Submission from Nursing Homes Ireland
Development of a National Strategy on Dementia

31st August 2012
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NURSING HOMES IRELAND

Nursing Homes Ireland is the representative organisation for the private and voluntary nursing home sector. This sector and the care our members provide, are key parts of the Irish health service. Private and voluntary nursing homes provide:

- Care for nearly 21,500 residents;
- Account for more than 75% of all long term care beds in the country; and
- Employ more than 22,000 staff.

We in NHI have a significant contribution to make in developing services for an ageing population, so that residential care for our older people is the best that it can be. We have the expertise, the commitment and the willingness to work alongside the Government, the Department of Health and other key stakeholders in the sector to create a service of which we all can be proud. Our experience and our ideas are important in informing the development of the National Dementia Strategy.

Our vision, that all residents of nursing homes will receive high quality care, is one which will be realised through meaningful partnership with the Government, the Health Service Executive (‘HSE’) and the NTPF (as purchasers), HIQA (as the regulator), our members and all the stakeholders in delivering that high quality care to those who need it.

Our members are committed to:
- Maintaining and enhancing the quality of life of residents;
- Preserving the autonomy of residents, guaranteeing free expression of opinion and freedom of choice;
- Maintaining a safe physical and emotional environment;
- Ensuring that the privacy and dignity of residents is respected;
- Being an employer of choice and providing continuous professional development and training to our employees; and
- Delivering value for money.
Background:

Nursing Homes Ireland’s Practice Development Facilitator was a member of the Dementia Advisory Committee which advised and supported the development of the report “Creating Excellence in Dementia Care: A research review for Ireland’s National Dementia Strategy”. NHI broadly supports the findings and recommendations contained within this review. Identified specific needs of the private and voluntary nursing home sector will be elaborated further within this submission.

In addition NHI has contributed to a number of related submissions, for example the National Positive Ageing Strategy and the Mental Capacity Bill [to be known as the Assisted Decision making (Capacity) Bill].

The recent Irish research “Creating Excellence in Dementia Care, A Research Review for Ireland’s National Dementia Strategy” estimates that approximately 66% of long-stay nursing home residents have a dementia. The report also states that the number of people diagnosed with dementia is set to rise from an estimated 41,447 in 2006 to between 67,500 and 70,000 in 2021 and between 140,500 and 147,000 in 2041.

The Central Statistics Office (CSO) estimates that there will be a 180% increase in the number of people aged 65 years and over in 2041 with a growth of over 400% in the population of the oldest old (i.e. those aged 85 years and over) in the same period. Dementia prevalence increases with age and therefore it is imperative that our systems and services are appropriately designed, resourced and prepared to meet this demand into the future.

We therefore welcome the opportunity to contribute further to the development of a national strategy on dementia.
Specific Comments

The following feedback is presented in the format specified (online template) as part of the consultation process:

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 Nursing Homes Ireland Private Nursing Home Survey 2007 listed 18,883 registered private nursing home beds in the country with 33% of residents having a diagnosis of dementia. The 2009/2010 Survey confirmed that the number of registered beds had risen to 20,590 with a corresponding rise in the percentage of residents diagnosed with dementia to 38%. However the research review “Creating Excellence in Dementia Care” estimates that approximately 66% of all people in long-stay care have a dementia. It is suggested that the difference between the actual and estimated prevalence of dementia can be attributed to difficulties in securing a formal diagnosis.

Nursing homes provide care for people with dementia both on a respite and long-term care basis. Some nursing homes also operate day care centres which support those still living at home. The estimation that two thirds of the nursing home population has a dementia signifies that nursing homes are a crucial part of service provision in the overall continuum of care throughout the person’s disease trajectory.

In the majority of nursing homes residents with dementia are integrated with other residents however there are an emerging number of nursing homes which have designated sections or units solely dedicated to Dementia Specific care.

Nursing home staff are committed to improving the quality of life of residents with dementia and employ a myriad of approaches to enable functioning, communication and participation in their care.

