Palliative Care Competence Framework

Health & Care Assistants

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

PALLIATIVE CARE

Tús Áite do Shábháilteacht Othar
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FORUM OF IRISH POSTGRADUATE MEDICAL TRAINING BODIES

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Palliative Care Competence Framework 2014

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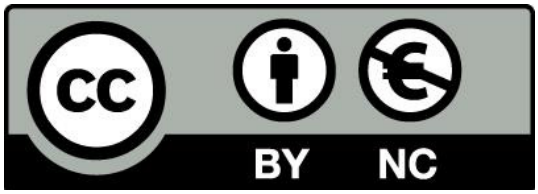

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FOREWORD

"As a society, perhaps the most sensitive measurement of our maturity is the manner in which we care for those who are facing the ultimate challenge – the loss of life."
(Report of the National Advisory Committee on Palliative Care, 2001)

The provision of high quality palliative care is a central responsibility of the whole health care system. It is essential that health and social care workers possess the right competences to effectively meet the needs of people with life-limiting conditions as they are among the most vulnerable of populations served by our health service. The development of the Palliative Care Competence Framework is a valuable tool in supporting staff to achieve this goal and serves as a signal of the areas of performance that are valued by the Department of Health.

Competences represent a dynamic combination of knowledge, understanding, skills and abilities. The purpose of continuing professional development is to foster competences and it is envisaged that the framework will initially be used by individuals and managers to identify specific training needs. The framework will also serve to focus dialogue when evaluating practice needs or demands.

Furthermore, the development of the framework affords a valuable opportunity to articulate and further our understanding of discipline-specific and inter-professional competences. This is particularly important as teamwork is an integral part of the philosophy of palliative care. Effective coordination and collaboration can occur only when each profession knows and uses the others' expertise and capabilities in a patient-centred way.

I would like to thank all the individuals and representative professional organisations who gave so generously of their time and expertise in the development of this framework.

As we work to meet the challenges posed by increasing demands for palliative care associated with our ageing population and greater incidence of chronic illness, I encourage you to read and share this document with your colleagues.

Kathleen Lynch T.D.
Minister for Primary Care, Social Care (Disabilities & Older People) and Mental Health

JOINT MESSAGE

Joint Message from the National Director of Clinical Strategy and Programmes and the Clinical Lead, National Clinical Programme for Palliative Care

The National Clinical Programme for Palliative Care continues to make a significant contribution to improving the care for patients, their families and society as a whole by focusing on our most important resource, our staff.

The development of the Palliative Care Competence Framework highlights the ability of the National Clinical Programmes to bring key stakeholders and professions together to work collaboratively. The framework supports health care staff in all care settings to self assess, develop and maintain skills, knowledge and attributes required for the provision of palliative care. This framework will help to embed a culture within our services to ensure high quality safe services for patients. It also provides a template for our partners in education and professional development to support health care professionals by including palliative care competences in education programmes at all levels.

This framework places a focus on the person with a life-limiting condition and their family. It helps in determining what health care staff can do to alleviate distress, pain and discomfort whether this is physical, emotional, spiritual or psychological. Applying the core and specific competences in practice, will help all health care staff (based in a hospital, hospice, GP practice, primary care centre or a community based setting) working with social care partners, to recognise their role in palliative care and to develop their own quality improvements.

The National Clinical Programme for Palliative Care and its partners will work with all stakeholders in order to ensure palliative care is at the heart of our health care service.

We are grateful for the support and enthusiasm from all stakeholders to date and look forward to building on this to meet our objective of improving the quality of life of people with life-limiting conditions.

Dr Áine Carroll,
National Director, Clinical Strategy and Programmes

Dr. Karen Ryan, FRCPI
Clinical Lead, National Clinical Programme for Palliative Care

STATEMENTS OF SUPPORT

In my role as Chairman of the Forum of Irish Postgraduate Medical Training Bodies I am very happy to both endorse and congratulate all those who have put together this Palliative Care Competence Framework. The Forum was established in 2006 with the aim of enhancing the effectiveness of the training bodies in maintaining the highest standards of medical education and training. Since that time its remit has expanded beyond matters solely to do with education and training but also into areas of professionalism and service provision, specifically focusing on the development of clinical leadership; whilst recognising, at the same time, the importance of team working and the pivotal roles of all those health care disciplines that are our partners in providing all that is the very best for our patients.

Few topics in medicine extend so widely across so many health care disciplines and care settings as Palliative Care. This kind of care is not simply about managing the physical symptoms of life threatening illness but extends necessarily into psychological, social, pastoral and spiritual support. Furthermore, the image and aspiration of the discipline of Palliative Care has changed from one of, not simply managing terminal illness and soothing the symptoms of disease and disorders, to a more positive one of wellness.

As in so many areas of medicine, change and knowledge is moving apace and it is difficult enough to keep abreast with one's own area of interest let alone what is available across other fields and what other skills can be brought to the table. It is in this context that this Palliative Care Framework document sets out, so helpfully, the core competences as to the knowledge, attitudes and skills that should be required, not just by specialists and part-time practitioners, but by all health care workers who look after patients with life-threatening illnesses. These competences are set out against six domains and across ten disciplines ranging from medicine and nursing to dietetics and nutrition and pharmacy.

Providing this information under the umbrella of a single document will not only promote better, harmonious and standardised care but will, I have no doubt, significantly improve the quality of life of patients and their families across Ireland and who are faced with all the problems associated with such a life-threatening illness.

Professor Frank Keane
Chairman, Forum of Irish Postgraduate Medical Training Bodies

The Nursing and Midwifery Board of Ireland (NMBI) welcome the development of the competency framework document for palliative care as a guide to ensure a common expectation of practice in all settings.

Nursing and Midwifery Board of Ireland

The Office of Nursing and Midwifery Services Director is very pleased to endorse the palliative care competency framework. The Nursing and midwifery profession acknowledge that professional competence is far more complex than demonstrating behaviour aspirations or undertaking a task. Collaborative decision making with service users and their families in care planning and provision requires a level of knowledge and skills that engages with values, beliefs and attitudes to make competent and effective decisions. The continuum of contemporary palliative care from early provision, concurrent with disease modifying treatments, to sole palliation recognises the increasing competency requirements on all health and social care providers. As partners in the advancement of the competences for nursing, midwifery and health care assistants we are confident of the potential of this framework to enhance knowledge, skills and development in providing positive palliative care outcomes for service users and their families.

Dr Michael Shannon
Office of Nursing and Midwifery Services Director

I welcome the opportunity to support the publication of the Palliative Care Competency Framework . This document will be an invaluable resource that will support standards of clinical practice in Palliative Care and ultimately enhance the quality of patient care and experience. Additionally, it will assist education providers and influence curriculum development in the relevant therapy professions in the future. For clinicians and employers it will be a positive tool that will help identify professional development and training needs to ensure high standards of service delivery to patients with life-limiting conditions. It will also promote interprofessional understanding of the multidisciplinary and holistic framework of Palliative Care service delivery . My thanks to the experienced clinicians & educators from the disciplines of Occupational Therapy , Physiotherapy , Dietetics & Clinical Nutrition , Speech & Language Therapy who have contributed to the production of this fine document .

Emma Benton
Therapy Professions Advisor, HSE Clinical Strategy and Programmes Directorate

As President of The Psychological Society of Ireland (PSI), I welcome and fully support the Palliative Care Competence Framework. The framework is an exciting and inspiring invitation to work with our colleagues from different disciplines and ensure that living and dying in Ireland is the best it can be. The framework clearly sets out the current expectations for psychologists working with individuals with life-limiting conditions and also provides a terrific guide to inform undergraduate and postgraduate curricula for the profession.
I wish to congratulate all those who contributed to this very important and excellent work. I am happy to endorse the Framework and I wish it great success. I believe that it will continue to be useful, challenging and inspiring for many years to come.
The document is an excellent example of collaborative practice and all who contributed should be proud of its clear communication, its practical utility and its enormous potential to bring compassionate and competent care to our citizens at life's most vulnerable times.

