

Institute of Community Health Nursing



Submission to

Joint Committee on Health & Children

Public Hearings

On

End of Life Care in Community

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Institute of Community Health Nursing

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'There is a season for everything

There is a time to be born

And a time to die' (ECC 3:1:2)



The Institute of Community Health Nursing (I.C.H.N.) is a professional and educational body established in 1985 representing Public Health Nurses and Community Registered General Nurses working in primary care, throughout Ireland. The membership is in the main made up of Public Health Nurses & Registered General Nurses including Directors and Assistant Directors of Public Health Nursing, Students PHN's and Lecturers from all the Higher Education Institutes.

ICHN Mission

'The Institute of Community Health Nursing will provide a professional forum for the Public Health Nursing Service, to identify and respond to the evolving health care needs in the community, working with our members, partners and decision makers'

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End of Life- Care at Home

Research indicates that 90% of the last year of life is spent at home and the expressed wish of 80% of people with end stage disease in this country is to die at home. It is apparent that there is great need **to improve home care services** to fulfil this desired wish.

What is end of life care?

End of life care refers to the care offered to an individual when death is imminent, when life expectancy is days or even hours. End of life care is only a PART of what palliative care is and by no means defines it.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems including physical, psychosocial and spiritual (WHO, 2004).

Palliative care for children differs from palliative care for adults in that many children requiring palliative care have life-limiting conditions, as opposed to advanced terminal conditions. Children may survive many years with these conditions. There are approximately 1,400 children with life limiting conditions living in Ireland and in the region of approximately 490 childhood deaths each year. A key finding of the Children's Palliative Care Needs Assessment was that the preferred location, of caring for a child with a life-limiting or life threatening condition, is the **family home** with parents receiving adequate professional support.

Chronic Illness: For over a decade it has been acknowledged that people with diseases **other** than cancer should have their palliative care needs met and this principle has been adopted in Irish policy documents since 2001. Services for people with life-limiting diseases, including COPD, dementia, heart failure and chronic neurological disorders are still under-developed and fragmented in Ireland. These conditions are major causes of disability and can have a profound effect on the individual's physical and psychological well being, employment, family life and self esteem over a prolonged period. There is growing evidence that patients with such life-limiting diseases have similar palliative care needs to those patients with malignant diseases. However it also must be acknowledged that it is common for people with these diseases to present with other co-morbidities which also need to be considered when adapting a palliative care approach. Patients with COPD, dementia, heart failure, neurological or renal disorders, can have palliative care needs of longer duration and equal to those of people with malignant diseases.

End of Life care at Home

There are many factors that prevent patients from receiving adequate care in the community and which result in the admission of patients to hospitals, nursing homes or specialist palliative care units. Studies found that the difficulties of relatives were more often a cause for hospital admission than those of the patients. Others found that support at home produced the strongest influence on place of death, with nursing and social services support, access to specialist equipment, and receipt of an attendance allowance all showing statistically significant effects.

Of the 27,000 people who die every year at home the majority of their care is provided by members of the Primary Care Team. There has been a lot of debate and consideration about Specialist Palliative service provision without due consideration, that Public Health Nursing & GPs provide care from diagnosis to end stage and their input requires equal consideration in the provision palliative care right through to end of End of Life Care .

Access to community supports generalist and specialist palliative care services and experience, can vary according to geographic location and diagnosis. There is a significant gap between the number of people who wish to die at home and those who actually achieve this wish. There exists a major inequity in the availability of palliative care and specialist palliative care in Ireland, due to the variation in how services have been developed. The institutionalisation of care at the end of life and eventual place of death does not reflect the wishes of the majority of the Irish population. In the next decade there will be significantly more people living with advancing life limiting disease in the community and all of these people will require a palliative approach to their care.

There is emerging evidence to suggest that **where** people die has an impact on **how** they die, and that those who die at home and in the place they prefer have a better 'quality of dying' than those who do not (McKay et al., 2012; Curtis et al., 2002). A National Audit of End-of-Life Care in Hospitals undertaken by the HFH Programme in 2008/09 found up to one quarter of the 1,000 hospital deaths examined could have been facilitated to occur at home. The cost of dying in an acute hospital is far greater than in other healthcare settings. Studies in Ireland also found several problem areas for carers in the community. These include emotional difficulties in coping with the terminal illness of their relative, the burden of time needed for caring, problems with night nursing, physical exhaustion and feelings of isolation.

The Public Health Nursing Service comprises of Public Health Nurses (PHNs) and Community Registered Nurses (CRGN's) who are responsible for a particular geographical area and are key members of the Primary Care team. They have ready access to the homes and families in their area, and have an important role in building links with other professionals and services in the community. Clinical Nurse Specialists (Continence, tissue viability, specialist palliative care) and Advanced Nurse Practitioners are part of the Public Health Nursing Service.

The Public Health Nurse as the primary carer assesses the holistic needs, palliative care/end of life nursing needs of **all** patients in the community. They also coordinate the nursing services delivered to the patient in the community, linking hospital, community and specialist service as appropriate. The public health nursing service is provided five days a week. At weekends and public holidays, a rostered public health nurse provides a limited service to patients who require nursing care on a daily basis. This usually involves pre-planned calls to particular patients in the area.

The National Advisory Committee on Palliative Care report in 2001 (NACPC) observed

- The public health nurse plays an important and integral role in the delivery of palliative care to patients in the community.
- GPs and Community Nursing services are the main providers of general palliative care to those dying with life limiting disease, that do not require the services of specialist Palliative care teams.
- Public health nurses carry out a diverse range of nursing services, responding to the needs of individuals, families and the community. Nursing care is provided in the community on the basis of need, as assessed by the public health nurse, taking into account the type and level of illness, the social supports available to the patient, and the carer's ability to cope.
- The role of the specialist palliative care nurse frequently overlaps with that of the public health nurse.

