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# Palliative Care Competence Framework



MEDICINE NURSING MIDWIFERY HEALTH CARE ASSISTANTS

SOCIAL WORK OCCUPATIONAL THERAPY PHYSIOTHERAPY

SPEECH AND LANGUAGE THERAPY DIETETICS / CLINICAL NUTRITION

PHARMACY PSYCHOLOGY CHAPLAINCY/PASTORAL CARE

















# Palliative Care Competence Framework 2014

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### CONTENTS

Foreword	6
Joint Message	7
Statements of Support	8
Membership of Steering Group	10
Acknowledgements	11
Introduction	12
Palliative Care	12
Competence Framework Development	14
Method	14
The context of the Palliative Care Competence Framework	15
Domains of Competence	15
Core Competences for Palliative Care	17
Discipline Specific Competences	
Medicine	20
Nursing	34
Midwifery	56
Health Care Assistants	64
Social Work	72
OccupationalTherapy	86
Physiotherapy	100
Speech and Language Therapy	114
Dietetics/Clinical Nutrition	128
Pharmacy	142
Psychology	156
Chaplaincy/Pastoral Care	170
References	184
Appendix 1	186
Appendix 2	187
Annendix 3	188

### **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 of State at the Department of Health and the Department of Justice, Equality & Defence with special responsibility for Disability, Equality, Mental Health & Older People

# 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

Laren Ryan

**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 Bentor

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 HSE 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











The Healthcare Chaplaincy Board



Chaplaincy Accreditation Board



National Association of Health Care Chaplains



Association of Clinical Pastoral Education (Ireland) Ltd





HOSPICEAND PALLIATIVE CARESOCIAL WORK GROUP



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#### 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
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# **ACKNOWLEDGEMENTS**

The development of the Palliative Care Competence Framework would not have been possible without the commitment of the Palliative Care Competence Framework Steering Group, Mary Ainscough, Karen Charnley, Dr Michael Connolly, Jackie Crinion, Cliona Hayden, Orla Keegan, Prof Philip Larkin, Marie Lynch, David McEvoy, Dr Regina McQuillan, Liz O'Donoghue, Morna O'Hanlon, Sheilagh Reaper-Reynolds, Dr Joan Regan, Deirdre Rowe, Mary Wynne, all of whom have played a crucial role in making this framework a reality.

#### 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.

# <u>INTRODUCTION</u>

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 lifelong 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.

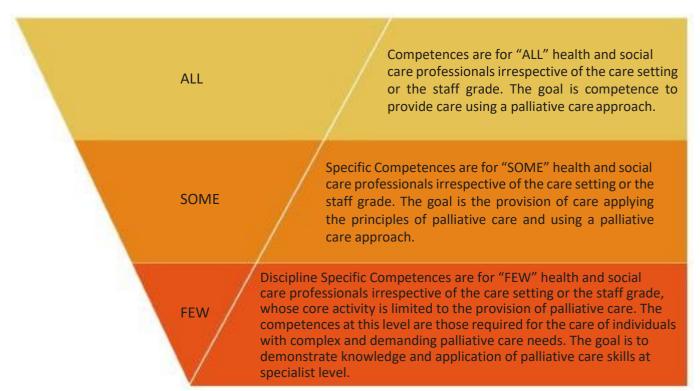


Figure 1: Competence Framework Model – adapted from Australian Model for Nursing in Cancer Control

### 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 be eavement.

#### **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 lifelimiting 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**

**MEDICINE** 



# MEMBERSHIP OF DISCIPLINE SPECIFIC WORK GROUP: MEDICINE

#### Dr Regina McQuillan (Chair)

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#### Dr Miriam Colleran

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#### Dr Anne Horgan

Consultant Oncologist, Waterford Regional Hospital

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#### Dr Denise Sadlier

Consultant Nephrologist, Mater Misericordiae University Hospital

#### Dr Catherine Sweeney

Medical Director, Services for Older People. St. Patrick's Hospital, Cork/Lecturer Clinical Science and Practice, School of Medicine, University College Cork

#### **Dr Emmet Walls**

Palliative Medicine Consultant, Waterford Regional Hospital













#### 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 be eavement.

#### **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 lifelimiting 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 onyou.