Dr Margaret O'Rourke
President, The Psychological Society of Ireland

The development of the Palliative Care Competence Framework is welcomed by the following professional bodies and group who have approved the discipline specific competences for their respective disciplines.

- ***Association of Occupational Therapists of Ireland (AOTI)***
- ***Irish Nutrition and Dietetic Institute (INDI)***
- ***Irish Society of Chartered Physiotherapists (ISCP)***
- ***Irish Association of Speech and Language Therapists (IASLT)***
- ***Hospice and Palliative Care Social Work Group***

The development of the Palliative Care Competence Framework is welcomed by the Healthcare Chaplaincy Board (HCB), The Chaplaincy Accreditation Board (CAB), The National Association of Healthcare Chaplains (NAHC) and the Association of Clinical Pastoral Education (Ireland) Ltd, who have approved the discipline specific competences for chaplains."

- ***Healthcare Chaplaincy Board (HCB)***
- ***Chaplaincy Accreditation Board (CAB)***
- ***National Association of Healthcare Chaplains (NAHC)***
- ***Association of Clinical Pastoral Education (Ireland) Ltd***

Irish Institute of Pharmacy is happy to support the Palliative Care Competence

Irish Institute of Pharmacy

IRISH SOCIETY OF CHARTERED PHYSIOTHERAPISTS

AOTI Association of Occupational Therapists of Ireland

INDI Irish Nutrition + Dietetic Institute

IASLT

The Healthcare Chaplaincy Board

Chaplaincy Accreditation Board

National Association of Health Care Chaplains

Association of Clinical Pastoral Education (Ireland) Ltd

The Psychological Society of Ireland
Cumann Síceolaithe Éireann

HOSPICE AND PALLIATIVE CARE SOCIAL WORK GROUP

Office of the Nursing & Midwifery Services Director

IIOP
INSTITIÚID CÓGAISÍOCHTA NA hÉIREANN
IRISH INSTITUTE OF PHARMACY

FORUM OF IRISH POSTGRADUATE MEDICAL TRAINING BODIES

STEERING GROUP MEMBERSHIP

Dr Karen Ryan (Chair) - HSE Clinical Lead Palliative Care, Palliative Medicine Consultant, St Francis Hospice and Mater Misericordiae University Hospital

Health Service Executive Representatives

- Dr Regina McQuillan - Palliative Medicine Consultant, St. Francis Hospice & Beaumont Hospital
- Liz O'Donoghue - Clinical Nurse Specialist in Palliative Care, Our Lady's Children's Hospital Dublin
- Morna O'Hanlon - Clinical Nurse Specialist in Palliative Care, St. James' Hospital Dublin
- Sheilagh Reaper-Reynolds - Health Service Executive General Manager Palliative Care
- Deirdre Rowe - Occupational Therapist Manager/Deputy Head of Clinical Services, Our Lady's Hospice & Care Services Harold's Cross
- Mary Wynne - Interim Area Director Nursing and Midwifery Planning & Development DNE

All Ireland Institute of Hospice & Palliative Care Representatives

- Dr Michael Connolly - Head of Education, All Ireland Institute of Hospice & Palliative Care
- Karen Charnley - Programme Manager Education, All Ireland Institute of Hospice & Palliative Care
- Dr Joan Regan - Palliative Medicine Consultant, Marie Curie Hospice and the Belfast Trust

Irish Association for Palliative Care Representatives

- Mary Ainscough - Chief Executive Irish Association for Palliative Care
- Cliona Hayden - Senior Pharmacist, Our Lady's Hospice and Care Services
- Prof Philip Larkin - Professor of Clinical Nursing (Palliative Care) University College Dublin and Our Lady's Hospice and Care Services
- David McEvoy - Medical Social Worker Specialist Palliative Care Services Meath

Irish Hospice Foundation Representatives

- Jackie Crinion - Acting Manager of the Hospice Friendly Hospice Programme
- Orla Keegan - Head of Education, Research & Bereavement Services
- Marie Lynch - Programme Development Manager

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Thanks are due to the following:

- Chairs of the Discipline Specific Working Groups: Dr Regina McQuillan (Medicine), Prof Philip Larkin (Nursing, Midwifery and Health Care Assistants), David McEvoy (Social Work), Deirdre Rowe (Occupational Therapy, Physiotherapy, Speech and Language Therapy and Dietetics/Clinical Nutrition), Cliona Hayden (Pharmacy), Dr Paul D'Alton (Psychology), Brian Gough (Chaplaincy/Pastoral Care)
- Brian Lee - National Programme Manager (Palliative Care, Obstetrics & Gynaecology) – for co-ordinating meetings of the Steering Group and Discipline Specific Working Groups
- Sinéad Fitzpatrick - Programme Manager, National Clinical Programme for Palliative Care– for assisting with finalising and editing the framework document.
- Colleagues from the Forum of Irish Postgraduate Medical Training Bodies, the Royal College of Physicians of Ireland, the Nursing and Midwifery Board of Ireland, the Therapy Managers Advisory Group, the Pharmacy Society of Ireland, the Association of Occupational Therapists of Ireland (AOTI), Irish Association of Speech and Language Therapists (IASLT), the Irish Nutrition and Dietetic Institute (INDI), the Irish Society of Chartered Physiotherapists (ISCP), the Psychological Society of Ireland, the Healthcare Chaplaincy Board, the Chaplaincy Accreditation Board (CAB), the National Association of Healthcare Chaplains (NAHC) and the Association of Clinical Pastoral Education (Ireland) Ltd and for their contributions and comments during the development of the framework
- Dr Claudia Gamondi - Palliative Care Physician, Palliative Care Department, Oncology Institute of Southern Switzerland, Ticino, Switzerland - for her critical review and constructive comments on the framework document
- Elaine Wilson – Lecturer, School Of Applied Social Science, University College Dublin - for her constructive comments on the social work section of the framework document
- Dr Michael Connolly and Karen Charnley (AIIHPC) – for their tireless work in bringing the entire document together
- Gareth Wescott (AIIHPC) – for final editing and graphic design of the framework document

Thanks are extended to the All Ireland Institute of Hospice and Palliative Care (AIIHPC), the Irish Association for Palliative Care (IAPC) and the Irish Hospice Foundation who provided both financial and personnel support for this project. The contribution of the Office of the Nursing and Midwifery Services Director to the publication of this document and their expert input to the project is gratefully acknowledged.

INTRODUCTION

The Health Service Executive (HSE) Palliative Care Programme Briefing Document (2012) identified the development of a Palliative Care Competence Framework as a key objective for the coming year.

The Health Service Executive's Palliative Care Programme convened a Project Steering Group to support, guide and oversee the development of the Palliative Care Competence Framework. The steering group comprises members from the Health Service Executive (HSE), All Ireland Institute of Hospice and Palliative Care (AIIHPC), the Irish Association for Palliative Care (IAPC) and the Irish Hospice Foundation (IHF).

The purpose of this project was to develop a Palliative Care Competence Framework for health and social care professionals working in various health care settings. The framework is intended to provide for core competences in palliative care whilst also detailing individual competences for each health and social care discipline. It is envisioned that the framework will inform academic curricula and professional development programs, and so will enhance the care of people with a life-limiting condition, fostering greater inter-professional and inter-organizational collaboration in palliative care provision.

The Palliative Care Competence Framework reflects a move to standardisation of undergraduate and postgraduate education in Europe and how this relates to the development of competence using the Tuning Approach. The Tuning Approach provides a guide for attainment of knowledge, skills and attributes for practice in the health and social care professions.

The Palliative Care Competence Framework was developed using the Tuning Approach which provided flexibility and autonomy to develop both core and discipline specific competences for generalist and specialist palliative care. The outcome is a clear framework for evidence-based, safe and effective palliative care for generalist and specialist practitioners irrespective of place of practice.