Nursing Homes Ireland provides advice and support to staff in member nursing homes and works closely with statutory and non-statutory agencies to champion the needs of residents with dementia, create awareness and understanding of dementia and highlight best practice within the sector. NHI recognizes the complexity of care that a diagnosis of dementia can bring and is committed to ensuring that members are prepared and equipped to meet the needs of residents, their families, friends, significant others and the wider community.
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

- **Primary prevention and ways of avoiding or delaying the illness**
  Existing public health campaigns and health promotional activities associated with smoking, alcohol consumption, diet, nutrition, exercise and healthy minds should highlight more prominently that these factors can increase the risk of developing a dementia.

- **Public awareness about dementia**
  Reducing the stigma of dementia is paramount in creating awareness and understanding in the wider public arena. Health information and education should be targeted at an early age to assist in developing “Dementia Friendly Communities” as well as a targeted approach to those providing public services so that they are cognisant of the needs of persons with dementia living in their community. Communication should challenge the misconception that dementia is a normal part of the ageing process.

Early diagnosis and Intervention

- **Early diagnosis**
  Having skilled professionals readily available and equipped to screen for and diagnose dementia is critical. GPs play an important role in identifying and referring persons with a potential diagnosis of dementia and are therefore a much valued resource to the nursing home sector. However GPs themselves have identified difficulties in diagnosing dementia and the need for more dementia-specific training as evidenced in the research review. A dedicated training programme for GPs should be developed and implemented and this should form part of the GP contract. It may also be necessary to incentivise GPs to maintain a register of persons diagnosed with dementia to facilitate early diagnosis and the prioritisation of the disease within their practice.

  In addition there is a significant under supply of Geriatricians and Psychiatrists available (particularly outside of Dublin) to complete the necessary testing to confirm the diagnosis. Furthermore the majority of services which are available are situated in acute services which are difficult to access and not dementia friendly in their design. It is recommended that there should be an increase in the numbers of available specialists and consultants and that there is expansion of these services to include an out-reach option.

  Furthermore there is also a critical shortage of memory clinics nationally. It is suggested that a memory clinic is developed in each HSE LHO area to improve access and reduce the time taken to secure a diagnosis.
There are a number of differing approaches to screening and diagnosis for dementia and it would be beneficial if there was a standardised policy approach for Ireland.

Coupled with the need for early diagnosis is the need for post diagnostic supports and information, as identified in the Alzheimer Society of Ireland's National Dementia Summit Report “Getting on with Life: Our action plan for living with dementia”. A co-ordinated approach to post-diagnostic support led by Dementia Specialists is recommended. Many nursing home providers have indicated that access to on-going dementia specific care following a diagnosis is limited.

It is recognised that the HSE have a number of National Clinical Programmes which they identify are based on three main objectives:

- To improve the quality of care that is delivered to all users of HSE services
- To improve access to all services
- To improve cost effectiveness

Whilst a number of specific diseases have an identified National Clinical Programme, there is no such programme for Dementia. The National Clinical Programme for Older People does not appear to identify any specific aims in relation to dementia care although it does highlight the need to integrate acute and community services, integrate with the private sector and improve access for patients. NHI recommends that the HSE develop a National Clinical Programme for Dementia which recognises that the majority of respite and long-term care of persons with dementia is provided within the private and voluntary sector.

- **Specific training in dementia for health care professionals**
  Pre-registration general, intellectual disabilities and psychiatric nursing as well as under graduate medical programmes and those for allied health professionals should incorporate a greater emphasis on dementia care and gerontology in general to prepare professionals for the future demographic changes predicted.

  Nationally co-ordinated, accessible and frequently occurring training programmes should be available for all health professionals to improve understanding of the needs of people with dementia as well as promoting early recognition of symptoms. Multi-disciplinary programmes are beneficial in creating greater awareness of roles among professionals thereby emphasising collaborative approaches to dementia care.
Dementia training in nursing homes has been prioritised and enhanced due to the publication of the HIQA (2009) National Quality Standards for Residential Care Settings for Older People in Ireland which includes supplementary criteria for those nursing homes with dementia specific units. However the standards fail to provide specific guidance to providers on the content or level of training which is recommended. In practice there are a number of competing providers of dementia training (statutory and non-statutory) offering a number of programmes at varying academic levels which can pose difficulties in selecting the most appropriate and accessible programme. Priority should be given to setting out the minimum requirements of certified/ accredited dementia training and the recommended academic level for health care professionals in all sectors.

