

Submission to the Department of Health On a National Strategy for Dementia

31 August 2012

Response from the Irish Medical Organisation National Strategy on Dementia Consultation Questions

The report Creating Excellence in Dementia Care: A Research Review for Ireland's National Strategy¹ highlights the devastating impact of Dementia on both patients and their carers. With Ireland's ageing population the prevalence of Dementia is estimated to rise from 41,447 in 2006 to up to 70,000 in 2021 and to up to 147,000 in 2041. The study also highlights the significant economic burden associated with Dementia and the pressure demographic change is likely to place on caregivers and the health and social care system.

The Irish Medical Organisation (IMO) urges the development and implementation of a National Strategy on Dementia as a matter of priority.

Question A

What is your particular interest in/experience of dementia, e.g. health-care professional/ diagnosed with dementia/ caring for someone with dementia?

The Irish Medical Organisation (IMO) is the representative body for all doctors in Ireland and represents over 5,000 members. The IMO is committed to a caring, efficient and effective health service.

Ouestion B

The report, *Creating Excellence in Dementia Care: A Research Review for Ireland's National Strategy* (Cahill et al, 2012) has outlined the following elements for inclusion in the Strategy, which have been grouped below under 6 broad headings.

Awareness

- Primary prevention and ways of avoiding or delaying the illness
- Public awareness about dementia

Early diagnosis and Intervention

- Early diagnosis
- Specific training in dementia for health care professionals
- Appropriate services for people with early-onset dementia, including people with Down Syndrome

Community-based services

• Dedicated and flexible community-based services

Long-stay residential care

- Psychosocial approaches to complement existing medical and neurological models of service delivery
- Dementia-specific residential care units

Acute care

¹ Cahill S. O'Shea E & Pierce M. Creating Excellence in Dementia Care: A Research Review for Ireland's National Strategy 2012

• Awareness, ownership and leadership of dementia in acute hospitals

Community/Acute/Long-stay residential care

- Case management models of integrated care
- End of life care services for people with a dementia

Research

 Information systems on the number of people with dementia, severity of disease, placement patterns and quality of life

Of the areas outlined, what should the main priorities for the Strategy be?

In order to develop a comprehensive National Dementia Strategy all elements as outlined in *Creating Excellence in Dementia Care: A Research Review for Ireland's National Strategy* are required and no element should be excluded:

- greater emphasis on primary prevention and on ways of avoiding or delaying the illness particularly in relation to heart disease and stroke
- enhanced public awareness about dementia
- early diagnosis through improving access to memory clinics and enhanced multidisciplinary training and education in dementia for primary care workers, hospital staff and people working in long-stay settings
- case management models of integrated care
- expansion of dedicated and flexible community-based services, for example, day care services and family support programmes, for people with dementia and their carers
- 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
- greater awareness, ownership and leadership of dementia in the acute care sector
- further expansion and availability of palliative care services for people dying of and with a dementia
- development of appropriate services for people with early-onset dementia, including people with Down Syndrome
- enhanced information systems on the number of people with dementia, severity of the disease, placement patterns and quality of life

Question C

What specific issues would you like addressed in any or all of the priorities that you have selected?

Prevention and Early Diagnosis

Brodaty suggests that delaying the onset of Dementia by 2 to 5 years would reduce the prevalence by 20 to $50\%^2$, therefore an investment approach to prevention and early diagnosis of Dementia is required and should include:

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² Brodaty 2008 in Cahill et al, 2012

- A public awareness campaign about Dementia to help patients recognise the symptoms and seek medical advice early, to reduce the stigma around Dementia and to promote healthy living in order to avoid Dementia.
- Training and support for GPs in the detection, diagnosis and disclosure of dementia including access to Specialist services.
- **Investment in Memory Clinics.**

Home Care Packages

The IMO strongly endorses the Home Care Package initiative which allows patients with Dementia to remain in their homes as long as possible. Currently the majority of home care packages are also provided by private care providers. The IMO welcomes plans to develop national standards to be applied to the delivery of Home Care Packages.

Demand for community-based care must be properly assessed and adequate resources provided. Funding for home care packages must ensure that standards are attained.

Carers

Creating Excellence in Dementia Care: A Research Review for Ireland's National Strategy highlights the State's reliance on informal carers to care for patients with Dementia in the Community with family and friends providing 81 million hours of care each year and bearing 48% (\colored 807.5 million) of the cost.

In a survey carried out by The College of Psychiatry and The Carers Association of Ireland over half of carers reported having been diagnosed with a significant mental health problem.⁴ Of those diagnosed with anxiety disorder 69% said it was caused or made worse by their caring role. Carers must be provided with adequate financial support, support services, and respite to enable them to care for someone as long as they wish and are able to do so, without jeopardising their own health and wellbeing.

Mental Health Services for Older People

A Vision for Change also recommended that mental illness affecting older people, including symptoms associated with dementia, should be treated in the community and that services should be home-based with appropriate recognition and support given to families and carers. This year the Independent Monitoring Group of A Vision for Change reported a worrying lack of development of Old Age Psychiatry Services and that these should be prioritised as a matter of urgency. 5

³ Cahill et al, 2012

⁴ The College of Psychiatry and The Carers Association of Ireland, Carers of Ireland Who cares? 2009

⁵ Independent Monitoring Group. A Vision for Change – the Report of the Expert Group on Mental Health Policy. Sixth Annual Report on implementation 2011 - June 2012

Approximately half the recommended 42 Community Mental Health Teams for Older People are in place. Most teams are under-staffed as a result of the HSE embargo on recruitment, while some areas have no specialised services at all. Service provision should be based on 1 team or 1 consultant per 10,000 older people rather than 1 per 100,000 general population as recommended in A Vision for Change.

Long-term residential care

The average cost of care in a public nursing home is 50% higher than in a private nursing home. In search of value for money, the model of care provision under the Nursing Homes Support Scheme is to shift from public provision to private provision with the closure of between 555 to 898 public beds in 2012 and all new funding is to go to the private system.

The majority of long-term care beds are provided by the private sector with just 1 in 4 beds provided by the public sector. Patients with Dementia have higher medical need and/or higher dependency levels and thus benefit from more intensive nursing and therapy support provided for in the public sector.

The IMO has serious concerns about the reliance on the private sector to adequately cater for patients with Dementia.

Question D

Is there anything else that should be considered for inclusion in the Strategy?

Legal Capacity Bill

Priority must be given to Legal Capacity legislation to replace Ireland's archaic mental capacity legislation and the ward of court system and provide a framework for decision making for the treatment of patients who lack capacity.

Funding of Long_Term Care

Neurodegenerative disease (stroke, dementia etc.) is the most common reason for admission to nursing home care, therefore nursing home care should be an integral part of the health services.

The IMO is concerned that the current mechanism of funding long-term care, the Nursing Home Support Scheme is unfair on many older people who have contributed to the health system all their lives through taxes and taking little from it in return, yet when they need services most are forced to contribute a further percentage of their assets including their home. The Scheme is also unfair on those who have worked hard to provide for families throughout their lives. Patients enter long-term care only when all other avenues have been explored. Patients and their families have often made Herculean efforts to stay at home for many years and often a family member has taken substantial time out of their working life to care for a relative at home. The IMO believe a fairer and more equitable system of funding long-term care than the Nursing Home Support Scheme is required and oppose any plans to expand the scheme to fund community-based care. The principle of solidarity must be applied to the funding of long-term care where the cost is spread over a wider population and access to the service is based on medical need, with minimal bureaucracy.