Palliative Care

The World Health Organisation (WHO) defines Palliative Care as:

> *an approach that improves the quality of life of individuals and their families facing the problem 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, physical, psychosocial and spiritual.*

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of individual care;
- offers a support system to help individuals live as actively as possible until death;
- offers a support system to help the family cope during the individuals illness and in their own bereavement;
- uses a team approach to address the needs of individuals and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care, both generalist and specialist, is provided in all care settings, including the community, nursing homes, hospitals, and specialist palliative care units. In recent years, the scope of palliative care has broadened so that palliative care is now provided at an earlier stage in the trajectory of both malignant and non-malignant disease.

Table 1: Levels of Palliative Care Specialisation (NACPC, 2001: 32)	
Level 1 – Palliative Care Approach	Palliative care principles should be practiced by all health care professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many individuals with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.
Level 2 – General Palliative Care	At an intermediate level, a proportion of individuals and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care, perhaps to diploma level. Such intermediate level expertise may be available in hospital or community settings. Health care professionals who wish to undertake additional training in palliative care should be supported in this regard by the health board or other employing authority.
Level 3 – Specialist Palliative Care	Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. These services are involved in the care of individuals with more complex and demanding care needs, and consequently, require a greater degree of training, staff and other resources. Specialist palliative care services, because of the nature of the needs they are designed to meet, are analogous to secondary or tertiary health care services.

In order to prepare health and social care professionals to apply the principles of palliative care in practice, irrespective of setting, education and training are important. Education for practice must ensure that health and social care professionals are competent to practice. In recent years competence-based education for health and social professionals has been promoted across the European Union.

Competence Framework Development

Competence assessment has evolved and been influenced by the learning taxonomy devised by Bloom (1984). Competence development takes into account the incremental nature of knowledge attainment for skills based on experience and education. It also provides a basis for the development of clinical knowledge and career progression in health and social care.

In a number of jurisdictions the development of competence frameworks has been influenced by the publication of a number of key documents

- ***The NHS Cancer Plan (2000)*** – determined a 'strategic direction development of a national, high quality, uniform and equitable cancer service' (Becker, 2007:14);
- ***RCN Core Competency Framework (2003)*** – attempted to bring together a uniform framework for cancer nursing across four levels of practitioner and a wide variety of skills;
- ***Canadian Hospice Palliative Care Nursing Standards of Practice (2009)*** –defined the standard of care that can be expected by all persons receiving HPC nursing and looked to guide, support and promote the provision of further education and training;
- ***National Association for Social Workers Standards for Palliative & End of Life Care (2004)*** (US) - standards were designed to enhance social workers' awareness of the skills, knowledge, values, methods and sensitivities needed to work effectively with clients, families, health care providers, and the community when working in end of life situations;
- ***Royal Australian College of General Practitioners Curriculum for Australian General Practice (2011)*** (Australia) Palliative Care – Sets out the training outcome of the five domains of general practice including details of learning outcomes across the GP professional life;
- ***Educating Future Physicians in Palliative and End of Life Care (EFPPEC) Canada (2006)*** – details palliative and end of life care undergraduate curriculum which was developed to integrate end of life competencies into existing curriculum. The curriculum was approved on a Pan-Canadian basis by the 17 faculties of medicine.

Educators have attempted to define the notion of competence for many years, but there is still a lack of consensus about a standard definition for competence (Becker, 2007). Competence standards do exist for pre-registration education and the proposed Palliative Care Competence Framework can assist health and social care programme co-ordinators in the updating and further development of curricula. In the context of continuing professional development, legislation now exists to ensure the maintenance of professional competence for health and social care professionals. However in some instances the legislation has specified a lead in period, so that statutory bodies have time to develop systems to support the maintenance of professional competence. Post-graduate education in Palliative Care can also be informed by the Palliative Care Competence Framework, which can provide guidance on the knowledge, attitudes and skills needed to provide palliative care in particular contexts and settings and at specialist level.

Method

A steering group was convened by the National Clinical Programme for Palliative Care programme to support, guide, and oversee the development of the Palliative Care Competence Framework.

The purpose of the project was to develop a Palliative Care Competence Framework for health and social care professionals working in various health care settings. The framework provides for core competences in palliative care whilst also detailing individual competencies for each health and social care discipline. It is envisaged that the framework will inform academic curricula and professional development programs, and so will enhance the care of people with life-limiting conditions and their families, fostering greater inter-professional and inter-organizational collaboration in palliative care provision.

An initial objective of the steering group was to analyse and evaluate existing competence frameworks, to agree the framework appropriate and applicable to the Irish context and to agree an approach to the framework development in light of this analysis. AIIHPC undertook a review of available international palliative care competence frameworks. The purpose of the review was to consider frameworks already in use in other jurisdictions in order to make an appropriate and informed recommendation to the Project Steering Group. A number of palliative care competence frameworks from the UK, US, Canada, Australia and Northern Ireland were reviewed and summarised. All frameworks reviewed

identified domains of competence with specific indicators for each. Many of the frameworks reviewed failed to indicate how the framework could inform curriculum development or support continued professional development and life-long learning in the clinical environment. The review recommended that the Palliative Care Competence Framework should be developed in line with Tuning Competences, which provide flexibility and autonomy to develop both core and discipline specific competences for generalist and special palliative (Connolly et al., 2012).

Over a series of meetings the Steering Group developed Six Domains of Competence and indicators (core competences) which describe what each health and social care professional should know at point of registration or first place of work.

The core competences formed the basis for the next phase of development which focused on the development of Discipline Specific indicators for health and social care professionals providing more than generalist palliative care. To proceed with the discipline specific work, a number of Development Working Groups were established in order to develop indicators for each distinct discipline (Phase 1). Over the period from August (2012) to February (2013) development working groups for Medicine, Social Work, Physiotherapy, Occupational Therapy and Pharmacy, met to develop discipline specific indicators.

The Development Working Group for Nursing, Midwifery and Health Care Assistants emerged from an already constituted group that had been brought together for a related project. This group was assisted in the work of developing discipline specific indicators within the divisions of nursing and midwifery and for health care assistants, by a project team from the School of Nursing and Midwifery at Trinity College Dublin led by Dr Honor Nicholl and funded by the Irish Hospice Foundation and the Office of the Director of Nursing and Midwifery Services HSE.

Discipline Specific Working Groups were established in January 2013 to facilitate work with Speech and Language Therapy and Dietetics/Clinical Nutrition (Phase 2), and in January 2014 to facilitate work with Psychology and Chaplaincy/Patoral Care. The Working Groups for these disciplines met over a period of several weeks to develop discipline specific indicators. Their work concluded in March 2013 and April 2014 respectively.

The context of the Palliative Care Competence Framework

The complexity of the health care system sometimes leads to fragmented services and care and collaborative practice has a vital role in enhancing continuity of care for people with life-limiting conditions. This is particularly true in the context of caring for people with life-limiting conditions who may access services from multiple agencies and have a range of complex care needs that require attention.

In most cases these complex needs are using a multidisciplinary approach to care that includes opportunities for discussions and care planning with members of the multidisciplinary team. Multidisciplinary care is characterised by a collaborative and person-centred approach to care planning and delivery and can lead to the achievement of realistic care goals. The multidisciplinary approach to care can lead to increased individual satisfaction with care and increase perception that the care of the individual with a life-limiting condition and their family is being managed by a team. The multidisciplinary approach to care can also ensure access to information and support for the person with a life-limiting condition and their family.

It is important to note that the Palliative Care Competence Framework recognises that health and social care professionals adhere to professional codes of conduct and guidelines and may also be required to work within an employer organisation's ethos, policies and practice.

Domains of Competence

The Domains of Competence are:

Domain of Competence 1 - Principles of palliative care
Domain of Competence 2 - Communication
Domain of Competence 3 - Optimising comfort and quality of life
Domain of Competence 4 - Care planning and collaborative practice
Domain of Competence 5 - Loss, grief and bereavement
Domain of Competence 6 - Professional and ethical practice in the context of palliative care

Each Domain of Competence is defined with a statement. The core competences are common to all health care professionals and represent the primary level of understanding required to provide Palliative Care, also described as using the Palliative Care Approach in daily work.

