Towards excellence in dementia care

A submission from the Irish Society of Physicians in Geriatric Medicine to the Minister for Health and Children for the National Dementia strategy

Background
The Irish Society of Physicians in Geriatric Medicine (ISPGM) welcomes the proposed National Strategy on Dementia, an initiative which has been long overdue for one of the most significant illnesses of later life.

ISPGM and dementia in Ireland
The ISPGM represents over 70 specialists in geriatric medicine, the largest group of senior healthcare personnel with postgraduate accreditation in gerontology, the science of ageing. Geriatricians have been to the fore in the development of clinical services, research and education in dementia care in Ireland, including the first surveys of cognitive impairment in the community¹ and general hospital², the first Memory Clinic³, as well as a strong presence, along with old age psychiatry, in the development of the national Dementia Services Information and Development Centre (www.dementia.ie), as well as emerging memory clinics/services around Ireland, most of which however are under-resourced in terms of personnel and diagnostic resources.

Of critical importance, as dementia is an age-related chronic disease syndrome with an appreciable aetiological contribution from vascular disease, those with dementia have a significant likelihood of multiple co-morbidity⁴, functional loss and other age-related syndromes that will benefit from the application of of the biopsychosocial principles and practice of geriatric medicine in both primary and secondary care.

In addition, a former nihilism about dementia care has been replaced by an awareness of significant opportunities to improve the lives of those with dementia and their families, as highlighted as long ago as 1992 by the US Congress Office of Technology, which outlined six very practical principles which can guide clinicians in their efforts to provide better care for their patients⁵. These are:

i) something can be done for individuals with dementia;

ii) many factors cause excess disability in individuals with dementia. Identifying and changing these factors will reduce excess disability and improve the individual’s functioning and quality of life;

iii) individuals with dementia have residual strengths. Building on these strengths will improve their functioning and quality of life;

iv) the behaviour of individuals with dementia represents understandable feelings and needs, even if the individuals are unable to express the feelings or needs. Identifying and responding to these feelings will reduce the incidence of behavioural problems;

v) many aspects of the physical and social environment affect the functioning of individuals with dementia. Providing appropriate environments will improve their functioning and quality of life;

vi) individuals with dementia and their families constitute an integral unit. Addressing the needs of the families and involving them in the individuals’ care will benefit both the individuals and their families.

We welcome the publication of the research review Creating Excellence in Dementia Care, which covered a great deal of the Irish and international literature⁶, and which builds on previous initiatives such as the Action Plan for Dementia by the NCAOP in 1999⁷. The ISPGM offers these considered recommendations arising from a very significant degree of experience in service delivery and development, research and education in Ireland.

Governance and infrastructure
The current system suffers from a lack of formal coordination at all levels, from the experience of patients and carers to the organizational structures of the HSE: the forthcoming Directorate structures pose a threat that the resources and policies of key groups associated with care provision – primary care, geriatric medicine and old age psychiatry – will lie within different directorates.
Therefore, our first recommendation is for a National Dementia Care Programme which provides an over-arching mechanism for coordination of these care groupings, with dedicated budget lines associated with it from each of the relevant directorates.

The governance of this programme should be inclusive of the major partners, representative in composition and aim for consensual decision-making. A helpful model in this regard has been the Council on Stroke of the Irish Heart Foundation, as well as the HSE/RCPI Clinical Programmes: the inclusion of advocacy, primary and secondary care facilitates a global perspective, from prevention, through primary to secondary care, extended care and palliative care. The ISPGM recommends not only this inclusive representative governance but also an approach which attends to the broad perspective of the illness.

This in turn should be reflected in structures, policies and resources to enable joint planning of dementia care within healthcare regions or localities between primary care, voluntary sector and geriatric medicine and old age psychiatry services. Such planning groups should also engage with other service providers, such as neurology and general psychiatry, in terms of also providing services for those aged under 65.