#### ALL

#### All doctors on completion of basic specialist training\* should:

- Understand and be able to recognise common trajectories of life-limiting conditions, including prognostic factors, common symptoms and problems
- Understand the impact that psychological responses, social stressors and spiritual dimensions to loss, may have on the mental health and decision making of the person with a life-limiting condition and their family and take this into account when planning care
- Understand, recognise and address the immediate management of pathological responses to loss which may impact on the mental health and decision-making of the person with a life-limiting condition and their family
- Provide education to people with life-limiting conditions, their carers and colleagues in the context of your role and at an appropriate level
- Take cognisance of the potential role of specialist palliative care services in supporting staff in other agencies to provide a palliative care approach to persons with a life-limiting condition.

#### SOME

Doctors with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions should:

- Demonstrate in-depth understanding of the full spectrum of trajectories of lifelimiting conditions in the context of your specialty or local work environment
- Understand, recognise and address the management of pathological responses to loss which may impact on the mental health and decision-making of individuals and families, referring to specialists where appropriate.





<sup>\*</sup>Basic Specialist Training (BST) is a two-year, curriculum-based programme of supervised clinical training at Senior House Officer (SHO) level.

- Demonstrate leadership in the delivery of general palliative care in your local work environment
- Demonstrate leadership in the delivery of palliative care education in your local work environment
- Lead, facilitate or engage in research in palliative care and in the context of your local work environment.

#### **FEW**

#### Doctors with higher medical training in palliative medicine should:

- Demonstrate an in-depth understanding of the full spectrum of trajectories of life-limiting conditions (including prognostic factors, symptoms and problems)
- Understand, recognise and address the management of pathological responses to loss which may impact on the mental health and decision-making of individuals and families
- Be able to identify and actively respond to the learning needs of people living with a life-limiting condition, their families and health care professionals, sharing palliative knowledge and supporting the provision of evidence-based practice in a variety of care settings
- Demonstrate leadership in the development and delivery of palliative care policy
- Demonstrate leadership in the development and delivery of palliative care provision
- Demonstrate leadership in the development and delivery of palliative care education
- Lead, facilitate and engage in audit and research in the field of palliative care.











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 differ. 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

#### AII

#### All doctors on completion of basic specialist training should:

- Be able to assess the person's current understanding of her/his health status
- Be able to communicate diagnosis and likely prognosis in an accurate and compassionate manner, taking account of the person's needs and wishes
- Understand that the communication of information which fundamentally changes the person's understanding of their situation and/or influences their decisionmaking or planning is an on-going process and not a single event
- Be able to recognise and address the immediate manifestations of conflict in decision-making in the context of palliative care.





#### **SOME**

Doctors with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions should:

- Demonstrate an ability to enlist the skills of the multidisciplinary team/colleagues to enhance and support communication with the person with a life-limiting condition and their family
- Be able to mediate conflict in decision-making in the palliative care setting and work towards consensus building in care planning.

#### **FEW**

#### With higher medical training in palliative medicine should:

- Demonstrate the ability to provide information regarding diagnosis and prognosis to a child or adolescent with a life-limiting condition where applicable in current practice
- Demonstrate the ability to provide information regarding diagnosis and prognosis to children of people with life-limiting conditions
- Be able to support colleagues to provide information regarding diagnosis and prognosis to children of people with life-limiting conditions
- Demonstrate leadership through the promotion of effective intra an interdisciplinary team communication in the palliative care setting
- Be able to guide and support colleagues in their management of communication challenges in the palliative care setting
- Be able to mediate and manage complex communication challenges in the team and with people with life-limiting conditions and their families.













