Palliative care and nursing practice
– providing guidance and support to enhance service

INTRODUCTION
Ask people what palliative care means and they are likely to tell you that it is the provision of hospice care for people who have cancer and are imminently dying. This is a vital aspect of palliative care, delivered by specialist palliative care (SPC) professionals.

However, palliative interventions can be and are being delivered by primary care teams and health professionals in disease-specific services.

WIDER ROLE OF PALLIATIVE CARE
The WHO definition of palliative care reminds us that it has a wider role. Palliative care is not just about death but about quality of life and may be applicable earlier in the care pathway and occasionally alongside active disease-modifying treatments. There is growing awareness in Ireland that palliative care has a role in the management of patients with all life-limiting diseases and in all care settings.

Ensuring that patients have a good quality of life, maintaining optimal symptom control, communicating clearly with patients and professional colleagues and showing caring support to families will be familiar as important components of nursing practice. They are also the principles of palliative care as outlined by WHO. Nurses in all services are key to including the palliative care principles in the care of their patients and it is important that a framework of information and support is available to them to assist this care delivery.

This article will feature two of the Irish Hospice Foundation’s (IHF’s) current programmes, Palliative Care for All and Primary Care Palliative Care, which seek to develop a range of supports, guidance tools and frameworks for patients, carers, nurses and other health professionals to assist the integration of palliative care into a patient’s care pathway.

RESEARCH PROJECTS AND NATIONAL INITIATIVES
The Palliative Care for All Action Research Projects focus on the palliative care needs of people with heart failure, dementia and advanced respiratory disease. They seek to identify, support and help introduce palliative care interventions for people with these life-limiting illnesses into disease management frameworks in care programmes in acute and primary care settings.

The Primary Care Palliative Care National Initiative is initially seeking to identify palliative care initiatives that will support primary care teams’ responses to adults with advanced progressive diseases who are living in the community and who are expected to die within 12 months.

PALLIATIVE CARE FOR ALL
People with life-limiting, non-malignant diseases can experience a range of physical and psychosocial symptoms throughout what can be a complex and prolonged disease trajectory. Evidence suggests that they and their families would benefit from the integration of palliative care into their routine care. The Palliative Care for All Action Research Projects are...
seeking ways to assist the integration of palliative interventions into the routine care and assessment of people with advanced respiratory disease, heart failure and dementia.

The projects arose from the 2008 report ‘Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks’ (IHF/HSE). This report found that, while nurses in disease-specific and other services were open to integrating the palliative care approach in their practices, they needed clarity on the nature of and extent of palliative interventions and the timing of palliative care within the patient’s care pathway.

SPC teams were found to have an important role in supporting their colleagues in other disciplines in the delivery of palliative interventions.

To help provide some clarity, in 2010 the IHF supported the development of three two-year action research projects which aim to devise, implement and evaluate palliative care interventions for people with dementia, heart failure and advanced respiratory disease within an Irish healthcare context. Primary care, disease specialists and SPC are partners in the projects, each of which is supported by a part-time research project officer. They are based at St James’s Hospital (advanced respiratory disease), Dublin, Clare Mental Health Services for Older People at St Joseph’s Hospital, Ennis (dementia) and Mater and Connolly Hospitals, Dublin (heart failure). Nurses are key partners and vital participants in each of the projects.

Action research has been shown to be effective in closing the theory/practice gap and to improve practice locally while gathering data to share with a wider audience. All key participants in the projects are research partners. The process is cyclical and collaborative, involving shared learning and planning and taking action with reflection and evaluation.

PROJECTS’ ANTICIPATED OUTCOMES

It is hoped that the outcomes of these projects will assist in the development of an evidence base for practical information and guidelines to assist nurses in services seeking to incorporate palliative care in their practice.

Specific anticipated outcomes of the projects include:

- Clarification of the nature, potential and timing of palliative interventions.
- Development of educational material for key nursing personnel and information for staff, patients and families.
- Guidelines on the introduction of palliative interventions and referral to specialist palliative care services.
- Development of a nationally applicable framework for use in HSE services.

PRIMARY CARE PALLIATIVE CARE NATIONAL INITIATIVE

Practice nurses, GPs and primary care teams provide 90 per cent of the care of patients in the last year of their lives, and we know that at least 7,000 of the 30,000 deaths in Ireland take place in the home.

Recent research in the UK has shown that introducing formal structures within primary care settings will assist in the co-ordination and response to palliative care needs of all patients who are facing death (Munday, 2007). Yet, within primary care settings in Ireland, formal responses to palliative care needs of patients are considered mainly for those patients who have complex care needs and require input from specialist palliative care.

With the emergence of the HSE Primary Care Teams, more people with a life-limiting disease will be cared for in the community. In recognition of the need for a more structured approach to planning for the end of life care needs of this population in primary care settings, the IHF in partnership with the ICGP and HSE established a National Steering group to progress this area.

NATIONAL STEERING GROUP

The initial work of the group is to review and consider issues arising in the provision of palliative care by practice nurses, GPs, members of the primary care teams and pharmacists. Policy and service priorities that will enhance quality delivery of palliative care in community settings will be identified in the report of the committee which will be prepared at the end of 2010.

It is anticipated, based on feedback to date, that such priorities will include development of prompts and guidance tools, as well as education initiatives on advanced communications.

In the meantime, local practices that are developing in this area will be shared on the development page of the IHF website and views of individuals and professional groups in this area will be welcomed on an ongoing basis.

CONCLUSION

These programmes will provide guidance, education and support to nurses who are caring for people with life-limiting illnesses in primary care, acute hospitals and residential settings. They will also assist in responding more comprehensively to the palliative care needs of patients facing death and in supporting their families.

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Programme resources and updates can be viewed and downloaded from the Development page on the Irish Hospice Foundation website (www.hospice-foundation.ie).