Nursing Homes Ireland Presentation to the Joint Committee on Health and Children

Public Hearings on End of Life Care

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Introduction:

On behalf of Nursing Homes Ireland thank you for the invitation to present to you today. I am a registered psychiatric nurse and registered general nurse. I commenced working with older people in a managerial role in a public hospital in 2008 prior to moving to my current role as Director of Care in a private nursing home in 2011.I am the current Chair of NHI National Nursing Committee. I have completed a BSc in Nursing; Masters in Advancing Healthcare Practice; Certificate in Nurse Prescribing and Certificate in care of older persons in Residential Care Centres. I have participated in the Irish Hospice Foundation's End of Life Care Audit and I am currently participating in HIQA's thematic inspection on End of Life Care.

Overview of the Private and Voluntary Nursing Home Sector:

There are 447 private and voluntary nursing homes in communities across Ireland providing care and a 'home from home' to almost 22,000 persons in local communities, near to their families, friends and neighbours. Our sector provides care to more than 75% of the country's long-term care residents. NHI members and nursing home staff are committed to improving and enhancing the quality of life of nursing home residents. Our member nursing homes are major employers in local communities with in excess of 23,000 staff directly employed. In 2012 78% of the 6,309 new persons supported by Fair Deal chose the care of private and voluntary nursing homes.

Our population is living longer, growing older. This is bringing with it significant growth in requirement for long-term residential care. The CSO is projecting a dramatic rise in the very old population – those aged 80+. This population cohort will grow by 37% to 2021. The ESRI projects additional requirement for 888 long-term residential care places per annum to 2021. The Centre for Ageing Research and Development in Ireland (CARDI) confirms ESRI projections and anticipates 59% increase in residential care requirements. "Even with greater emphasis on care at home and more resources provided to realise it, the demand for residential care is going to increase significantly in the next decade," it states. So it is not a choice between increased community supports and homecare and residential care as some

seek to suggest. This is about ensuring that we have a continuum of care and the most appropriate care provided. The HSE warns in its National Operational Plan 2013 that within our sector there will be a "significant national deficit of beds by 2016". It states there are areas currently that have an under supply of beds, particularly Dublin and other urban centres.

Recent Developments in End of Life Care in Residential Care Settings:

There have been many positive developments in end of life care in residential care settings since the joint publication by the National Council on Ageing and Older People (NCAOP) and the Irish Hospice Foundation (IHF) in 2008 entitled "*End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland*". Most notably perhaps is the establishment of the Health Information and Quality Authority (HIQA) as the independent regulator of designated centres for older people which has placed a regulatory emphasis on end of life care. This is evidenced in Standard 16 of the National Quality Standards for Residential Care Settings for Older People in Ireland (2009) and underpinned by legislation in the Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009 (as amended). Most recently HIQA has commenced a thematic inspections pilot in 50 nursing homes which requires nursing homes to self-assess their performance in end of life care in advance of an unannounced inspection. This process also collects information from relatives of recently deceased residents thereby examining the perceptions of quality of care at end of life from all perspectives. NHI has a long-standing positive relationship with HIQA and continues to work closely with the Authority to enhance the care of the older person in residential care.

The Irish Hospice Foundation continues to show strong supportive leadership in palliative and end of life care and we in NHI are pleased to have strong collaborative partnerships with IHF on many initiatives. NHI collaborated with the IHF and local hospices in 2008 to develop a pilot providing end of life care education for staff working in residential care settings for older people. This programme was rolled-out nationally during April- November 2009, across seven hospice centres. A second phase of this pilot commenced in 2010 which aimed to develop the palliative and end of life care knowledge, skills and attitudes of staff working in residential care settings, by means of developing and implementing palliative care link and associate nurses

who would be a resource, disseminate information and also teach their colleagues. This education was very well evaluated however sustainability of the education and supports was a concern in the absence of dedicated funding.

The establishment of the End of Life Forum in 2009 sparked a national debate about life and death in Ireland among health professionals and the public alike thereby raising expectations of care and promoting a degree of self-regulation. NHI contributed to the initial work of the Forum and continues to support its work through consultation and communication with members.