#### 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 lifelimiting 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 far as possible

#### ALL

#### All doctors on completion of basic specialist training should:

- Be able to carry out a consultation with a person with a life-limiting condition and recognise the role of palliative care in enhancing that person's care
- Demonstrate an ability to assess and manage uncomplicated symptoms associated with life-limiting conditions using standard guidelines or protocols of care
- Be able to recognise potentially reversible causes of clinical deterioration and employ the level of investigation/ assessment that is appropriate to their management
- Be able to recognise and provide immediate care of emergencies that may arise in palliative care (e.g. spinal cord compression, hypercalcaemia, major haemorrhage)
- Be able to anticipate (where possible) and recognise a need for change in the focus of care and treatment goals at critical decision points in the course of a lifelimiting condition
- Be able to help the person with a life-limiting condition and their family adapt to a transition from life prolonging treatment to a focus on palliative care, where appropriate
- Be able to recognise when a person with a life-limiting condition is actively dying and communicate to family and staff the expectation of imminent death
- Be able to provide guidance and support to the individual and their family preparing them for what to expect during the normal dying process
- Be able to verify and pronounce death
- Understand the role of the coroner and know when to report a death to the coroner.



#### SOME

Doctors with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions should:

- Demonstrate an ability to assess and manage common symptoms (Appendix 2) associated with life-limiting conditions
- Demonstrate an ability to consider the benefits, burdens and risks of investigations and treatments and make decisions regarding the appropriateness of these for each person living with a life-limiting condition
- Demonstrate an ability to appropriately manage decisions about withholding or withdrawing treatment
- Demonstrate an ability to appropriately modify the management of co-morbidities in the context of life-limiting conditions.

#### **FEW**

#### With higher medical training in palliative medicine should:

- Be able to provide expert leadership and guidance on the management of complex symptoms to colleagues when requested and to manage complex symptoms when acting as Most Responsible Physician
- Demonstrate appropriate judgment on when to refer individuals and family members
  to other health care professionals in order to assess, treat and manage individual
  and family care issues outside the scope of palliative care practice, and be able to
  collaborate with them
- Be able to lead discussion with the multidisciplinary team/colleagues promoting the appropriate recognition of the evolving needs and preferences of the individual and family over time, and facilitating the management of complex, competing and shifting priorities in goals of care.









### **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 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.

#### ALL

#### All doctors on completion of basic specialist training should:

- Be able to participate in key events in the care of the person with a life-limiting condition, such as family meetings and advance care planning
- Demonstrate ability to recognise that the person with a life-limiting condition may lose capacity to make decisions towards end-of-life
- Understand that in situations where a person lacks capacity to make decisions, decisions must be made in the best interests of the person and should follow the Irish Medical Council Guidelines in respect of decision-making
- Demonstrate understanding of the Irish Medical Council Guidelines on end-of-life care and an ability to apply these guidelines in practice.





#### **SOME**

Doctors with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions should:

- Be able to facilitate key events in in the care of the person with a life-limiting condition, such as family meetings and advance care planning, involving other team members as appropriate
- Be able to provide guidance on issues of organ donation or post-mortems
- Be able to refer the person with a life-limiting condition and their family members
  to other health care professionals to assess, treat and manage individual and
  family care issues outside the scope of palliative care practice and collaborate with
  them.

#### FEW

With higher medical training in palliative medicine should:

- Demonstrate leadership in the conduct of facilitation of key events in individual care, such as family meetings and advance care planning, involving other team members and services as appropriate
- Demonstrate clinical leadership of the specialist palliative care team in order to enhance the quality of care of people with life-limiting conditions and their family
- Demonstrate leadership in the development and maintenance of effective relationships with referring doctors, other health care providers, managers of services and the public.











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
- 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.

#### ALL

All doctors on completion of basic specialist training should:

- Demonstrate understanding of normal and pathological responses to the diagnosis/prognosis of a life-limiting condition and an ability to address the immediate management of such responses
- Work in partnership with parents, guardians and other family members in order to prepare and support children and vulnerable adults for the loss of loved ones
- Facilitate the person with a life-limiting condition and their carers to express their thoughts and feelings relating to illness and loss.

#### **SOME**

Doctors with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions should:

- Demonstrate an ability to identify those experiencing complicated grief and utilise resources to support them
- Appreciate the nature of disenfranchised grief in individuals, families, and carers and appropriate methods of addressing this grief.