The HSE 'Report on Current Public Health Nursing services' (ONMSD 2012) observed

- The ratio of DPHN to population size ranges from 53 000 to 275,000 with a mean average of 137,000.
- While all DPHNs have responsibility for End of Life Care for all clients 30% of DPHNs have responsibility for both Generalist & Specialist Palliative Care Nursing Services.
- There was acknowledgement that the Palliative Care Needs of Children require the support of a Palliative Care Nurse with paediatric experience

Levels of care

End of Life Care/ Palliative Care/ can be provided at home and at different levels of speciality, based on the needs of the patient and family and on the level of expertise of the staff providing the service, as follows:

- **Level 1 – Palliative Care Approach:** Palliative care principles should be appropriately applied by all health care professionals.
- **Level 2 – General Palliative Care:** At an intermediate level, a proportion of patients and families will benefit from the expertise of health professionals who, although not engaged in full-time palliative care, have had some additional training and experience in palliative care.
- **Level 3 – Specialist Palliative Care(SPCC):** Specialist palliative care services are those services which are limited, in terms of their core activities, to the provision of palliative care.

Comment: While it is recognised that Public Health Nursing can deliver Level 1 & Level 2 Care, Public Health Nursing and GPS are central to the continuity of care for patients and their families up to End of Life alongside the Specialist Palliative Care service (Level 3) and should be considered in the debate on resourcing services at this stage.

It needs to be recognised that the PHN is the primary carer in the community he/she assesses, plans, evaluates and co-ordinates the care for all patients with palliative care needs at all levels 1, 2, and 3. However often it is not recognised and the PHN service, is often not sufficiently resourced or skilled to carry out what is what is required, even with the support of the SPCS.

Dignity Care Intervention

The Institute of Community Health Nursing have recently engaged in a collaborative service improvement initiative for patients and their families at the end of life in community settings.

The aim of this service development initiative is to implement and evaluate a dignity care intervention (DCI) that will be delivered by Community Registered General Nurses, Public Health Nurses (PHN), Irish Cancer Society Night Nurses and Specialist Palliative Care Nurses based in a community setting to help conserve the dignity of people at the end of life in community settings. The DCI was originally developed, implemented and evaluated by Dr. Bridget Johnston and colleagues based in the University of Dundee (Scotland). Previous research by Johnston et al. clearly indicated that community nurses and community palliative care nurses found the tool added to the quality of their work with patients who have palliative care needs across a range of illnesses, chronic diseases and cancer. Patients and Family Carers reported

a greater sense of worth in being respected and listened to by nurses and ultimately, that dying with dignity was achieved.

It is envisaged that the project will have several positive outcomes towards improving care at the end-of-life and improving support for informal caregivers including (1) improving partnership working in palliative and end of life care across boundaries and across disciplines working in the HSE, social and voluntary sector, regarding palliative and end of life care; (2) supporting and developing the role of the PHN in the delivery of person centered dignified care; and (3) contributing to the development and recognition of the importance of palliative care within primary care settings.

The DCI project is co-funded by the Irish Hospice Foundation (IHF) and the Irish Cancer Society and it is anticipated that the outcomes of the project will inform the work of the IHF, HSE and ICGP Primary Palliative Care programme. The project is co-led by Dr Sonja McIlpatrick (Head of Research, All-Ireland Institute of Hospice & Palliative Care) and Professor Phil Larkin (Assoc. Professor of Clinical Nursing [Palliative Care], University College Dublin) in collaboration with the Institute of Community Health Nursing (ICHN) and Public Health Nursing (Limerick, Wicklow & Dublin locations).

This project is currently being implemented in four Public Health Nursing pilot sites across both rural and urban locations. It is envisaged that up to 100 nurses will receive training on the implementation of the Dignity care Intervention. With government support and additional funding the DCI project has the potential to be implemented nationally within Public Health Nursing services with several positive benefits for patients and their families. The Dignity Care Intervention provides a framework to improve the care of patients at the end of life with the potential to support knowledge and practical competence in addressing issues of concern and distress as identified by the patient and by providing evidence of best practice for Community Nursing.

This enhanced delivery of palliative care by primary care teams can result in a holistic and structured care that helps to support patients to remain at home in the community throughout their final journey.

ICHN endorse the Palliative care clinical programme which focuses on equity of access, based on need of the individual and efficient use of resources and recommend that:

- Leadership is required from all the relevant stakeholders within service delivery, education, policy and academia to ensure that the necessary steps are taken to ensure that appropriate home care services are available for end of life care in the community.
- Choice for location for care at end of life should be fully supported by health providers.
- All patients who have a diagnosis of life-limiting disease should have equal access to all levels of palliative care and end of life care in the community which will meet their individual needs.
- Due cognisance given to the role of Public Health Nursing service across the disease trajectory including 'End of Life', alongside the specialist Palliative care service
- Increased resources for Paediatric Nursing care in community for 'End of Life' care be made available as a matter of urgency
- Opportunities for education and training in palliative care are urgently provided for all levels of staff (including, disease-specific specialties and primary care staff) that interface with people with both cancer and life-limiting, non-malignant disease in the community.
- Increase access to home support including access to 24/7 nursing care and specialist palliative care on call support in the community .
- Access to aids & appliances should be immediately available for 'End of Life' care in the community
- Promotion of '*Think ahead – Speak for yourself*' (Irish Hospice Foundation) by Health Care providers.

Notes :