Training of health care professionals in community and acute settings is required to maximise early recognition of the illness, manage symptoms and to improve the experience of the person with dementia in receipt of such care.

Increasingly residents with dementia requiring transfer to acute services are being requested to be escorted by nursing home staff. In our view this represents a significant deficit in the knowledge, skills and numbers of staff (particularly in emergency departments) whom are competent to care for persons with dementia. It is essential therefore that acute services up-skill their staff to enable safe and efficient transfer of the duty of care, where required.

Training for junior medical staff in acute services should also focus on the need to consult with primary and specialist services known to the person with dementia. This is required to ensure that treatment options and decisions on prescribing are multi-disciplinary and holistic in nature and consider the individual needs of the person with dementia and their carers.

The Irish Hospice Foundation in conjunction with the HSE have developed and implemented a very successful training initiative for end of life care which was predominately focused on acute services entitled “Hospice Friendly Hospitals”. It is suggested that a similar project could be developed for “Dementia Friendly Hospitals” which could encompass the areas for development previously highlighted.

It is suggested that all health professionals require specific training on the assessment of capacity and consent for persons with varying levels of cognitive ability. Education on the application of the new Assisted Decision Making (Capacity) Bill is highly recommended.

Specific training is also required for regulators of health services to ensure that they are both informed and equipped to make clinical judgements on the quality of service provision. For example, inappropriate referrals to Senior Caseworkers for the Protection of Older people have been requested by inspectors for residents with frontal lobe dementias. Persons with dementia may have communication needs or difficulties with their insight which cause them to exhibit certain behaviours.
In addition these communication difficulties may be a barrier to effective participation in the inspection process for persons with dementia. Inspectors need to be cognisant of these issues during the inspection process and in formulating their clinical judgements.

Furthermore assessors in the National Treatment Purchase Fund as negotiators and purchasers of care under the NHSS (Fair Deal) need to be adequately informed of the specific needs and care of residents with dementia to understand the level of resources required. NHI strongly recommends the engagement by the NTPF of appropriate clinical and gerontological input to support its commissioning of care.

- **Appropriate services for people with early-onset dementia, including people with Down Syndrome**
  Dedicated services for persons under the age of 65 years need to be developed and coordinated at strategic level to champion the unique needs of this population. As identified in the ASI (2009) “Getting on with Life: Our action plan for living with dementia” there is no service/departments with specific responsibility for people under 65. Indeed nursing homes (which are registered as designated centres for older people) in the NHI Annual survey 2009/2010 reported that 4% of their residents were under the age of 65 years. It is not known how many of these residents have a diagnosis of early-onset dementia however there is an acknowledgement in the sector that there is a lack of supports which are age-specific, targeted and appropriately resourced to meet the unique needs of this population.

**Community-based services**

- **Dedicated and flexible community-based services**
  Nursing homes should be recognised as key service providers within the community and should play an active role in the design and provision of additional community supports which complement existing services. Independent living services are an increasing feature of some nursing homes affording residents the independence of their own home whilst also permitting easy and accessible additional supports as required. It is recommended that nursing homes are represented on all future planning and policy frameworks in relation to service delivery models for dementia care.

Respite care should be provided on the basis of need rather than on allocated resources. NHI welcome the publication of the National Carer’s Strategy which includes an objective to “enable carers to have access to respite breaks” and recognises that respite can be in-home, residential and emergency. Nursing homes are equipped to provide both residential and emergency respite within the person’s own community and acknowledge the importance of continuity in respite provision, particularly for the person with dementia.
The Respite Care Grant for persons with later or end stage dementias that wish to remain in their own home is insufficient to promote regular and timely respite provision. It is suggested that persons with this stage of dementia would most likely have higher levels of dependency and hence require more intensive and complex care than those in earlier stage dementias. Therefore the current level of the grant would most probably only permit one to two weeks residential respite per annum for persons in advanced stages.