#### FEW

With higher medical training in palliative medicine should:

Be able to act as a resource to support the multidisciplinary team in the management of loss, grief and bereavement.





### **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 people's wishes about their care and options/ preferences. This includes:
  - Recognising 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

#### ALL

#### All doctors on completion of basic specialist training should:

- Be aware of and act according to the Irish Medical Council Ethical Guidelines as it applies to the care of people with life-limiting conditions
- Demonstrate an understanding of the difference between managing a life-limiting condition and providing end-of-life care.

#### SOME

Doctors with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions should:

 Participate in processes of clinical governance and quality assurance to maintain and improve clinical practice in palliative care.









#### FFW

#### With higher medical training in palliative medicine should:

- Demonstrate a commitment to working in partnership with health care managers and providers to assess, coordinate, promote and improve individual safety in the context of palliative care
- Demonstrate an understanding of the process of quality improvement in the context of palliative care
- Demonstrate a commitment to advancing Palliative Care through the generation and application of knowledge and research
- Demonstrate leadership through advocating for on-going and continuous service development
- Facilitate appropriate engagement of service users in the development of palliative care services
- Be able to facilitate the discussion and resolution of ethical issues that may arise in palliative care
- Communicate and advance the distinct contribution of palliative medicine.











## **DISCIPLINE SPECIFIC COMPETENCES**

### NURSING

(GENERAL NURSING, PUBLIC HEALTH NURSING, PSYCHIATRIC NURSING, INTELLECTUAL DISABILITY NURSING, CHILDREN'S NURSING)



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

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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 be eavement.

#### 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 lifelimiting 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 onyou.

#### **ALL NURSES**

As a registered nurse caring for people with life-limiting conditions you should:

- Understand and recognise common trajectories of life-limiting conditions
- Understand the impact that psychological responses, social stressors and spiritual dimensions to loss may have on the mental health and decision making of the person with a life-limiting condition and their family and take this into account when planning care
- Understand, recognise and address pathological responses to loss which may impact on the mental health and decision-making of individuals and families
- Provide education to people with life-limiting conditions, their carers and colleagues in the context of your role and at an appropriate level
- Take cognisance of the potential role of specialist palliative care services in supporting staff in other agencies to provide a palliative care approach to persons with a life-limiting condition.

#### **GENERAL NURSING**

#### SOME

As a RGN with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate a more in-depth understanding of the full spectrum of trajectories of life-limiting conditions in the context of your current clinical practice
- Understand, recognise and address the management of pathological responses to loss which may impact on mental health and decision-making of the person with a life-limiting condition and their family and take this into account when planning care
- Be able to recognise when the person's care needs are complex and warrant referral to Specialist Palliative Care

- Demonstrate leadership in the delivery of care using a Palliative Care approach
- Demonstrate leadership in the delivery of palliative care education in your local work environment
- In the context of your clinical role facilitate the application of research into practice.

#### FEW

#### As a palliative care nurse specialist you should

- Demonstrate an in-depth understanding of the full spectrum of trajectories of lifelimiting conditions (including prognostic factors, symptoms and problems)
- Understand, recognise and assist in the management of pathological responses to loss which may impact on behaviour and decision-making of individuals and families
- Demonstrate leadership in the development and delivery of palliative care policy and provision
- Demonstrate leadership in the development and delivery of palliative care education
- Be able to identify and actively respond to the learning needs of people living with a life-limiting condition, their families and health care professionals, sharing palliative knowledge and supporting the provision of evidence-based practice in a variety of care settings
- Be able to influence policy by highlighting evidence to support palliative care practice developments
- Demonstrate a commitment to research in the field of palliative care and its application to practice
- Demonstrate a commitment to continued professional development appropriate to current role in specialist palliative care.