The domain statement remains the same irrespective of the level at which or the setting where palliative care is provided. However the domain indicators outline the competences required by health care professionals in the context of their role and at the level at which palliative care is provided irrespective of care setting.

In the context of the Palliative Care Competence Framework the level of expertise is key and is influenced by the critical mass of individuals treated, advanced palliative care knowledge, understanding and skills, the currency of this knowledge and maintenance of palliative care evidence base, access to on-going palliative care clinical, multidisciplinary expertise in the daily work environment and involvement in the area of education and professional development at local and national level.

ALL – In the context of individual disciplines, further indicators are identified for "ALL". These reflect the particular competences required for that discipline at point of registration or related to current role. The indicators are applicable irrespective of the care setting or the staff grade. The goal is competence to provide care using a palliative care approach.

SOME - Specific Competences are for "SOME" health care professionals irrespective of the care setting or the staff grade. The goal is the provision of care applying the principles of palliative care and using a palliative care approach. This is achieved through additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions, developing deeper knowledge, understanding and application of competences in palliative care.

FEW - Discipline Specific Competences are for "FEW" health care professionals irrespective of the care setting or the staff grade, whose core activity is limited to the provision of palliative care. The competences at this level are those required for the care of individuals with complex and demanding palliative care needs. The goal is to demonstrate knowledge and application of palliative care skills at specialist level.

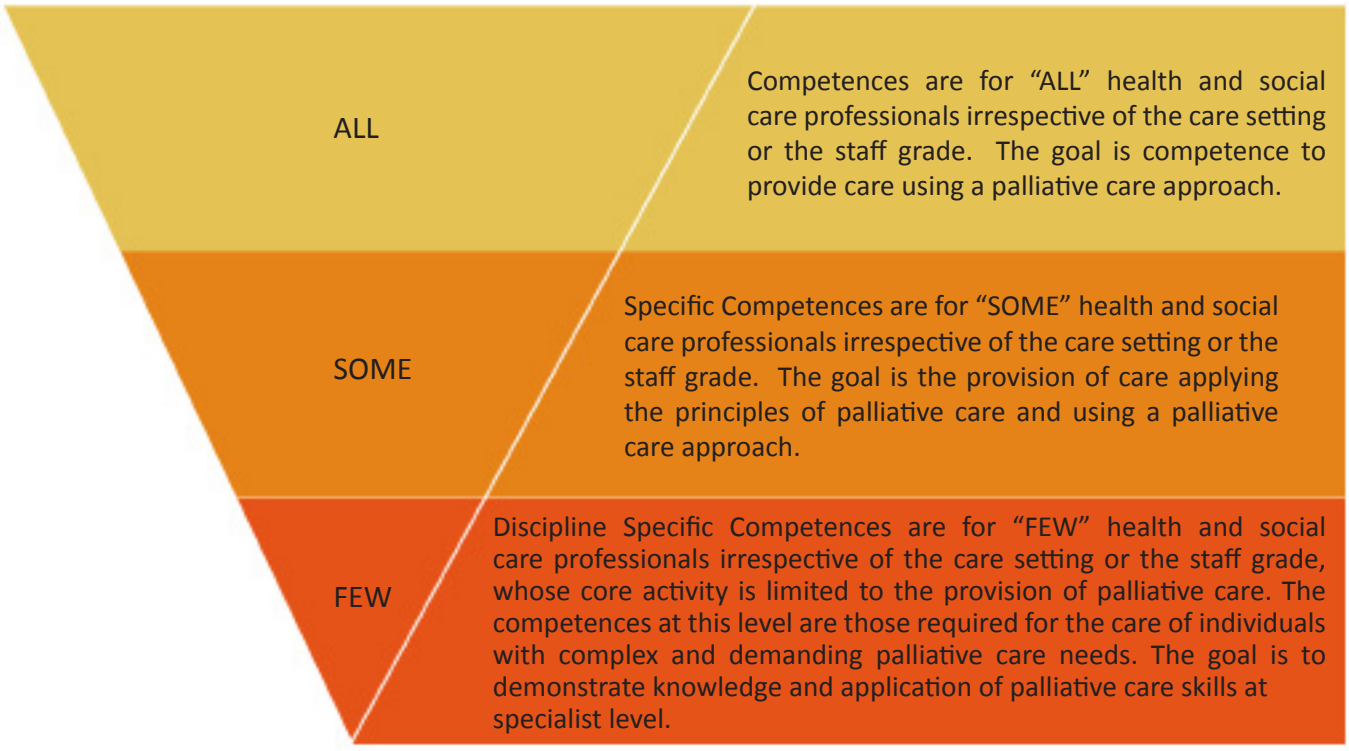

Figure 1: Competence Framework Model – adapted from Australian Model for Nursing in Cancer Control

Core Competences for Palliative Care

DOMAIN OF COMPETENCE 1 - PRINCIPLES OF PALLIATIVE CARE

Palliative care aims to improve the quality of life of people with life-limiting conditions and their families, not only by treating their physical symptoms but also by attending to their psychological, social and spiritual needs. Palliative care is applicable for people of any age and may be integrated at any point in the disease trajectory from diagnosis through the continuum of care to bereavement.

Indicators

As a health care professional you should:

- Understand and be able to describe the meaning of the term 'life-limiting condition'
- Understand and be able to apply the principles of palliative care that affirm life, offer people with life-limiting conditions a support system to help them live as actively as possible until death with optimal quality of life and help families cope during illness
- Understand the significance of the physical, psychological, social and spiritual issues that affect people with life-limiting conditions and their families throughout the continuum of care
- Demonstrate the ability to use the palliative care approach as early as is appropriate in order to facilitate person-centred practice that recognises the concerns, goals, beliefs and culture of the person and her/his family
- Provide empathetic care to individuals with life-limiting conditions and their families, with clear regard to the individuality of each person
- Show a commitment to one's own continued professional development and learning and facilitate the learning and development of others, in order to improve care for those with life-limiting conditions and their families
- Show a commitment to developing self-care strategies and to attending to any impact that working with people facing life-limiting conditions and their families may have on you.

DOMAIN OF COMPETENCE 2 - COMMUNICATION

Effective communication is essential to the application of palliative care principles and to the delivery of palliative care. Communication is also important where circumstances are ambiguous or uncertain and when strong emotions and distress arise. Specific consideration should be given to communication as a method of:

- Supporting and enabling therapeutic relationships with the person with a life-limiting condition and her/his family;
- Ensuring that the person and her/his family understand and participate in decision-making regarding care to the extent that she/he is able to and wishes to be involved
- Enabling inter-professional teamwork.

Indicators

As a health care professional you should:

- Understand the essential role communication plays in palliative care
- Understand the different types of communication e.g. verbal, non-verbal, visual, written, and interpersonal interaction (either one-to-one or with a group or team)
- Demonstrate the ability to communicate effectively with the person with a life-limiting condition, their family and the interdisciplinary team in order to establish, maintain and conclude a therapeutic relationship
- Demonstrate the ability to communicate effectively with individuals and families from diverse cultures and different backgrounds, using professional interpreters (Appendix 1) where necessary and/or assistive communication technology where necessary
- Be able to modify your own communication style to facilitate communication with individuals with a range of communication impairments or seek facilitation in this area if required.
- Understand the importance of using strategies that empower effective communication e.g. active listening, plain language, appropriate tone, clarifying statements, inviting questions
- Demonstrate an ability to be attentive to the person through careful listening to help the person and their family feel they have been heard
- Support individuals (or parents in the case of children and minors) to make informed decisions regarding the level of information they wish to receive and want to share with their family
- Act as an advocate for the person and their family to ensure appropriate and timely palliative care intervention

DOMAIN OF COMPETENCE 3 - OPTIMISING COMFORT AND QUALITY OF LIFE

Individuals with life-limiting conditions and their families can be affected not only in physical, but also in psychological, social and spiritual ways. Optimising comfort and quality of life for the person with a life-limiting condition and her/his family is a dynamic process that involves anticipating, acknowledging, assessing and responding to a range of symptoms and needs in a proactive and timely manner in order to prevent and relieve suffering.