Initiatives such as the Alzheimer’s Café and the GENIO Dementia project should be embraced and expanded to provide crucial supports to those living with dementia.

Out-reach services such as Clinical Nurse Specialists in Dementia from the secondary/acute sector should be developed to further enhance access and support to persons with dementia in the community.

**Long-stay residential care**

- *Psychosocial approaches to complement existing medical and neurological models of service delivery*
  Further research is required to identify the most effective psychosocial approach(s) for use in long-stay residential care which deliver real outcomes for residents and staff. Education and training in the selected methods should be provided for all registered designated centres to maximise implementation.

- *Dementia-specific residential care units*
  It is suggested that the Health Information and Quality Authority (as the independent regulator of residential care services) should maintain a database of dementia specific units in Ireland and that this information is accessible to the general public to assist in the identification and access to services at local level.

  The resources required to implement meaningful psychosocial approaches supported by professional therapists should be recognised and reflected in the Nursing Homes Support Scheme legislation.

  Residential care for dementia is much more complex than just building designated dementia specific units. It must be based on
  - diagnosis and individual assessment of need
  - access to a variety of settings to meet these needs
  - a continuum of care being available within each setting to meet the inevitable physical dependency of all dementia sufferers

  A national policy on the size, design, layout, location and resourcing of Dementia-Specific Units is recommended.
Acute care

- **Awareness, ownership and leadership of dementia in acute hospitals**
  As previously stated dementia specific education and training is paramount to ensure that acute services are equipped to realise their duty of care when persons with dementia need to access their services.

Community/Acute/Long-stay residential care

- **Case management models of integrated care**
  Dementia advisors/ specialist nurse services should be available to persons with dementia throughout their disease progression regardless of their location including nursing homes. This service could assist in the identification and expression of need and would complement existing independent advocacy services available.

In addition persons with dementia should have access to individualised budgets which enable them to access the services appropriate to their specific needs at any given point in time. This will enable greater choice and empower persons to have control over their own pathway of care. The “Money Follows the Patient” scheme announced by Minister Reilly at the National Healthcare Conference on 24th March 2011 needs to be realised and the Strategy must demonstrate how this links with the Review of the Nursing Homes Support Scheme and Universal Health Insurance for persons with dementia.

- **End of life care services for people with a dementia**
  It is recommended that residents with late stage dementia in private and voluntary nursing homes are facilitated to remain in place when they develop complex, palliative or end of life care through the enhancement of services available to support the nursing home with these specialist needs. This may be achieved through the provision of appropriate and accessible out-reach services for specialised interventions as necessary.

In addition hospice at home teams should have tailor made on-going education and training to ensure that they have the knowledge, skills and competencies required to support nursing homes in providing specialist palliative and end of life care for residents with dementia.

The recommendations contained in the Irish Hospice Foundation (2008) “Palliative Care for All” report in relation to service model, research, education and policy must be implemented through the National Strategy on Dementia to ensure that services for persons with dementia recognise and address their palliative care needs at the end of life.
Furthermore, the recently published Centre for Ageing Research and Development in Ireland’s research briefing “Medication use in patients with dementia at the end of life” highlights the need for practice guidelines for doctors prescribing for residents with dementia at the end of life and greater legal clarity around advanced care directives. NHI suggests that both of these recommendations are addressed within the strategy to assist decision-making at the end of life.

Research

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

A register of persons diagnosed and/or awaiting a diagnosis of dementia (including the severity or stage of the disease) should be maintained by General Practitioners and accessible to other relevant health care professionals as required.

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

As a population, we are living longer and growing older. Census 2011 revealed over a five year period to 2011, the number of persons aged over 65 grew by 14.4 per cent, an increase of 67,467 (535,393 in 2011 compared with 467,926 in 2006). Over the corresponding period, the numbers living in nursing homes grew by 21.8%, with 26,265 living in residential care in 2011 compared with 21,553 in 2006, an increase of 4,712.