#### PUBLIC HEALTH NURSING

#### ALI

#### As a RPHN caring for people with life-limiting conditions you should:

- Take cognisance of the potential role of specialist palliative care services in supporting staff working in the community to provide a palliative care approach to persons with a life-limiting condition
- Demonstrate a commitment to research in the field of palliative care and its application to practice

#### SOME

As a RPHN with additional preparation for professional practice and increased clinica engagement with people with life-limiting conditions you should:

- Demonstrate a more in-depth understanding of the full spectrum of trajectories of life-limiting conditions in the context of your current clinical practice
- Understand, recognise and address the management of pathological responses to loss which may impact on mental health and decision-making of the person with a life-limiting condition and their family and take this into account when planning care
- Be able to recognise when the person's care needs are complex and warrant referral to Specialist Palliative Care
- Demonstrate leadership in the delivery of care using a Palliative Care approach
- Demonstrate leadership in the delivery of palliative care education in your local work environment
- In the context of your clinical role facilitate the application of research into practice









#### **PSYCHIATRIC NURSING**

#### SOME

#### As a RPN you should:

- Understand and engage with the relevance of the principles of palliative care to mental health nursing across acute, residential and community care settings
- Demonstrate the ability to apply a palliative approach to care in the mental health setting
- Understand the scope of continuing palliative care provision across different dynamic mental health care settings
- Take cognisance of the role of specialist palliative care services in supporting staff when providing a palliative care approach to persons with a mental illness and a life-limiting condition

#### FEW

As a RPN working with people with enduring mental illness and life-limiting conditions you should:

- Demonstrate an ability to manage death and dying across mental health settings in the context of other residents with ambient and environmental stressors
- Understand the scope and limitations of meeting complex care needs in a specific dynamic care setting
- Demonstrate a commitment to research in the field of palliative care and its application to practice.

#### INTELLECTUAL DISABILITY NURSING

#### SOME

#### As a RNID you should:

- Demonstrate an understanding of the principles and philosophy of palliative care as applied to the care of people with an intellectual disability and life-limiting conditions and their families
- Appreciate the need to apply a palliative care approach when caring for persons with intellectual disability who have a life-limiting condition
- Be able to recognise and identify a range of life-limiting conditions that are more prevalent in persons with intellectual disability which may require palliative care
- Seek to develop knowledge and skills to support the person with an intellectual disability who has a life-limiting condition.

#### FFW/

As a RNID working with people with an Intellectual disability and life-limiting conditions you should:

- Take cognisance of the role of specialist palliative care services in supporting intellectual disability staff when providing a palliative care approach to persons with intellectual disability and a life-limiting condition
- Support other health and social care professionals to understand the unique issues that may present in a person with an intellectual disability and a life-limiting condition
- Demonstrate leadership in the areas of development and delivery of palliative care education
- Demonstrate a commitment to research in the field of palliative care and its application to practice.





#### CHILDREN'S NURSING

#### **SOME**

#### As a RCN you should:

- Demonstrate an understanding of the principles and philosophy of palliative care as applied to children and young people with life-limiting conditions and their families
- Understand the essential role of the family in the child's or young persons care
- Understand the actual and potential impact of a life-limiting condition on the child or young person and their family
- Work in collaboration with the team in providing care and support to the child or young person and family from the point of diagnosis/suspicion of diagnosis throughout the illness trajectory
- Take cognisance of national and international policies and directives in children's palliative care
- Take cognisance of the role of specialist palliative care services in supporting staff when providing a palliative care approach to children or young people with lifelimiting conditions

#### FFW

As a RCN working with children and young peoplewith life-limiting conditions you should:

- Demonstrate an understanding and knowledge of the four broad categories of conditions identified as life-shortening conditions for children or young people
- Be able to influence policy by highlighting evidence to support palliative care practice developments
- Demonstrate a commitment to research in the field of palliative care for children and young people and its application to practice.









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# **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 differ. 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 a 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 families 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.

#### **ALL NURSES**

As a registered nurse caring for people with life-limiting conditions you should:

- Be able to assess the person's current understanding of their health status
- Be able to address questions regarding diagnosis and likely prognosis in an accurate and empathetic manner, taking account of the person's needs and wishes, and referring where appropriate
- Understand that the communication of information which fundamentally changes the person's understanding of their situation and/or influences their decisionmaking or planning is an on-going process and not a single event
- Recognise and contribute to the management of potential conflict in decision-making in the context of palliative care.