**Prevention**
Emerging literature suggests that the prevalence and severity of Alzheimer’s disease, vascular dementia and mixed Alzheimer’s/vascular dementia can be significantly reduced by primary and secondary prevention of vascular risk factors. The ISPGM recommends that the national cardiovascular strategy should include cognitive function as an endpoint for public health monitoring, as well as an incentive for population adherence to lifestyle adaptation and other methods of health promotion.

**Memory Services**
The development of Memory Clinics represented an important developmental stage in the provision of assessment services for people with dementia. However, the degree to which these evolving services engage with other services involved in care and support during the course of the dementia is highly variable, and the ISPGM recommend that the service model should move towards the concept of Memory Services whose remit extends beyond early diagnosis to a more comprehensive model of care. This approach is comprehensive not only in terms of the spectrum from prevention to palliative care, but also in terms of a sophisticated approach to encompass issues such as driving and dementia and the impact of early dementia on occupational performance.

Virtually all those currently engaged in dementia diagnosis and care suffer from under-provision in terms of resources, in particular adequate and comprehensive staffing and access to diagnostic resources, and the ISPGM recommends that the National Dementia Programme develops templates for the provision of such services, in a manner analogous to such initiatives in stroke care, and that such care provision is designed to cover all areas of Ireland to provide equitable and high-quality assessment, treatment and support.

For service-users, access to services and support currently require engagement with a multitude of agencies and services which can be challenging: built into the National Dementia Strategy should be a system or care- or case-management which provides a unitary portal to provide coordination between the various services and supports, as recommended in 1999 Action Plan for Dementia.

**National Audit on Dementia Care**
A review of current care practices is critical in terms of service planning, provision and delivery, and the ISPGM recommend early implementation of a National Audit on Dementia Care, similar to that undertaken in the UK, and mirroring the broad scope of the Irish National Audit of Stroke Care.

**Dementia awareness and care training**
A hallmark of ageing is increased complexity, and dementia not only adds further levels of complexity but is also commonly encountered in virtually all domains of adult health and social care. Training in dementia care is effective and the ISPGM recommends that dementia care training should become a core part of training for all providers of health and social care working with adults: this training could dovetail with the commitment to provide gerontological training to all primary healthcare
workers arising from commitments for Ireland inherent in the adoption of the Madrid International Plan of Action on Ageing (MIPAA) by the United Nations\textsuperscript{12}.

As outlined in the research review, older people with dementia are particularly vulnerable in the general hospital setting, and the ISPGM recommends universal training in dementia awareness and care (including the prevention, detection and management of delirium) among hospital staff of all categories, as well as the provision of specialized, responsive structures, staffing and policy to minimize iatrogenic harm to those with dementia who require hospital care.

**Extended care**

The ISPGM was one of the earliest professional organizations in Ireland to call for specific standards for training of staff in nursing homes\textsuperscript{13}. Although the HIQA guidelines have significantly improved the clarity of standards in general, much remains to be done, and the ISPGM recommends formal guidelines for the training and accreditation of staff in dementia care as a core component of their gerontological training and continuing education. This might be best accomplished in coordination with the development of gerontological and palliative care skills at all levels within the care work-force in nursing homes\textsuperscript{14}.

**Population registers**

The interRAI tool, recently selected as the common assessment tool for care needs for older people in Ireland across care sectors, should provide a useful substrate for the development of population registers for those affected by dementia, and the ISPGM recommends that a national register is developed which allows for seamless transmission of relevant data between services, as well as serving as a critical instrument for the planning and delivery of services.

**Research**

In terms of evidence-based practice, given the enormity of the impact of dementia at personal, family and societal levels, the ISPGM recommends that a substantive focus on Alzheimer’s disease and related dementias should be formally included in the research strategies of all research councils in Ireland, consistent with, and supportive of, the pioneering initiative on Alzheimer’s disease in the Joint Programme for Neurodegenerative Disease of the European Union (www.neurodegenerationresearch.eu/home/).

**Dublin, 31 August 2012**
References