Indicators

As a health care professional you should:

- Understand the significance of anticipating and responding to the needs of people with life-limiting conditions and their families (e.g. physical, psychological, social and spiritual) in a proactive and timely manner
- Understand how the palliative care approach can enhance the assessment and management of symptoms
- Exhibit an ability to apply a range of assessment tools to gather information
- Be able to evaluate non-complex interventions and propose alternative actions if deemed necessary
- Recognise the importance and benefit of multidisciplinary working in optimising comfort and enhancing the quality of life of the person with a life-limiting condition and her/his family
- Recognise the ways in which people with life-limiting conditions and their families can be engaged in self-management of their condition
- Demonstrate professional awareness of the scope of, and benefits of timely and appropriate access to specialist palliative care services
- Be aware of the uniqueness of a good death and facilitate the achievement of this as much as possible

DOMAIN OF COMPETENCE 4 - CARE PLANNING AND COLLABORATIVE PRACTICE

Care planning in palliative care is characterised by coordinating and integrating person-centred care in order to promote quality of life for people with life-limiting conditions and their families. It involves assessing need, promoting and preserving choice, predicting likely problems and planning for the future in the context of a changing and deteriorating disease trajectory. Care planning ensures that multiple disciplines and agencies can be accessed and referred to as required in a timely manner. People with life-limiting conditions should be helped to engage with care planning to the extent that they are able to and wish to be involved. The concerns of families and carers should be taken into account as part of this process.

Indicators

As a health care professional you should:

- Recognise the impact of a life-limiting condition on the person and her/his family and be able to provide support in order to help the individual to adapt to the changes in her/his condition
- Recognise the impact of a life-limiting condition on the person and her/his family's mental health and coping mechanisms and be able to provide support in order to help the individual to adapt to the bereavement and loss
- Appreciate the roles, responsibilities and professional boundaries of individual members of the interdisciplinary team
- Understand the collaborative relationship between the person with life-limiting conditions, the health care professional, the family and all the other agents of care involved with the person and the family in order to develop an individualised and coherent plan of care to assist the person and the family to attain realistic goals and outcomes in all care settings
- Collaborate effectively with others as a member or leader of a multidisciplinary team
- Be able to identify priorities or concerns for the individual with a life-limiting condition and their carers, taking account of the individual's coping strategies and how the person perceives their diagnosis
- In the context of professional scope of practice be able to critically evaluate outcomes of interventions against established standards and guidelines
- Demonstrate an understanding of advance care planning and an appreciation of the appropriate time(s) to engage in discussions about preferences for care with the person with a life-limiting condition and her/his family
- Demonstrate an ability to communicate sensitively and clearly about advance care planning with the person, the family and the range of professionals and agencies involved.

DOMAIN OF COMPETENCE 5 - LOSS, GRIEF AND BEREAVEMENT

Dealing with loss, grief and bereavement for the person themselves, their family and the professionals who care for them is intrinsic to palliative care provision. Most people manage their loss by combining their own resources with support from family and friends. However, a minority of people are at risk of developing complications or difficulties in their grieving. Professionals using the palliative care approach have an important role to play in supporting bereaved people by providing information and support to all and by identifying those who require bereavement therapy or counselling.

Indicators

As a health care professional you should:

- Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced
- Recognise the range of individual physical, psychological, spiritual, emotional and social responses to loss and grief
- Recognise the factors which may put a person at risk of encountering difficulties in their grief, whilst also remaining aware of the resources and resiliencies that are particular to each person and family
- Demonstrate an ability to engage with a person who is experiencing loss in the context of professional scope of practice and/or role
- Assist the family to access bereavement information and support at a level that is appropriate to their needs
- Be cognisant of the psychological impact of death and dying on individuals with increased stress vulnerability
- Understand the personal impact of loss, grief and bereavement and recognise your own loss responses and engage in activities that maintain your resilience on an on-going basis
- Possess a level of self-awareness that prevents your own experiences of loss from negatively impacting on the person with a life-limiting condition or their family.

DOMAIN OF COMPETENCE 6 - PROFESSIONAL AND ETHICAL PRACTICE IN THE CONTEXT OF PALLIATIVE CARE

The goal of health care is to help people sustain health that is essential to their well-being. However, there comes a time when specific treatments or interventions may be futile or overly burdensome. Integrity in palliative care practice refers to the importance of respecting the person's values, needs and wishes in the context of a life-limiting condition. It guides all health care professionals to reflect on the relationship between their contribution to a person's care and the necessary contributions of other professionals. Professional and ethical practice is about considering how best to provide continuing and integrated care to people as their health care needs change in the course of life-limiting conditions.

Indicators

As a health care professional you should:

- Work within your current Code of Professional Conduct and engage ethically, knowledgably and respectfully with other disciplines.
- Recognise and respect your professional responsibility to care for people with life-limiting conditions and their families to ensure their comfort and dignity
- In the context of your current professional role establish collegial partnerships and in the context of palliative care contribute to the professional development of students, peers, colleagues and others through consultation, education, leadership, mentorship and coaching
- Use the resources available fairly in the context of providing appropriate care to the person with a life-limiting condition
- In the context of professional scope of practice and/or role anticipate and demonstrate the ability to address potential ethical issues that may be encountered when caring for the person with a life-limiting condition and her/his family such as: Do Not Attempt Resuscitation Orders, withdrawal and withholding of treatment, use of artificial hydration and feeding, palliative sedation and requests for euthanasia
- Be able to establish and respect person's wishes about their care and options/ preferences. This includes:
    - Recognising the person's right to make informed decisions to refuse additional treatment(s)
    - Seeking, responding to and implementing people's preferences about where they are cared for (e.g. in their own homes) if this is practicable
    - Respecting advance care plans made by people where the decision is an informed choice and relates to the situation that has arisen (Medical Council, 2009)
    - Demonstrate a commitment to engage in anti-discriminatory practice in relation to end of life care and service delivery

DISCIPLINE SPECIFIC COMPETENCES

Health Care Asssistants

MEMBERSHIP OF DISCIPLINE SPECIFIC WORK GROUP NURSING, MIDWIFERY AND HEALTH CARE ASSISTANTS

Prof Philip Larkin (Chair)
Professor of Clinical Nursing (Palliative Care) University College Dublin/Our Lady's Hospice and Care Services

Lucille Bradfield
Clinical Nurse Manager III Neonatal, Cork University Maternity Hospital

Miriam Cass
Lecturer, Department of Nursing, Waterford Institute of Technology

Elaine Clifford
Health Care Assistant, St James's Hospital

Dr Michael Connolly
Head of Education All Ireland Institute of Hospice and Palliative Care

Jackie Crinion
A/Manager of the HFH Programme

Judith Foley
Education Officer, An Bord Altranais agus Cnáimhseachais na hÉireann

Dr Geralyn Hynes
Ussher Associate Professor in Palliative Care, School of Nursing and Midwifery, TCD

Orla Keegan
Head of Education, Research and Bereavement Services, Irish Hospice Foundation

Prof Catriona Kennedy
Professor of Nursing, University of Limerick

Doreen Lynch
Director, Centre for Nurse Education, Mercy University Hospital, Cork

Anne Lynott
A/Director of Public Health Nursing, Ballyfermot, Dublin 10

Lasarina Maguire
Nurse Practice Development Co-ordinator, Stewart's Care

Prof Kathy Murphy
Professor of Nursing, National University of Ireland Galway

Marina O'Connor
A/Director of Nursing, Our Lady of Lourdes Hospital, Drogheda

Liz O'Donoghue
Clinical Nurse Specialist in Palliative Care, Our Lady's Children's Hospital, Crumlin

Morna O'Hanlon
Clinical Nurse Specialist in Palliative Care, St. James' Hospital, Dublin

Lorna Peelo-Kilroe
National Practice Development Coordinator (HSE and HFH Programme)

Michael Shasby
Director of Nursing, North Dublin Psychiatry of Old Age Service

Fiona Woods
Programme Co-ordinator, Caring for the Child with Life-limiting Conditions, Our Lady's Children's Hospital Crumlin

Mary Wynne
Interim Area Director Nursing and Midwifery Planning and Development DNE, HSE

DOMAIN OF COMPETENCE 1

PRINCIPLES OF PALLIATIVE CARE

Palliative care aims to improve the quality of life of people with life-limiting conditions and their families, not only by treating their physical symptoms but also by attending to their psychological, social and spiritual needs. Palliative care is applicable for people of any age and may be integrated at any point in the disease trajectory from diagnosis through the continuum of care to bereavement.