#### **GENERAL NURSING**

#### SOME

As a RGN with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate an ability to enlist the skills of the multidisciplinary team/colleagues to enhance and support communication with the person with a life-limiting condition and their family
- Demonstrate an understanding of palliative care related issues and difficulties which may arise and which may impact on interactions with the individual and her/his family
- Demonstrate an ability to employ communication strategies to manage such events.

#### FEW

As a palliative care nurse specialist you should:

- Demonstrate competence in communicating with individuals and their families in the context of palliative care
- Demonstrate the ability to respond to the needs of the family of a person with a life-limiting condition when information regarding diagnosis and prognosis is being provided
- Demonstrate leadership through the promotion of effective intra and interdisciplinary team communication in the palliative care setting
- Be able to analyse complex individual situations and share insights with colleagues.

#### PUBLIC HEALTH NURSING

#### ALL

As a RPHN caring for people with life-limiting conditions you should:

- Demonstrate an understanding of palliative care related issues and difficulties which may arise and which may impact on interactions with the individual and their family
- Demonstrate an ability to employ open communication strategies to manage difficult and distressing situations with individuals and their families.

#### **SOME**

As a RPHN with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate an ability to enlist the skills of the multidisciplinary team/colleagues to enhance and support communication with the person with a life-limiting condition and their family
- Demonstrate an understanding of palliative care related issues and difficulties which may arise and which may impact on interactions with the individual and her/his family
- Demonstrate an ability to employ communication strategies to manage such events.

#### **PSYCHIATRIC NURSING**

#### **SOME**

As a RPN you should:

• Understand specific and dynamic communication and comprehension challenges that individuals with serious mental health difficulties may experience.

#### **FEW**

As a RPN working with people with enduring mental illness and life-limiting conditions you should:

- Demonstrate capacity to support and manage clear lines of communication with family members, carers and colleagues in all locations of care
- Demonstrate capacity to accommodate communication and comprehension challenges on palliative and end of life care in community and residential care settings.









#### INTELLECTUAL DISABILITY NURSING

#### SOME

#### As a RNID you should:

- Demonstrate effective person-centred communication with persons with intellectual disability who have life-limiting conditions
- Be able to convey information regarding diagnosis, treatment and prognosis to people with an intellectual disability using appropriate communication aids
- Support colleagues in the development of knowledge regarding communication with the person with an intellectual disability
- Act as advocate for the person with intellectual disability in all interactions with members of the multidisciplinary team, including intellectual disability nurses, family carers, acute hospital services, the primary care team and the specialist palliative care team.

#### FFW

# As a RNID working with people with an Intellectual disability and life-limiting conditions you should:

- Be able to identify and actively respond to the learning needs of the person with an intellectual disability and life-limiting condition, their family and members of the multidisciplinary team
- Promote a greater understanding of the role of specialist palliative care services in providing care to the person with an intellectual disability who has a life-limiting condition.

#### CHILDREN'S NURSING

#### SOME

#### As a RCN you should:

- Demonstrate an ability to communicate with a child or young person appropriately and sensitively taking cognisance of age, cognitive and sensory ability and ethnicity
- Demonstrate an understanding of the various specific communication strategies to be implemented at different points through the child's or young persons illness trajectory
- Demonstrate the ability to support the child or young person with a life-limiting condition and their parents/guardians when information is being provided regarding diagnosis and prognosis
- Demonstrate an ability to use sensitive and effective communication strategies with distressed children or young person
- Demonstrate an ability to use sensitive and effective communication strategies with parents/guardians and the extended family.

#### FEW

# As a RCN working with children and young people with life-limiting conditions you should:

- Demonstrate your professional role as a key worker for a child or young person with a life-limiting condition and their family
- Provide seamless and effective communication between the child's hospital team and community team(s).





