470	100%

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## 2. Service Review

- Primary and Community Care
- General hospital care
- Residential care

# Primary and Community Care

- Dementia remains invisible and diagnosis exception rather than the rule
- Most GPs reluctant to diagnose
- No dementia registers or financial incentives to diagnose
- Memory clinics thinly distributed
- Family members report diagnosis not well managed
- No PHNs, CMHNs or PNs with a dementia remit
- Great paucity of day care centres and home care services
- No Case-Worker or Key Contact person



## 2. General Hospital Care

- Prevalence (Hickey, Clinch and Groarke, 1997)
- Medical condition rather than dementia precipitates hospital admission
- Detection and assessment poor (Afzal et al., 2010)
- Length of stay four times longer than other people over 65 (ESRI, 2010)
- Hospital environment inappropriate (Nolan, 2007)
- Need for staff training (De Siún and Manning, 2010)
- Unlikely to be offered palliative care (Afzal et al., 2010)

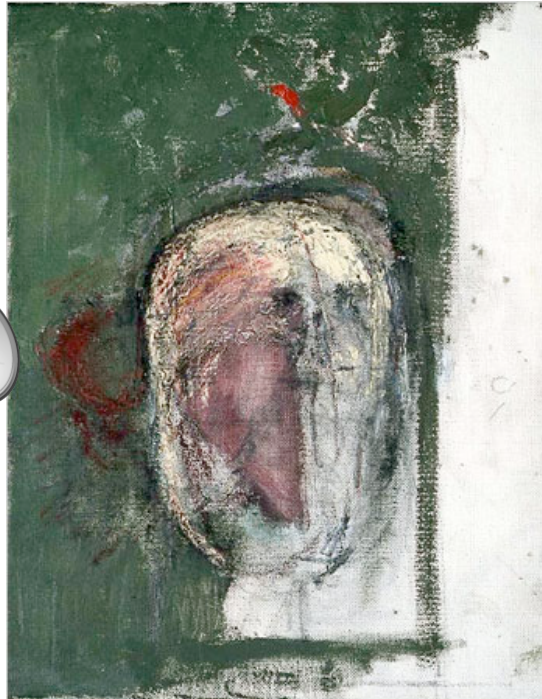
# General Hospital Services



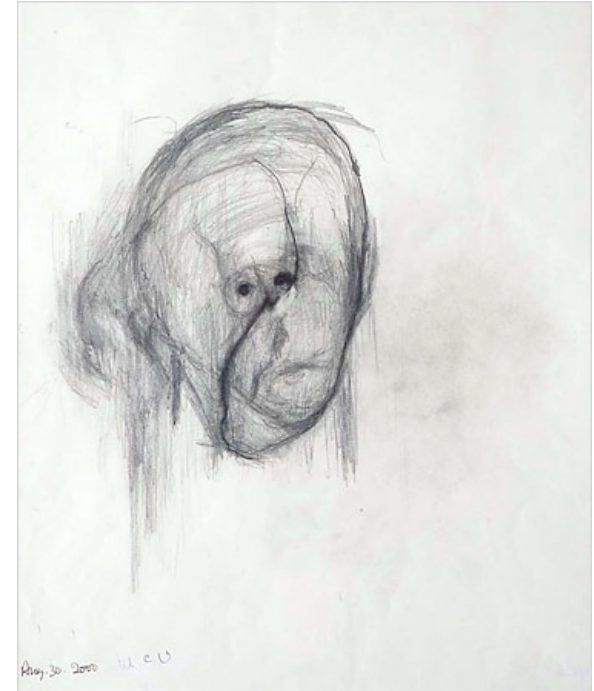




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1999



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## 3. Residential Care

- Prevalence – 2/3 of all people in long stay care have dementia
- Few alternatives to nursing home
- Only 14% (21 out of 151) public units have dementia beds
- Few dedicated specialist care units in the private sector (about one in five)
- Quality of Life
- No information collected by HIQA on dementia

# Stereotypical View of Residential Care





# Best Practice Models in Ireland



  
The Alzheimer Café  
Donnybrook, Dublin 4



Join us for a cup of tea and cake



# Best Practice Models Internationally

- Case Management Models (Netherlands, England and Scotland)
- Dementia community care teams (Sweden, Norway)
- In-Hospital Dementia Programs with champions (Scotland, USA and Australia)
- Specialist Care Units (Netherlands, Norway)
- SCUs for those with severe challenging behaviours (France)

## 3. Best Practice internationally: 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
- **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



# ■ Core Area for Ireland's Future Dementia Strategy

- Primary prevention
- Public awareness
- Training and Education for primary care workers
- Increase in early diagnosis through improving linkages between GPs, hospital services and Memory Clinics
- Development of a Case Management model of integrated care
- Expansion of dedicated community-based services (for example, day care services) for people with dementia and their carers



## Core Areas (Ctd)

- Development of new and expanded psychosocial approaches to complement existing medical and neurological models of service delivery in the community and in residential care units
- Development of small-scale, appropriately designed, residential care units
- Development of appropriate services for people with dementia, including those with early-onset dementia
- Enhanced information systems on the number of people with dementia, severity of the disease



# Summary

- New estimates on prevalence, 42,000 people in Ireland now living with dementia, the majority (26,000) in the community
- By 2026 figures will increase to 67,493 (a 64% increase from 2006) and to 140,580 by 2041 (a 240% increase)
- The most marked increase in dementia will be in people in the oldest old population (85 +)
- Urgent need for dementia to be made a national health priority – and for adequate resources to be allocated

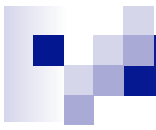
# What has been achieved

- A review that generates convincing evidence - the baseline profile of services for people with dementia in Ireland is very low
- Next step is to formulate a Strategy, which will broaden and deepen work undertaken
- Need broader, more in-depth consultation with older people with dementia, their family caregivers and all the key stakeholders
- Need a sustained focused approach with coalition between main advocacy organizations and professional groupings for dementia care so that our National Strategy will draw wide support from everyone

# Conclusion

We must help to create an Ireland where:

- The public at large are better informed and educated about dementia and the risk factors associated
- Differential diagnosis of dementia becomes the norm as does diagnostic disclosure, except in cases where people affected chose not to be told
- Thinking about dementia (myths, shame, stigma and negativity) changes so that people can live well despite a dementia and are supported to enjoy a good quality of life
- People can live well with dementia and die in dignity with dementia, assured that their complex needs are holistically addressed by an educated workforce skilled in both dementia care, gerontological nursing and palliative care



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PhD student



It's so important to get a person's name and to feel that they listened to what you said and that you don't have to repeat the story again. In the end I got a Case Worker and my whole life changed ... I wanted to fall down and kiss her feet!

(from Robinson et al., 2012: 205)

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