Enhancing Quality of Care and Quality of Life for People with Dementia and their Carers

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Irish demography

• Fastest growth in the Irish population is experienced by oldest subgroups over 65 years
• Currently 11.1% of population is aged 65+
• CSO projects population of over 65s to increase to 1.1 million in 2036 from its 2002 level of 436,001
• Most notable increase in 80+ age group
Prevalence of Dementia

- Not caused by ageing
- Not inevitable part of ageing process
- BUT Is age related
- Prevalence doubles for every 5 year interval
- Dementia more prevalent among women
- Prevalence differences across countries
- Number with dementia set to increase greatly in Ireland in line with population ageing in the country
The Number of People with Dementia in Ireland 2002: EURODEM Rates

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Males</th>
<th>Females</th>
<th>All Persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-59</td>
<td>1,547</td>
<td>772</td>
<td>2,319</td>
</tr>
<tr>
<td>60-64</td>
<td>1,241</td>
<td>383</td>
<td>1,624</td>
</tr>
<tr>
<td>65-69</td>
<td>1,436</td>
<td>759</td>
<td>2,186</td>
</tr>
<tr>
<td>70-74</td>
<td>2,379</td>
<td>2,356</td>
<td>4,735</td>
</tr>
<tr>
<td>75-79</td>
<td>1,869</td>
<td>3,513</td>
<td>5,384</td>
</tr>
<tr>
<td>80-84</td>
<td>2,696</td>
<td>4,937</td>
<td>7,633</td>
</tr>
<tr>
<td>85-89</td>
<td>1,747</td>
<td>4,602</td>
<td>6,349</td>
</tr>
<tr>
<td>90-94</td>
<td>840</td>
<td>2,336</td>
<td>3,176</td>
</tr>
<tr>
<td>95-99</td>
<td>120</td>
<td>573</td>
<td>693</td>
</tr>
<tr>
<td>Total</td>
<td>13,875</td>
<td>20,222</td>
<td>34,097</td>
</tr>
</tbody>
</table>
### Annual Cost of Care per Person with Dementia: Cross-Country

<table>
<thead>
<tr>
<th>Country</th>
<th>Average Annual Cost €</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>10,610</td>
</tr>
<tr>
<td>Finland</td>
<td>19,458</td>
</tr>
<tr>
<td>France</td>
<td>5,981</td>
</tr>
<tr>
<td>Germany</td>
<td>12,583</td>
</tr>
<tr>
<td>Ireland</td>
<td>9,856</td>
</tr>
<tr>
<td>Norway</td>
<td>16,415</td>
</tr>
<tr>
<td>Belgium</td>
<td>15,435</td>
</tr>
<tr>
<td>Sweden</td>
<td>11,321</td>
</tr>
</tbody>
</table>
Irish Costs

- Family care accounts for over half of overall care costs
- Residential care accounts for approximately one third of overall costs
- Community care only accounts for less than one tenth of overall costs
- Expenditure on training and education is minimal
Carer Estimates

• 100,000 carers of person(s) over 65 years in Ireland
• 50,000 of these caring for person exhibiting at least one of 6 specified symptoms of dementia on regular or occasional basis e.g. marked forgetfulness
• 50 per cent of these 50,000 carers were looking after some one with marked forgetfulness on regular or occasional basis
• 30 per cent looking after someone with confusion to point of interfering with everyday life
Family Care in Ireland

- Carers are mainly women, married, aged between 40 and 54 and engaged in home duties
- Significant number of carers are themselves old - over 25%
- Average care provision per day is 12 hours
- Constant nature of care for people with dementia
Carer Stress

- Caring is source of major strain and psychological distress
- Two thirds of carers find job of caring completely overwhelming at times
- 70% find caring a financial strain
- Majority of carers experience confinement
- Majority score poorly on General Health Questionnaire (73%)
## Carer Strain Index: Percentage of Carers who Experience Strain as Carers

<table>
<thead>
<tr>
<th>Items</th>
<th>Carers of People with Dementia</th>
<th>All Carers (Blackwell et al., 1992 Study)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upsetting</td>
<td>96</td>
<td>43</td>
</tr>
<tr>
<td>Confining</td>
<td>91</td>
<td>65</td>
</tr>
<tr>
<td>Emotional Adjustments</td>
<td>78</td>
<td>28</td>
</tr>
<tr>
<td>Disruption of sleep</td>
<td>73</td>
<td>20</td>
</tr>
<tr>
<td>Financial Strain</td>
<td>70</td>
<td>37</td>
</tr>
<tr>
<td>Completely Overwhelming</td>
<td>65</td>
<td>38</td>
</tr>
<tr>
<td>Adjustment to work</td>
<td>61</td>
<td>19</td>
</tr>
</tbody>
</table>
Community Care in Ireland

- Estimated 22,000 people with dementia live at home; majority remain undiagnosed
- Inadequate provision of services
- Absence of flexibility
- Spatial inequality
- Weak family support structures
- Co-ordination and integration problems
Residential Care

- Estimates suggest between 20 and 40 per cent of long-stay residents have mental infirmity/dementia. No estimates for acute care settings
- Some good models - specific, small scale, good design: but not the general rule
- No general evidence of person-based care
- Education, training and development deficiencies
Recent Health Strategy

- Emphasis on Health and Social Gain
- Quality of life issues
- Wholeness and well-being dimensions
- Person-centred models of delivery
- BUT training and education necessary to achieve these goals
- System not geared to deliver change
Regulatory Framework

• Care focus
• Health (Nursing Homes) Act 1990 focused on Nursing Homes only: statutory sector exempt
• Emphasis on environmental and physical elements of care
• Voluntary Code of Practice for Nursing Homes in 1995- includes quality of life dimensions
• BUT routine care prevails over person-centred care in most places
Quality of Life

• Health and functional competence
• Ethos of Care
• Identity
• Social relationships
• Meaningful activities
• Safety and security
• Spirituality
Education and Training

• Educating citizens: public awareness campaign
• Educating and training GPs for early diagnosis
• Training for dementia-recognition in community, residential and acute care settings
• Dementia-specific training for statutory and family carers
Information for Change

• Needs assessment - community and residential care
• Information on best practice
• Information for design - the built environment
• Care standards for person-centred care
• Quality of life domains for people with dementia