Indicators

As a health care professional you should:

- Understand and be able to describe the meaning of the term 'life-limiting condition'
- Understand and be able to apply the principles of palliative care that affirm life, offer people with life-limiting conditions a support system to help them live as actively as possible until death with optimal quality of life and help families cope during illness
- Understand the significance of the physical, psychological, social and spiritual issues that affect people with life-limiting conditions and their families throughout the continuum of care
- Demonstrate the ability to use the palliative care approach as early as is appropriate in order to facilitate person-centred practice that recognises the concerns, goals, beliefs and culture of the person and her/his family
- Provide empathetic care to individuals with life-limiting conditions and their families, with clear regard to the individuality of each person
- Show a commitment to one's own continued professional development and learning and facilitate the learning and development of others, in order to improve care for those with life-limiting conditions and their families
- Show a commitment to developing self-care strategies and to attending to any impact that working with people facing life-limiting conditions and their families may have on you.

As a health care assistant you should:

- Appreciate the role of the health care assistant in addressing physical, psychological, social, cultural and spiritual issues in individuals receiving palliative care and their families.

DOMAIN OF COMPETENCE 2

COMMUNICATION

Effective communication is essential to the application of palliative care principles and to the delivery of palliative care. Communication is particularly important where bad news has to be relayed, when difficult decisions regarding treatment continuance and/or cessation are to be made and where the communication needs of the person with a life-limiting condition and their family. Communication is also important where circumstances are ambiguous or uncertain and when strong emotions and distress arise. Specific consideration should be given to communication as a method of:

- Supporting and enabling therapeutic relationships with the person with a life-limiting condition and her/his family
- Ensuring that the person and her/his family understand and participate in decision-making regarding care to the extent that she/he is able to and wishes to be involved
- Enabling inter-professional teamwork.

Indicators

As a health care professional you should:

- Understand the essential role communication plays in palliative care
- Understand the different types of communication e.g. verbal, non-verbal, visual, written, and interpersonal interaction (either one-to-one or with a group or team)
- Demonstrate the ability to communicate effectively with the person with a life-limiting condition, their family and the interdisciplinary team in order to establish, maintain and conclude a therapeutic relationship
- Demonstrate the ability to communicate effectively with individuals and families from diverse cultures and different backgrounds, using professional interpreters (Appendix 1) where necessary and/or assistive communication technology where necessary
- Be able to modify your own communication style to facilitate communication with individuals with a range of communication impairments or seek facilitation in this area if required.
- Understand the importance of using strategies that empower effective communication e.g. active listening, plain language, appropriate tone, clarifying statements, inviting questions
- Demonstrate an ability to be attentive to the person through careful listening to help the person and their family feel they have been heard
- Support individuals (or parents in the case of children and minors) to make informed decisions regarding the level of information they wish to receive and want to share with their family
- Act as an advocate for the person and their family to ensure appropriate and timely palliative care intervention.

As a health care assistant you should:

- Demonstrate the ability to use appropriate communication strategies which meet the needs of the person with a life-limiting condition and their family
- Appreciate and respect the confidential nature of information about the person with a life-limiting condition
- Demonstrate sensitivity towards the person with a life-limiting condition and their family as they encounter challenging situations as part of their illness
- Within the context of your role engage in meaningful relationships/interactions with families of people with a life-limiting condition, offering support to them as needed
- Seek clarification from members of the multidisciplinary team if uncertain regarding any aspects of care/information that they share
- Demonstrate an ability to accurately report any concerns and/or changes regarding the care of the person with a life-limiting condition to the registered nurse/midwife/team manager
- Be aware of family / individual dynamics and treat with sensitivity.

DOMAIN OF COMPETENCE 3

OPTIMISING COMFORT AND QUALITY OF LIFE

Individuals with life-limiting conditions and their families can be affected not only in physical, but also in psychological, social and spiritual ways. Optimising comfort and quality of life for the person with a life-limiting condition and her/his family is a dynamic process that involves anticipating, acknowledging, assessing and responding to a range of symptoms and needs in a proactive and timely manner in order to prevent and relieve suffering.

Indicators

As a health care professional you should:

- Understand the significance of anticipating and responding to the needs of people with life-limiting conditions and their families (e.g. physical, psychological, social and spiritual) in a proactive and timely manner
- Understand how the palliative care approach can enhance the assessment and management of symptoms
- Exhibit an ability to apply a range of assessment tools to gather information
- Be able to evaluate non-complex interventions and propose alternative actions if deemed necessary
- Recognise the importance and benefit of multidisciplinary working in optimising comfort and enhancing the quality of life of the person with a life-limiting condition and her/his family
- Recognise the ways in which people with life-limiting conditions and their families can be engaged in self-management of their condition
- Demonstrate professional awareness of the scope of, and benefits of, timely and appropriate access to specialist palliative care services
- Be aware of the uniqueness of a good death and facilitate the achievement of this as much as possible.

As a health care assistant you should:

- Anticipate comfort needs and within the context of your role initiate appropriate interventions to meet those needs
- Facilitate a sense of security and support the person with a life-limiting condition and her/his family at this time
- Be aware of the uniqueness of a good death and facilitate the achievement of this as much as possible
- Encourage timely referral of people with life-limiting conditions and their families to specialist palliative care services, so as to maximise comfort and quality of life.

DOMAIN OF COMPETENCE 4

CARE PLANNING AND COLLABORATIVE PRACTICE

Care planning in palliative care is characterised by coordinating and integrating person-centred care in order to promote quality of life for people with life-limiting conditions and their families. It involves assessing need, promoting and preserving choice, predicting likely problems and planning for the future in the context of a changing and deteriorating disease trajectory. Care planning ensures that multiple disciplines and agencies can be accessed and referred to as required in a timely manner. People with life-limiting conditions should be helped to engage with care planning to the extent that they are able to and wish to be involved. The concerns of families and carers should be taken into account as part of this process.

Indicators

As a health care professional you should:

- Recognise the impact of a life-limiting condition on the person and her/his family and be able to provide support in order to help the individual to adapt to the changes in her/his condition
- Recognise the impact of a life-limiting condition on the person and her/his family's mental health and coping mechanisms and be able to provide support in order to help the individual to adapt to the bereavement and loss
- Appreciate the roles, responsibilities and professional boundaries of individual members of the interdisciplinary team
- Understand the collaborative relationship between the person with life-limiting conditions, the health care professional, the family and all the other agents of care involved with the person and the family in order to develop an individualised and coherent plan of care to assist the person and the family to attain realistic goals and outcomes in all care settings
- Collaborate effectively with others as a member or leader of a multidisciplinary team
- Be able to identify priorities or concerns for the individual with a life-limiting condition and their carers, taking account of the individual's coping strategies and how the person perceives their diagnosis
- In the context of professional scope of practice be able to critically evaluate outcomes of interventions against established standards and guidelines
- Demonstrate an understanding of advance care planning and an appreciation of the appropriate time(s) to engage in discussions about preferences for care with the person with a life-limiting condition and her/his family
- Demonstrate an ability to communicate sensitively and clearly about advance care planning with the person, the family and the range of professionals and agencies involved.