# 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 lifelimiting 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

#### **ALL NURSES**

As a registered nurse caring for people with life-limiting conditions you should:

- Be able to assess a person with a life-limiting condition and recognise the role of palliative care in enhancing that person's care
- Be able to describe common chronic illnesses, the expected natural course and trajectories, common treatments and complications
- Be able to assess and manage uncomplicated symptoms associated with lifelimiting conditions using guidelines and standard protocols of care and in the context of current scope of practice
- Demonstrate and ability to assess and manage common symptoms associated with life-limiting conditions (Appendix 2)
- Be able to recognise, plan and implement the care and management of potentially reversible causes of clinical deterioration
- Be able to recognise and assist in the provision of immediate care of emergencies that may arise in the palliative care setting (e.g. spinal cord compression, hypercalcaemia, major haemorrhage), and know when to escalate
- Be able to anticipate (where possible) and recognise a need for change in the focus of care and treatment goals at critical decision points in the course of a lifelimiting condition
- Be able to help the person with a life-limiting condition and their family adapt to a transition from life prolonging treatment to a focus on palliative care
- Be able to anticipate, recognise and respond effectively to signs and symptoms of imminent death
- Take a lead in providing guidance and support to the individual and their family, preparing them for what to expect during the normal dying process
- Ensure last offices are attended to in the context of the individuals beliefs, culture and religious practice
- Understand the process for verifying and pronouncing death
- Be aware of circumstances where a coroner's examination is required.









#### SOME

**GENERAL NURSING** 

As a RGN with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate an ability to contribute to the consideration of the benefits, burdens and risks of investigations and treatments and make decisions regarding the appropriateness of these for each person living with a life-limiting condition
- Be able to recognise and provide immediate care of emergencies that may arise in palliative care (e.g. spinal cord compression, hypercalcaemia, major haemorrhage) and know when to escalate
- Demonstrate understanding of the reasons for modifying the management of comorbidities in the context of life-limiting conditions
- Demonstrate an ability to appropriately contribute to discussion regarding decisions about withholding or withdrawing treatment.

#### FEW

As a palliative care nurse specialist you should:

- Demonstrate advanced knowledge of disease processes, treatments, concurrent disorders and likely outcomes to guide clinical decision-making so as to optimise comfort and quality of life
- Demonstrate an ability to analyse complex clinical information to inform diagnosis and decision making
- Be able to participate in the discussion with the multidisciplinary team/colleagues
  promoting the appropriate recognition of the evolving needs and preferences of
  the individual and family over time, and facilitating the management of complex,
  competing and shifting priorities in goals of care
- In the context of scope of practice, provide advice on the appropriate pharmacological management of symptoms
- In the context of scope of practice, registration and locally agreed policy prescribe medication for the management of symptoms.

#### PUBLIC HEALTH NURSING

#### ΔΙΙ

As a RPHN caring for people with life-limiting conditions you should:

- Be able to identify and anticipate those individuals for whom the home environment/circumstances may be unsuitable in which to provide end-of-life care
- Be able to recognise the importance of developing collaborative relationships with other professionals/agencies /medical suppliers when caring for people with life-limiting conditions and their families.

#### SOME

As a RPHN with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate an ability to contribute to the consideration of the benefits, burdens and risks of investigations and treatments and make decisions regarding the appropriateness of these for each person living with a life-limiting condition
- Be able to recognise and provide immediate care of emergencies that may arise in palliative care (e.g. spinal cord compression, hypercalcaemia, major haemorrhage) and know when to escalate
- Demonstrate understanding of the reasons for modifying the management of comorbidities in the context of life-limiting conditions
- Demonstrate an ability to appropriately contribute to discussion regarding decisions about withholding or withdrawing treatment





- In the context of scope of practice provide advice on the appropriate pharmacological management of symptoms
- In the context of scope of practice, registration and locally agreed policy prescribe medication for the management of symptoms.

#### **PSYCHIATRIC NURSING**

#### SOME

#### As a RPN you should:

- Facilitate the meeting of palliative needs as far as practical for the individual with a life-limiting condition and other individuals in a residential setting
- Demonstrate an ability to engage with the individuals experiences and provide psychoeducation to the person and their family.

#### **FEW**

As a RPN working with people with enduring mental illness and life-limiting conditions vou should:

- Facilitate the development of a shared plan of care accommodating the individuals experience and the palliative care team's recommendations
- In the context of scope of practice, provide advice on the appropriate pharmacological management of symptoms
- In the context of scope of practice, registration and locally agreed policy prescribe medication for the management of symptoms.