Most recently NHI has commenced participation in the Irish Hospice Foundation's "*Changing Minds: Promoting Excellence in End of Life Care for People with Dementia*" programme. NHI is represented on the Governance and Advisory Board and the Project Group (Projects 4/5). This programme has three main outcomes, the second of which has a particular relevance to residential care: Better end of life care in residential care settings for older people, with a particular focus on people with dementia. Recognising the end of life care/ dying phase for persons with Dementia is a considerable challenge to healthcare staff due to the unpredictable illness trajectory. This multifaceted programme involving all disciplines of healthcare and the wider public will therefore bring greater clarity to this area and ensure that all staff are person-centered in their approach. This is especially important given the estimation that up to 66% of residents in long term residential care have a Dementia (Cahill et al., 2012). This programme will also extend existing IHF education programmes and initiatives, such as the "*What Matters to Me*" education programme and the "*Hospice Friendly Hospitals*" programme to larger numbers of private and voluntary nursing homes. This was one of the recommendations in the NCAOP/ IHF (2008) report.

Furthermore the establishment of the All Ireland Institute of Hospice and Palliative Care (AIIHPC) has been a significant development in raising standards, increasing and standardising communication across the island of Ireland and promoting shared learning both on a national and international basis. Many positive developments are currently underway which include core competencies for palliative and end of life care; a communication hub which will be a central portal for information regarding palliative care for the whole community and a learning platform which will enhance

the offerings and access to palliative care education. NHI is represented on the Policy and Practice Steering Committee; the Education Network and the Learning Platform Working group of the AIIHPC.

The HSE National Clinical Programme for Palliative Care is in the process of developing a number of tools which will assist everyday clinical practice including an end of life care pathway; national clinical guidelines; a standardised referral form for specialist services; guidance on palliative care needs assessment; a national tool for end of life care and a national advance care planning programme.

Finally NHI is also represented on the *HSE Working Group on Implementing the National Policy on Do-Not-Attempt-Resuscitation Decisions*. This working group chaired by Professor Seán O' Keeffe is currently exploring how to implement the recommendation in the *HSE National Consent Policy* (National Consent Advisory Group, 2013) that service providers should develop specific mechanisms for the documentation and dissemination of decisions relating to resuscitation.

End of Life Care in Residential Care Settings:

25% of all deaths in Ireland occur in residential care settings (Mc Keown, 2012). This is not surprising given that long stay residents accounted for 96% of all residents in nursing homes that responded to the NHI Annual Survey 2009/ 2010.

The *National Audit of End of Life Care in Hospitals in Ireland 2008/2009* recognised that a substantial proportion of patients who die in hospital could be cared for more appropriately at home, in a hospice, or in a nursing home. However it also highlighted that over half of all admissions to hospital (56%) from a nursing home were mostly for patients with dementia signalling a need for further analysis to examine the reasons why it appeared that nursing homes were unable to meet the end of life needs of persons with dementia. The overall balance of forces affecting the hospitalisation of dying suggests that most people do not die at home because the majority of deaths follow a period of chronic illness related to conditions such as circulatory disease, cancer, respiratory disease or dementia/frailty. (Mc Keown et al., 2010). This reflects the wider need for increased consultant-led chronic disease management in the

nursing home and greater communication between regular and out of hours GP services. It is intended that the Changing Minds programme should address the many factors involved here.

It is widely recognised that there should be greater consultation with older people so that it can be established what their needs and preferences with respect to end-of-life

care are, to include place of death. In addition NHI supports the concept that these conversations should commence as early as possible in the person's illness to enable full participation in the process and to enable adequate communication and planning to occur.

- Greater cultural awareness and understanding of dying and death is needed
- Policy reform to ensure that end-of-life care is recognised as an important public health issue.
- To develop practice to ensure that end-of-life care for older people is integrated into the everyday life and work of acute hospitals and long-stay facilities.
- To test new approaches that brings about a greater fusion between end of life care and gerontological care within all long-stay settings in Ireland.

End of Life Care: The Challenges and Possible Solutions for Nursing Homes

Access to Services:

Allied Health Professionals

The HSE Quality and Patient Safety Audit report (QPSA, 2013) identified that "there is greater and more consistent access to PCT [Primary Care Team] services among PB LTRC [Public Long-term Residential care units]" and that services in general were inconsistent nationally. This supports the acknowledgement by HIQA (2012) that there is inadequate access to all care services, reflecting "a wider funding and access issue in the sector and is an issue in particular for some private centres who are not able to access HSE services". The National Audit of Stroke Care (Irish Heart Foundation, 2008) highlighted the impact of inconsistent service provision on the

resident where 61% of residents were paying for physiotherapy services in private nursing homes versus only 5% in public nursing homes. This is unsurprising as Allied Health Services are specifically excluded in the Deed of Agreement under the Nursing Home Support Scheme (Fair Deal).

The role of allied health professionals in the palliation of symptoms and increasing the quality of life of residents at end of life is widely acknowledged. It is recommended therefore that the HSE immediately needs to publish the findings of the audit and outline the actions taken to address the inconsistency of service provision and promote greater access to these services for all nursing home residents but particularly for those in receipt of palliative care.

