



National Strategy on Dementia Consultation Questions

Throughout our community we are caring for an older population with varying needs and conditions including Alzheimer's disease and other dementias. These are progressive conditions that not only have a huge impact on the physical, psychological and emotional state of the person with dementia but also on their families and carers.

Introduction

Older & Bolder welcomes the opportunity to make this written submission on the National Dementia Strategy. We have addressed the questions as posed in this consultation questionnaire viewed through the lens of the needs of both older persons and older persons with dementia. We see a critical dependency between this strategy and that of the National Positive Ageing Strategy and the National Carers Strategy in addressing the future needs of providing a continuum of care, throughout the life-cycle, for all ages.

Question A

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

Older & Bolder is an alliance of eight NGOs in the age sector in Ireland. The members of the alliance are: Active Retirement Ireland, Age & Opportunity, The Alzheimer Society of Ireland, Carers Association, Irish Hospice Foundation, Irish Senior Citizens Parliament, Older Women's Network and Senior Help Line.

Our vision is of an Ireland that affirms ageing and the rights of all older people, enabling everyone to live and die with confidence and dignity as equal, respected and involved members of society.

In representing the rights of all older people Older & Bolder is cognisant of the need to be an advocate for all voices & experiences of older people which includes older people with dementia or older people who care for people with a dementia.

As noted in "Future Dementia Care In Ireland" population ageing will inevitably result in an increasing number of people suffering age-related health problems especially Alzheimer's disease and the related dementias. Increasing age is by far the single strongest risk factor for dementia with a person at the age of 90 running a 50% higher risk of developing a dementia compared with someone in their 60s. In fact, over the age of 65 the prevalence of dementia nearly doubles every five years.

Question 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.*

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

Awareness

Based on recent research the number of people in Ireland with dementia will increase very significantly in future years, given our ageing population. Calculations show that by 2041 the numbers of people in Ireland with dementia will have tripled. Indeed a conservative estimate suggests that by 2041 some 140,000 people will have dementia

There is a need therefore as matter of public health information policy to focus attention now on providing dementia education and dementia awareness across every sector of mainstream society and health care services. Specific awareness campaigns should focus on areas such as early intervention, risk reduction and brain health.

Key stakeholders should be identified and prominent members of Irish Society used as 'Dementia Champions' developed specifically within the stakeholder group to help highlight the issue and tackle in particular any stigma that may surround the illness.

The overall framework for delivery of health care services in Ireland should be structured to be 'Dementia Friendly' across every access point to or within the service. Such a framework should be backed up within Dept of Health & HSE corporate structures to reflect the importance of the issue by having dedicated clinical management & oversight of Dementia Policies in Ireland following the introduction of a National Strategy on Dementia.

An increased awareness amongst the general population will contribute to advances in crucial early self-identification of dementia symptoms and will also play a major role in educating the population at large around preventative measures to be taken across a person's lifecycle.

Early diagnosis and Intervention

Expert opinion is that earlier and accurate diagnosis is important for the individual and for family members due to the benefits such a diagnosis delivers. It is imperative that coming out of the implementation of National Dementia Strategy resources will be put in place or reconfigured that will result in a nationwide health service that provides timely diagnosis and the provision of early intervention supports & services.

Roll out a Single-Assessment tool

A crucial component of this will be access to a uniform assessment of needs for both the patient and their carer. Older & Bolder understands that the HSE is currently piloting a Single Assessment Tool – this tool will need to be such that it provides the necessary early indication of the possible onset of a dementia and acts as an early detection mechanism which leads on to the necessary follow up of interventions & support services.

At present the first port of call for most patients who present themselves to our health service with possible symptoms of a dementia is at GP level. Making a diagnosis of dementia is not easy and Irish research has shown that many GPs, like their counterparts in other countries, are reluctant to get involved in the area because of lack of confidence, lack of training, stigma, difficulties differentiating normal ageing from the signs and symptoms of dementia and resource issues. There is a requirement therefore to ensure that all health care officials at GP, Primary Care or Residential Care levels are skilled in the detection and diagnosis of Dementia and are suitably equipped with the necessary people skills to handle the delivery of the diagnosis to the patient and their families.

Community-based services

Following on from the early diagnosis of a dementia and consistent with stated Dept of Health policy around shifting the emphasis of care back into community settings there is a need to ensure that these settings are 'Age & Dementia friendly'. Access to clinical dementia experts at local community levels will form the basis of key community services for those with Dementia and their carers. People who need and receive community care (e.g. Home Help, respite, Home Care Packages, hospice & palliative care services) value these supports enormously. However access is discretionary, unequal and problematic.

Introduce legislation re a Statutory entitlement to Home & Community Care

The root of this issue is the lack of legislation to underpin access to these services – there is no statutory entitlement to home care and community care services. Since access is discretionary, it is extremely difficult for individuals, families and carers to get information and reliable access at critical points e.g. discharge from hospital, onset of disability, diagnosis of dementia, long-term or life-limiting illness.

Older & Bolder stands with the Ombudsman who observes that “people do not know where they stand in terms of their entitlements and in terms of the HSE’s obligations to provide services”.

Older and Bolder, consistent with its previous calls in submissions to other National Strategies, calls for the inclusion as part of a National Dementia Strategy of the development of long promised legislation to establish a clear right to community care. Only this can provide the clarity and security to individuals and families.