The significant growth in demand for nursing home care, coupled with the continued reduction of public sector capacity, means Ireland is facing into a significant shortfall of capacity to meet the long-term care requirements of our ageing population. The ESRI is projecting a requirement for 35,820 persons to use long-term care in 2021, meaning an additional 12,839 places will need to be supported by 2021.

NHI recommends that the collection and analysis of data on persons living with dementia is developed and improved so that service planning and resourcing of services can be undertaken on a sound evidential basis. The demand for care services, including residential care, for people with dementia is also expected to grow at a rate that outstrips supply.
Nursing Home Support Scheme (Fair Deal)
Projected demand for nursing home care including specialised dementia care will place great pressure upon the health service and on the private and voluntary nursing home sector. It will require significant investment to meet this sustained growth.

For the private and voluntary sector to invest in the facilities and increase capacity and levels of service, Fair Deal needs to be future-proofed to meet ongoing demand and certainty surrounding it is an imperative requirement for people requiring residential care and providers of that care. The private and voluntary sector requires a framework that provides certainty.

Given the recent and predicted significant increase in demand for long-term residential care and the continued reduction in the provision of public care, Fair Deal must ensure private and voluntary care providers are provided with the framework to meet this demand as they provide the most cost efficient basis both for the resident and the state.

Fair Deal must continue to operate on the principles that have guided it thus far, and the framework must continue to ensure access to long-term residential care is accessible, affordable and anxiety free. It must continue to adhere to its core guiding principles.

The review of the NHSS (Fair Deal) must recognise and address the additional costs on service providers associated with providing dementia care and this should be evident in the National Dementia Strategy.

The NTPF negotiators who negotiate with the Private and Voluntary sector (under the NHSS) have no gerontological, dementia specific, nursing or clinical experience and therefore have very limited understanding of the clinical care, services, needs of residents and the underlying costs attached to the provision of nursing home care.

The NTPF has generally refused to negotiate or agree a maximum separate price to be paid to private and voluntary nursing homes for specialised care services including stroke, acquired brain injury and dementia.

However, in a limited number of cases the NTPF appears to have deviated from its general approach of negotiation in that it has agreed with a limited number of private nursing home owners a price which acknowledged the higher costs associated with dementia care.

There are three nursing homes nationally in respect of whom the NTPF have agreed different/higher rates for a “secure unit/secure dementia unit”. The fees agreed in 3 cases range from €100 - €120 per resident per week higher than the ‘standard’ fee.

This approach however is not consistent or widespread despite many other nursing homes that provide dementia care also requesting such a provision. Higher levels of care with more specialist provision have higher costs and the introduction of a sophisticated funding model that would recognise differing levels of care and associated costs is required to support both the resident and the care provider. Key to this is the introduction of a recognised and validated assessment tool for determining dependency levels associated with a cognitive impairment.
The majority of tools currently in use for measuring dependency focus predominately on the physical dependencies only and are therefore not reflective of the unique needs of persons with dementia. Implementing a standardised cognitive dependency tool would assist service planners and purchasers of care in ensuring greater equity of access and appropriate allocation of resources.

NHI recommends that the agreed fees should reflect the care needs and the NTPF must introduce a mechanism for agreeing a dementia specific care fee in the negotiations. The development of a dementia specific fee is vital to ensure that the private and voluntary sector can invest in the provision of high quality residential care in much needed new builds and extensions to meet future requirements.

**Question D**

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

Access to trained and professional advocates for persons with dementia, their carers, families, friends and significant others is essential to improve effective consultation and participation and empower persons to assert their rights and access their entitlements. NHI recommends that the concept of advocacy and individual trained advocates for persons with dementia are at the core of the Strategy.

Cohesion with other relevant legislation, strategies and policy documents needs to be evident, for example, the Positive Ageing Strategy, the Review of the Nursing Home Support Scheme (Fair Deal), HIQA National Quality Standards, Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009 (as amended), National Carers’ Strategy, Eligibility legislation, Assisted Decision Making (Capacity) legislation, the Mental Health Act and Palliative Care for All (not an exhaustive list).

We thank you for the opportunity to make our submission on the development of a national dementia strategy and trust that our comments will be given full consideration. We are available to meet with the Department on the content of our submission.

**August 2012**