GPs

A survey of Directors of Nursing by the Irish National Extended Care Medicine Association (INECMA, 2012) emphasised a high level of satisfaction with GP services in the nursing home however this may not be representative due to the low response rate (21.9%). The survey however highlighted areas for improvement which centred around three main themes: Accessibility and Quality of Service; Service Delivery; and Accountability and Sector Awareness.

It could be argued that the GP is the gatekeeper of care and is therefore in a prime position to commence discussions and plans about end of life care before admission to long-term care. Following admission the GP then has a lead role in facilitating the resident's needs and wishes around end of life care to be met. This includes advanced care planning; do not attempt resuscitation (DNAR) orders; pre-emptive prescribing; documentation and greater communication with out-of-hours services to prevent un-necessary transfers/ hospital admissions at end of life.

A formal mechanism for GPs to communicate with out-of-hours services was one of the recommendations highlighted by IHF et al. (2011). Other issues highlighted by NHI members with out-of-hours services include an "administrative" fee charged by some service providers for visiting residents with medical cards; refusal to visit in some instances resulting in triaging by telephone and time taken to attend the nursing home due to distance to travel (particularly in rural settings) and prioritisation of

cases. The latter is of particular concern to palliative and end of life residents who may require prescribing for symptom relief. IHF et al. (2011) highlighted the potential of Nurse Prescribing "to enhance the access to medications for people with advancing progressive illness in the community". It is disheartening therefore that it is current policy not to issue a prescription pad to Registered Nurse Prescribers who work in

private healthcare facilities including nursing homes (HSE, 2011). In our view this discriminates against nurses working in private facilities and prevents access to timely symptom relief for residents with medical cards living in private and voluntary nursing homes.

The Irish College of General Practitioners has run a series of education seminars on the role of the GP in nursing homes in 2013 and has also indicated their intention to develop a working group to examine this role in further detail. This is a welcome development however it is important that any such working group would have full representation from all stakeholders involved. There is an immediate need to review the role of the GP particularly in line with the requirements for medical and medication review as outlined in the National Quality Standards (HIQA, 2009). Such a review would be most effective if it coincided with a full review of the GP contract. There is a need however to provide additional education and supports to GPs who provide a service to nursing homes due to the complexity of residents and the regulatory requirements.

Consultant Geriatrician Services

Cahill et al (2012) reports that up to 66% of residents in nursing homes have a Dementia. Due to the unpredictable illness trajectory and fluctuating capacity of residents with dementia, many clinical, ethical and legal challenges present to nursing home staff. Residents with Dementia are most likely to be admitted to hospital at end of life (Mc Keown et al., 2010). This highlights the need for more specialist Geriatrician input to assist and support nursing home staff to adequately address the resident with dementia's needs within the nursing home throughout the illness and at the end of life. In addition "international evidence indicates that people with non-malignant diseases benefit most when palliative care service models are based on a collaborative and/or shared care approach between the disease-specific specialist,

primary care staff and the specialists in palliative care" (HSE and IHF, 2008) thereby highlighting the need for a multi-disciplinary approach which includes Geriatricians and Consultants in Palliative Care.

It has been identified that there are "insufficient numbers of these specialists [Geriatricians] to cater for the growing demands of our burgeoning ageing population" (Cahill et al., 2012). It is recommended that there should be additional Geriatrician posts created to fill the geographical gaps identified by Cahill et al. (2012) and the much valued Connolly Hospital out-reach service led by Dr Siobhán Kennelly should be replicated and extended nationally to all nursing homes.

Specialist Palliative Care Services

The nurse led Hospice at Home service provides an invaluable support to residents, families and nursing home staff alike however this service is predominately during office hours and therefore out-of-hours supports are limited. This view was supported by General Practitioners who highlighted the need for greater access to out-of-hours services and in particular access to consultant-led palliative care teams (IHF et al., 2011). Mc Keown et al. (2010) recommend that specialist palliative care is known to be effective and has a positive impact on other outcomes which improve care such as communication with families, family meetings and availability of single rooms. Increased access to both the nurse-led service and the consultant led palliative care teams out-of-hours is warranted. In addition specialist palliative care services need to be extended to all residents and not only those with a malignancy (Palliative Care for All) to enable greater equity of access to care. Increased statutory funding is required to make this a reality.