As a health care assistant you should:

- Appreciate the contribution of the health care assistant in providing quality palliative / end of life care to people with life-limiting conditions and their families
- Contribute to the multidisciplinary team functioning in providing palliative care to people with life-limiting conditions and their families
- Promote activities of daily living, as part of an agreed care plan, to support optimal functioning for those receiving palliative care
- Participate in multidisciplinary team meetings, while promoting the valuable contribution of the health care assistant to the person with a life-limiting condition and their family.

DOMAIN OF COMPETENCE 5

LOSS, GRIEF AND BEREAVEMENT

Dealing with loss, grief and bereavement for the person themselves, their family and the professionals who care for them is intrinsic to palliative care provision. Most people manage their loss by combining their own resources with support from family and friends. However, a minority of people are at risk of developing complications or difficulties in their grieving. Professionals using the palliative care approach have an important role to play in supporting bereaved people by providing information and support to all and by identifying those who require bereavement therapy or counselling.

Indicators

As a health care professional you should:

- Understand that grief is a normal and appropriate response to loss which has physical, psychological, spiritual, emotional and social aspects that affect how it is experienced
- Recognise the range of individual physical, psychological, spiritual, emotional and social responses to grief and loss
- Recognise the factors which may put a person at risk of encountering difficulties in their grief, whilst also remaining aware of the resources and resiliencies that are particular to each person and family
- Demonstrate an ability to engage with a person who is experiencing loss in the context of professional scope of practice and/or role
- Assist the family to access bereavement information and support at a level that is appropriate to their needs
- Understand the personal impact of loss, grief and bereavement and recognise your own loss responses and engage in activities that maintain your resilience on an on-going basis
- Possess a level of self-awareness that prevents your own experiences of loss from negatively impacting on the person with a life-limiting condition or their family.

As a health care assistant you should:

- Understand and appreciate the role of the health care assistant and seek assistance when required
- Be able to recognise that there are a variety of psychological responses to diagnosis and illness.

DOMAIN OF COMPETENCE 6

PROFESSIONAL AND ETHICAL PRACTICE IN THE CONTEXT OF PALLIATIVE CARE

The goal of health care is to help people sustain health that is essential to their well-being. However, there comes a time when specific treatments or interventions may be futile or overly burdensome. Integrity in palliative care practice refers to the importance of respecting the person's values, needs and wishes in the context of a life-limiting condition. It guides all health care professionals to reflect on the relationship between their contribution to a person's care and the necessary contributions of other professionals. Professional and ethical practice is about considering how best to provide continuing and integrated care to people as their health care needs change in the course of life-limiting conditions.

Indicators

As a health care professional you should:

- Work within your current Code of Professional Conduct and engage ethically, knowledgably and respectfully with other disciplines.
- Recognise and respect your professional responsibility to care for people with life-limiting conditions and their families to ensure their comfort and dignity
- In the context of your current professional role establish collegial partnerships and in the context of palliative care contribute to the professional development of students, peers, colleagues and others through consultation, education, leadership, mentorship and coaching
- Use the resources available in the context of providing appropriate care to the person with a life-limiting condition
- In the context of professional scope of practice and/or role anticipate and demonstrate the ability to address potential ethical issues that may be encountered when caring for the person with a life-limiting condition and her/his family such as: Do Not Attempt Resuscitation Orders, withdrawal and withholding of treatment, use of artificial hydration and feeding, palliative sedation and requests for euthanasia
- Be able to establish and respect people's wishes about their care and options/ preferences. This includes:
    - Recognizing peoples right to make informed decisions to refuse additional treatment(s)
    - Seeking, responding to and implementing people's preferences about where they are cared for (e.g. in their own homes) if this is practicable
    - Respecting advance care plans made by people where the decision is an informed choice and relates to the situation that has arisen (Medical Council, 2009)
- Demonstrate a commitment to engage in anti-discriminatory practice in relation to end of life care and service delivery

As a health care assistant you should:

- Be aware of local policies and procedures in the context of caring for people with life-limiting conditions and their families.

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APPENDIX ONE

USEFUL RESOURCES

British Association of Perinatal Medicine (2010) Palliative Care (Supportive and End of Life Care)
A Framework for Clinical Practice in Perinatal Medicine. Report of the Working Group August 2010
http://www.bapm.org/publications/documents/guidelines/Palliative_care_final_version_%20Aug10.pdf

Palliative Care for People with Learning Disabilities (PCPLD) Network
http://www.pcpld.org/links-and-resources/

Sands. Stillbirth and Neonatal Death Charity
http://www.uk-sands.org/improving-care/the-sands-guidelines-2007/principles-of-care.html

USEFUL RESOURCES FOR INTERPRETING SERVICES & CULTURAL AWARENESS

Health Service Executive (2009) On Speaking Terms: Good Practice Guidelines for HSE Staff in the Provision of Interpreting Services
http://www.hse.ie/eng/services/Publications/services/SocialInclusion/emaspeaking.pdf

Health Service Executive (2009) Health Services Intercultural Guide: Responding to the needs of diverse religious communities and cultures in health care settings
http://www.hse.ie/eng/services/Publications/services/SocialInclusion/InterculturalGuide/

http://www.hse.ie/eng/services/Publications/services/SocialInclusion/InterculturalGuide/interculturalguide.pdf

APPENDIX TWO

COMMON SYMPTOMS ASSOCIATED WITH LIFE-LIMITING CONDITIONS

PAIN

The World Health Organisation defines pain as "an unpleasant sensory or emotional experience associated with actual or potential tissue damage, or described in terms of such damage".
It should be remembered that pain is 'whatever the experiencing person says it is, existing wherever the experiencing persona says it does' (McCaffery, 1968).

NAUSEA

Is a subjective symptom involving an unpleasant sensation in the back of the throat and the epigastrum, which may or may not result in the person experiencing nausea vomiting.

VOMITING

Is the forced expulsion of the contents of the stomach through the mouth.

CONSTIPATION

'A decrease in the frequency of passage of formed stools and characterized by stools that are hard and small and difficult to expel.' (Caraccia Economou, 2010).

ANOREXIA

The loss of desire to eat (Wholihan & Kemp, 2010)

CANCER CACHEXIA

'Cancer cachexia is a complex, multifactorial wasting syndrome involving loss of skeletal muscle and fat that is caused by an abnormal host response to tumor presence or tumor factors.' (Stewart et al., 2008)

FATIGUE

NCCN defines fatigue as a persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning.

SWEATING

'The secretion of fluid onto the skin surface to aid cooling. Sweating is a normal phenomenon in the regulation of body temperature, but in illness can be a troublesome and distressing symptom.' (Watson et al., 2009:359)

FEVER

'A rise in body temperature exceeding 38oC (100.4oF) from the norm (37o ± 1o C) (98.78oF).' (Larkin, 2010)

BREATHLESSNESS

Is an unpleasant sensation of difficulty in breathing and is a common, disabling, and distressing symptom (Galbraith et al., 2010)

COUGH

'Cough is an explosive expiration that can be a conscious act or a reflex response to an irritation of the tracheobronchial tree.' (Dudgeon, 2010)

APPENDIX THREE

GLOSSARY OF TERMS

Adapted from Health Service Executive (2014) Glossary of Terms. Palliative Care Programme, Clinical Strategy and Programme Directorate
http://www.hse.ie/eng/about/who/clinical/natclinprog/palliativecareprogramme/glossary.pdf

ACTIVE LISTENING:

Involves being fully attentive to another person without being distracted. It also involves the ability to demonstrate that the person has been heard and understood by re-stating or paraphrasing what has been said in order to confirm what they have heard and the understanding of both parties.

ADVANCE CARE PLANNING:

Advance care planning is a process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in the individual's condition with loss of capacity to make decisions and communicate these to others.