One key stakeholder in the effective delivery of home & community services for people with dementia is the family carer. Concurrent with the National Carers Strategy and the soon to be published National Positive Ageing Strategy formal recognition of the role played by family carers needs to be part of the National Dementia Strategy. In the absence of the required community level of care supports the burden has always fallen on families to compensate for inadequate community services. This places families under huge stresses and strains particularly those looking after family members with dementia as often this is an around the clock demand. Families go to great lengths to keep their loved ones out of long term residential care settings and thus should be provided with all necessary supports to do this for as long as it is clinically and morally the right thing to do for the patient.

Older & Bolder recommends immediate implementation of the Law Reform Commission's call to set up a register of professional home carers to protect vulnerable people requiring care in their home.

Long-stay residential care

Older & Bolder, consistent with current best practice & research, recommends that where older people with dementia need to access long term residential units that these units must be dementia specific purpose-built units which are domestic (home-like) in design and have separate rooms for separate functions. In particular, large institutional multi-bed wards are totally inappropriate for people with a dementia. Consistent with previous points all long term care workers must be educated in dementia specific health care practices. Long-stay residential patients should also be assigned an independent trained advocate as part of their care plan.

Acute care

Research suggests that up to 25% of all hospital patients may have Dementia, yet since dementia is often hidden in the community it may continue to remain undetected following hospital admission. Older people are often admitted to hospitals through Accident and Emergency and whilst they may undergo careful general assessment, dementia is often overlooked. In addition, a general hospital ward is a daunting and frightening experience for a person with dementia who needs a stable and consistent environment. Older and Bolder recommends that A&E staff are specifically trained in the area of dementia awareness and that dementia specific units or indeed hospitals are developed as part of a National Dementia Strategy.

Community/Acute/Long-stay residential care

The advice for more than 20 years has been that policymakers need to plan to meet a continuum of care needs among the older population. Home and community care services are at one end of the continuum and nursing home care are at the other end.

Older & Bolder recommend that planning of access to and funding of community care services be given due priority within the continuum of care. This needs to be reflected not only in terms of policy initiatives but also in terms of budgetary processes.

Older & Bolder supports The Alzheimer Society's of Ireland call for the development of integrated dementia care pathways which would enable service providers to work in an integrated way through the focused support of a case worker mechanism.

Within the overall continuum of care Government policy has now recognised the need to move towards a primary health care model where health services (GP, Local Health Nurse, Physiotherapist, Chiropodist etc) link-up effectively at a local level and where community and hospital services work together efficiently. While, in most villages and towns in Ireland this is not a reality Older & Bolder welcomes the recent Government announcement (17/08/12) that primary care facilities will be developed at twenty locations across the country. Older & Bolder appreciates that this represents a commitment to primary care. In particular we welcome the use of the Haase-Pratschke Deprivation Index to identify which areas are least well served and to better inform the provision of posts.

Furthermore Older & Bolder believe that, if older people's health and social care needs are to be addressed effectively, the new HSE Directorates corporate structure must function collaboratively. It is imperative that the new legislation will promote integrated working between the management and staff of the directorates for the benefit of all older people including those with Dementia.

Older & Bolder recommends as a matter of urgency that an audit of community care services be carried out so that we can map the services that are available, identify the deficits, plan effectively for the future and introduce greater transparency into an opaque system. The HSE's existing HealthStat system should be developed to provide this much needed information. Ultimately, if used effectively, this information could reduce premature admissions to nursing homes and unnecessary stays in expensive acute hospital beds.

Older Persons with multiple chronic conditions should be supported to manage their own health locally for as long as is safe & sensible for them to do so. Diagnosis and management of conditions such as dementia, stroke, falls, incontinence, bone health and immobility should all be available in the community.

Community care services, though patchy, are vital and existing levels of service must be retained. These budgets are under threat; they must be protected against cuts and safeguarded from pressures in other parts of the health system.

Older & Bolder recommends that the Nation Dementia Strategy adopts the expertise of the Irish Hospice Foundations recommendations contained in its 'Palliative Care for all Programme' which supports the development of palliative care for people

with advancing life-limiting diseases other than cancer and includes action research projects in relation to dementia specific palliative care services.

Research

A National Dementia Strategy must contain a long term plan and commitment towards the development of an ambitious research agenda with the goal of becoming a world renowned leader in the area of Dementia clinical sciences, health & social care services and health policy research.

In the immediate term however currently neither the department of health's long stay activity statistics nor the national register on public & voluntary beds provides reliable data on people with dementia in residential long-stay care. We have already outlined the deficit of information surrounding community care services.

Both of these deficits in information should be addressed as a matter of urgency by the statutory authorities through either current systems such as the HSE's HealthStat system or through the audit process of HIQA who have a statutory responsibility for Health Information.

Question C

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

Core elements for any new Dementia strategy include the need for;

- Greater emphasis on primary prevention and on ways of avoiding or delaying the illness
- 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 small-scale, appropriately designed, residential care units
- Enhanced information systems on the number of people with dementia, severity of the disease, placement patterns and quality of life

People of all ages at different stages of their lives may need to access home, community or residential care. Thanks to TILDA and ESRI we now have evidenced-based projections about long term health and social care needs. The next step is not about whether we can or we cannot address these needs but how we will meet these needs.

For Older & Bolder a core value in terms of systems of health and social care is social solidarity and the pooling of risk across the generations.

It is not just about our economic choices but also about our political priorities underpinned by our core values of social solidarity and equality between all citizens.

Our view is that there is duty on the State to uphold the right to care at all stages of the continuum of care – which incorporates self-care, community care, long-term residential care and end-of-life care.

Question D

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

N/A