Furthermore there is a need to extend the availability of hospice provision in Ireland. A HSE framework document published in 2008 which identified priority actions to deliver a further 203 hospice beds between 2009 and 2013 has not been achieved to date (HSE, 2008). There are large parts of the country that do not have access to in-patient hospice services thereby eliminating hospices as a preferred place of death or respite choice for many residents. It is essential that the intended priority actions within this report are fulfilled in a timely manner.

Funding of Nursing Home Care

A complete disconnect exists between the costs associated with the *National Quality Standards for Residential Care Settings for Older People* and the fees that are negotiated with the National Treatment Purchase Fund under the Fair Deal scheme.

The fee negotiation process is not giving consideration to the responsibility placed upon private and voluntary nursing homes to meet their statutory requirements.

The current 'one-size-fits-all' model fails to address the complex care requirements of persons requiring nursing home care. Nursing homes are equipped to manage complex medical needs and disabilities among their residents and this must be acknowledged through the Fair Deal. What is required is a more sophisticated commissioning model that recognises the costs associated with providing complex care to nursing home residents. The review of the Fair Deal scheme presents an opportunity to introduce an evidence-based cost of care model that acknowledges the true cost of residential nursing home care.

NHI, in tandem with many other stakeholders, is extremely concerned at the narrow definition of Long Term Residential Care Services under the Nursing Home Support Scheme (Fair Deal). Ombudsman Emily O'Reilly highlighted this anomaly on a number of occasions and in reports. "Another issue of concern is that in practice the range of services covered by the NHSS is quite narrow and excludes many elements which, on the face of it, are services which one would expect to be included as part of long-term nursing home care," she stated in her report *Who Cares – An Investigation into the Right to Nursing Home Care* (November 2010).

This includes for example access to allied health services (where there is no access to HSE services); aids and appliances; and items not covered under the Primary Care Reimbursement Service. The Committee will be aware that the NHSS (Fair Deal) scheme is currently under review by Government and this is an opportunity to address – we cannot let this opportunity pass to address this matter.

The HSE in 2012 published a policy which set out the specialised (non-standard) aids and appliances that would be provided to residents of designated centres for older

people. This policy excludes many items which may be required for symptom control and comfort at end of life such as oxygen (including tubing and masks); nebulisers; Syringe drivers (and giving sets) and dressings, to name a few.

In addition many items previously accessible under the Primary Care Reimbursement Service are now currently unavailable providing further hardship to residents and families at the end of life. For example, a resident with a fungating tumour requiring specialised dressings at least daily could be required to pay upwards of €20-30 per day for the dressings alone. Whilst the HSE policy purports to supply specialised/ non GMS dressings, in reality getting access to these dressings is proving extremely difficult.

There is an urgent need to develop a Department of Health led Forum/ Expert Group on Long-Term Residential Care to involve all the relevant stakeholders involved in provision of care if we are to deliver an equitable service which is truly person-centred. As part of this Forum the NTPF, HIQA, HSE and service providers need to work together to ensure the NTPF review the true costs of the provision of care. The dependency levels of residents in nursing homes has risen dramatically and therefore the NTPF need a funding model which supports this change to allow residents to die with dignity and receive quality care. Consideration should also be given to prioritising palliative care patients on Fair Deal waiting lists to enable them to access residential care in a timely manner to facilitate death in a more appropriate setting.

The Physical Environment

The physical environment of many acute hospitals and public long-stay facilities are not the ideal setting for people who are dying. Unfortunately some people die on nightingale style wards with up to six or more other people around them. The availability of single rooms is very limited and where available these are predominately used for isolation purposes (IHF, 2007). Conversely 67% rooms in private and voluntary nursing homes are single rooms, 54% of these rooms are single en-suite. This therefore provides for greater access to single rooms for residents at end of life in private and voluntary nursing homes.

The National Quality Standards (HIQA, 2009) outline minimum room sizes for existing and newly built designated centres and also identify that shared rooms can accommodate no more than two residents except for a room which can accommodate up to six highly dependent residents where the resident needs 24-hour high support nursing care or is in transition from hospital to nursing home care. The deadline for compliance with the physical environment standards is July 2015 however the application of these standards by HIQA inspectors appears to be inconsistent between public and private nursing homes. Private providers are being required to provide specific details of the work to be commenced (as well as costed plans) and a deadline for the work to be completed in the action plan to their published inspection report, whereas public nursing homes are being permitted to provide a less detailed response with on-going timescales. The application of the physical environment standards needs to be equally applied across the whole sector to ensure that we address choice and privacy for all nursing home residents.