ANTI-OPPRESSIVE PRACTICE:

Addresses social divisions and structural inequalities and aims to provide more appropriate and sensitive services by responding to people's needs regardless of their social status. *(Dominelli (2009) Anti-Oppressive Practice: The Challenge of the twenty first century. In R. Adams, L.Dominelli & M Payne (Eds.) Social Work; Themes, Issues and Critical Debates, 3rd Edition. Palgrave Macmillan, Basingstoke).*

BEREAVEMENT:

Bereavement is the total response to a loss and includes the process of 'recovery' or healing from the loss. Although there are similarities in people's responses, there are also marked differences. Each person will grieve and 'recover' in their own way.

COMPLEX PALLIATIVE CARE PROBLEMS:

Complex palliative care problems are defined as those that are severe and intractable, involving a combination of difficulties in controlling physical and/or psychological symptoms, the presence of family distress and social and/or spiritual problems. They exceed the resources of the generalist palliative care provider to meet the needs and expectations of the individual/carer/family.

CHILDREN'S PALLIATIVE CARE:

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.

END OF LIFE CARE*:

End of life care is a continuum of palliative care and is usually used to describe the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less.

* "End-of-life care" is an imprecise term but implies time-defined care. It is a quantitative rather than qualitative descriptor that excludes the purpose of care. In contrast, palliative care is not time-confined but goal-oriented.(4) The discipline of palliative care helps individuals to "live until they die" whenever that occurs.(5) The Palliative Care programme is of the opinion that promotion of the term 'end of life care' as a descriptor of palliative care practice will send a message to the general public that care is limited to the imminently dying. We also are concerned that the phrase will promote among potential referring physicians a transitional "discontinuous" care model rather than a more desirable seamless "collaborative" care with early referral.(6) Therefore, the programme recommends that the term 'end of life care is used to describe the care that is offered during the period when death is imminent, and life expectancy is limited to a short number of days, hours or less. 'Palliative care' is the preferred term of the programme when describing care which is focused on improving the quality of life of individuals and their families facing the problems associated with life-threatening illness

FAMILY:

'A family is defined as those who are closest to the individual in knowledge, care and affection. The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets)'. (Palliative Care Australia (2005) Standards for Providing Quality Palliative Care for all Australians, Page 11).

GENERAL PALLIATIVE CARE:

Care provided by health and social care professionals who, although not engaged full time in palliative care, apply the principles of palliative care in the course of their work. Some health and social care professional providing general palliative care will have additional training and experience in palliative care.

GENERALIST PALLIATIVE CARE PROVIDERS:

Generalist providers refer to all those services, health and social care providers who have a primary or 'first contact' relationship with the person with a life-limiting condition and palliative care needs. The use of the term 'generalist' in this context refers to general practitioners, primary care team members and staff of residential care services. It also includes other specialist services and clinical staff of emergency departments and acute care hospitals.

HOSPICE CARE:

Hospice care is a term that is often used to describe the care offered to individuals when the disease process is at an advanced stage. The term may be used to describe either a place of care (i.e. institution) or a philosophy of care, which may be applied in a wide range of care settings.

INDICATORS:

'… describe the evidence that is to be produced for assessing competency in that domain.'
http://www.nursingboard.ie/competency/comp2/competency.asp

Indicators describe the knowledge, skills and behaviour necessary for competence in that domain.

INFORMED CONSENT:

Informed consent is given voluntarily by the individual when decisions about care are being made or when permission is needed for an intervention to be carried out by competent professionals.
In order to exercise their right to make informed decisions, individuals should be provided with sufficient understandable information, which will inform their judgement.

LIFE-LIMITING CONDITION:

Life-limiting condition means a condition, illness or disease which:

- Is progressive and fatal; and
- The progress of which cannot be reversed by treatment.

MOST RESPONSIBLE PHYSICIAN:

The physician who has final responsibility and is accountable for the medical care of a individual.

MULTIDISCIPLINARY TEAM:

A team of health and social care professionals who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified needs of the individuals and families being care for. A multidisciplinary team typically includes members from the following disciplines:

- Medicine
- Nursing
- Social Work
- Occupational Therapy
- Physiotherapy
- Psychology
- Chaplaincy
- Pharmacy

- Volunteers
- Other disciplines, such a Speech and Language Therapy, Dietetics, Complimentary and Creative Arts Therapy may also be part of the team.

NON-COMPLEX INTERVENTIONS:

Represent the response to palliative care problems by the generalist palliative care provider. Normally non-complex interventions are used to respond to problems which are not severe or intractable, do not represent difficulties in controlling symptoms or represent excess family distress.

OCCUPATIONAL THERAPY:

Occupational therapy is a client-centred health profession concerned with promoting health and well- being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement. (World Federation of Occupational Therapists 2012)

OCCUPATIONAL PERFORMANCE:

The ability to perceive, desire, recall, plan and carry out roles, routines, tasks and sub-tasks for the purpose of self-maintenance, productivity, leisure and rest in response to demands of the internal and/or external environment (Chapparo & Ranka, 1997).

OCCUPATIONAL PERFORMANCE ROLES:

Are the patterns of occupational behaviour composed of configurations of self-maintenance, productivity, leisure and rest occupations. Roles are determined by individual person-environment-performance relationships. They are established through need and/or choice and are modified with age, ability, experience, circumstance and time (Chapparo & Ranka, 1997).

PALLIATIVE CARE:

Palliative care is an approach that improves the quality of life of individuals 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, physical, psychosocial and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of individual care;
- Offers a support system to help individuals live as actively as possible until death;
- Offers a support system to help the family cope during the individuals illness and in their own bereavement;
- Uses a team approach to address the needs of individuals and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(WHO, 2002)

PALLIATIVE CARE FOR CHILDREN:

Palliative care for children represents a special, albeit closely related field to adult palliative care. Palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed

at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

(WHO, 1998)

PALLIATIVE CARE APPROACH:

The palliative care approach aims to promote both physical and psychosocial wellbeing. It is a vital and integral part of all clinical practice, whatever the illness or its stage, informed by a knowledge and practice of palliative care principles.

PALLIATIVE CARE REHABILITATION:

- Helps individuals gain opportunity, control, independence and dignity;
- Responds quickly to help people adapt to their illness;
- Takes a realistic approach to defined goals;
- Is continually evolving, taking its pace from the individual.

PALLIATIVE CARE SUPPORT BEDS:

Terms such as 'level 2 beds' and 'intermediate palliative care beds' have been used as synonyms for palliative care support beds. It is recommended that the term 'palliative care support beds' replace all other descriptors.

PALLIATIVE MEDICINE:

Palliative medicine is the appropriate medical care of individuals with active, progressive and advanced disease, for whom the prognosis is limited, and the focus of care is the quality of life. Palliative medicine includes consideration of the family's needs before and after the individual's death.(13)

SPECIALIST PALLIATIVE CARE SERVICES:

Specialist palliative care services are those services with palliative care as their core speciality and which are provided by an interdisciplinary team, under the direction of a consultant physician in palliative medicine.

THERAPEUTIC RELATIONSHIPS:

'Therapeutic relationships require that the carer individualises care for the person with end-of-life needs as well as the individual's family.' (Baldwin M.A. (2011) Attributes of Palliative Caring. In Key Concepts of Palliative Care (M.A. Baldwin & J. Woodhouse Eds.) London, Sage. Page 7)

ROLE DELINEATION:

Role delineation is a process which determines what support services, staff profile, minimum safety standards and other requirements are provided to ensure that clinical services are provided safely and appropriately supported.

UNSTABLE:

Unstable is where the individual experiences the development of a new problem or rapid increase in the severity of existing problems, either of which require an urgent change in management or emergency treatment, and/or the family/carers experience a sudden change in their situation requiring urgent intervention by the specialist palliative care team.

Health Services Executive Palliative Care Competence Framework Steering Group (2014),
Palliative Care Competence Framework.

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