Advanced Care Directives:

There are two different methods of advanced care planning available for use, the Irish Hospice Foundation's 'Think Ahead' form and the 'Let Me Decide' form developed by Professor William Molloy. The HSE Clinical Programme for Palliative Care also intends to develop a national advanced care planning tool. There is no current legislation in Ireland which addresses the case of advanced directives. Therefore there is confusion in the sector in respect of which, if any form to use in the absence of such legal certainty. It is recommended that legislation pertaining to Advanced Care Directives is developed and implemented without delay. Any such legislation will require education for both the general public and health professionals.

The Assisted Decision Making (Capacity) Bill will change the landscape of the way decisions and consent is gained. This will have huge implications for the daily practice of nursing home staff due to the presumption of capacity and the need to continually review and reassess decisions, particularly for residents with Dementia. The impact of this Bill on decisions around Advanced Care Plans and Do Not Attempt Resuscitation Orders is not yet known and therefore on publication of the legislation it is essential that there is a public campaign together with tailored education for service

providers and healthcare professionals on the scope and implementation of the legislation.

Recruitment of Staff

It is becoming increasingly difficult to recruit nursing staff to work in the nursing home sector. Many undergraduate nursing students are being discouraged from working in the sector due to the misconception that there are limited opportunities to practice their newly acquiring nursing skills and that continuous professional development or career progression opportunities are limited. This is a misconception that NHI is working tirelessly to address.

Due to the inability to recruit Irish nurses there is a heavy reliance on nurses that trained overseas. This is evidenced in the NHI Annual Survey which highlighted that 42% of nurses employed were from outside the European Union with a further 9% from EU countries (NHI, 2010). This presents challenges for the provision of palliative care as identified by Walsh and O'Shea (2009) who reported that "*cultural differences in specific aspects of caring for older adults were highlighted, the most prominent of which concerned palliative care and death and dying. Nevertheless, the majority of employers and nurse managers praised migrant carers' work ethic, their willingness to learn and their commitment to providing care to older people.*" There is a huge investment by nursing home providers in the induction, training and supervision of overseas staff which includes both a financial and time output, however providers are willing to commit to this level of investment if they can secure long-term staff. The difficulties with recruiting from overseas however lies in the nurse registration process with Bord Altranais agus Cnáimhseachais na hÉireann (Nursing and Midwifery Board of Ireland). Many of the nurses from outside the EU are required to complete an "Adaptation programme" to address gaps in their initial undergraduate training however there is currently only one centre in Ireland facilitating these placements and the demand is of such a level that all of the places for 2014 are currently full. A survey of NHI members in July 2013 identified that there are currently at least 43 nurses trying to access an "Adaptation Programme" (NHI, 2013).

Similarly there is no current provision in Ireland for “Return to Work” nursing programmes which are aimed at nurses (predominately Irish nurses) that have been out of clinical practice work for more than 5 years.

The provision of “Adaptation” and “Return to Work” placements urgently requires attention if we are to obtain a sustainable nursing workforce.

Recommendations:

- The HSE publish the findings of the QPSA (2013) audit on Primary Care Team Services and outlines the actions taken to address the deficits in service provision.
- A formal mechanism for GPs to communicate with out-of-hours services is implemented without delay
- The role of the GP in providing services to residents in nursing homes is clarified and that this is done in tandem with a full review of the GP contract and education for GPs involved.
- Registered Nurse Prescribers working in private healthcare facilities are issued with a prescription pad and enabled to prescribe for residents with Medical Cards.
- There is an increase in the number of Geriatricians nationally to improve access to diagnosis and chronic illness management in the nursing home thereby reducing un-necessary hospital admissions. An extension and replication of the Connolly Hospital Out-reach service is the preferable option.
- The Hospice at Home Service be extended to residents with non-malignant terminal illnesses and provides for out-of-hours access.
- Access to consultant-led palliative care teams is made available to residents with non-malignant terminal illnesses and access is facilitated out-of-hours.
- The priority actions identified in the HSE (2008) Palliative Care Services Framework are implemented as promised to enhance the access to in-patient and respite hospice services nationally.

- The development of a Department of Health led Forum/ Expert Group on long-term care.

- Consideration be given to the prioritisation of palliative care patients on the Fair Deal waiting list to facilitate death in a more appropriate place.

- Legislation pertaining to Advanced Care Directives is implemented in Ireland and its publication is accompanied by a general public awareness campaign and specialised education for healthcare professionals.

- There is a public awareness campaign and tailored education for health care professionals prior to enactment of the Assisted Decision Making (Capacity) Bill.

- Immediate action is taken to address the deficits in 'Adaptation' and 'Return to Practice' nursing programmes.

NHI, November 2013

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