#### INTELLECTUAL DISABILITY NURSING

#### **SOME**

#### As a RNID you should:

- Be able to demonstrate the ability to develop, implement, evaluate and use developmentally appropriate and validated assessment tools for an individual with an intellectual disability
- Be able to develop knowledge in the use of appropriate assessment tools that will
  facilitate the recognition of pain and other symptoms in people with a learning
  disability.

#### FEW

As a RNID working with people with an Intellectual disability and life-limiting conditions you should:

- Be able to participate in the discussion with the multidisciplinary team/colleagues
  promoting the appropriate recognition of the evolving needs and preferences of
  the person with an intellectual disability and family over time, and facilitating the
  management of complex, competing and shifting priorities in goals of care
- In the context of scope of practice, provide advice on the appropriate pharmacological management of symptoms
- In the context of scope of practice, registration and locally agreed policy prescribe medication for the management of symptoms.

#### CHILDREN'S NURSING

#### SOME

#### As a RCN you should:

- Demonstrate the ability to evaluate and use developmentally appropriate assessment tools for the neonate, child, young person or a child with a cognitive impairment
- Understand the importance of working with parents/guardians when assessing pain and other symptoms
- Be able to recognise the various actual and potential symptoms that may occur in











- Demonstrate an understanding and ability to address these symptoms using effective interventions
- Understand the non-pharmacological methods of managing symptoms in children
- Demonstrate an ability to assess, guide and support parental care giving
- Be able to recognise and implement appropriate intervention strategies to support families in their role as care-givers
- Be able to recognise the importance of continuing play and education for children and young people with life-limiting conditions and the need to engage in childhood activities.

#### FFW

As a RCN working with children and young people with life-limiting conditions you should:

- In the context of scope of practice, provide advice on the appropriate pharmacological management of symptoms
- In the context of scope of practice, registration and locally agreed policy prescribe medication for the management of symptoms
- Demonstrate an awareness of subtle changes in condition which mark deterioration in a child or young person with a life-limiting condition
- Where appropriate support parents to recognise signs of general deterioration and overall decline with the aim of making memories and recognising that time is precious.





# 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

#### **Indicators**

As a health care professional you should:

should be taken into account as part of this process.

- 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 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.

#### **ALL NURSES**

As a registered nurse caring for people with life-limiting conditions you should

- Be able to facilitate and participate in key events in the care of the person with a life-limiting condition, such as family meetings and advance care planning
- Demonstrate ability to recognise that the person with a life-limiting condition may lose capacity to make decisions at end-of-life
- Understand that in situations where a person lacks capacity to make decisions, the nurse acts as an advocate to ensure decisions made are in the best interests of the person and follow the current Code of Conduct for each Nurse and Midwife
- Be able to address questions regarding issues of organ donation or post mortem
- Understand the importance of timely referral to primary care and palliative care teams in the management of the person with palliative care needs
- Demonstrate an awareness of the need for communicating with primary care teams and other teams that may impact on the delivery of care to people with life-limiting conditions and their families.









#### **GENERAL NURSING**

#### SOME

#### As a RGN you should:

- As a member of the multidisciplinary team take an active role in key events in individual care, such as family meetings and advance care planning
- Be able to refer the person with a life-limiting condition and their family members to other health care professionals to assess, treat and manage individual and family care issues outside the scope of palliative care practice.

#### FEW

#### As a palliative care nurse specialist you should:

- Demonstrate clinical leadership in specialist palliative care nursing practice to enhance the quality of care of people with life-limiting conditions and their family
- Be able to develop effective relationships with other health care providers, managers and those responsible for governance and quality management.

#### PUBLIC HEALTH NURSING

#### ALL

#### As a RPHN caring for people with life-limiting conditions you should:

- Demonstrate an understanding of the respective contributions of the primary care and palliative care teams in providing palliative care to persons with life-limiting conditions who require palliative care
- Collaborate with all members of the multidisciplinary team to optimise the care delivered to individuals and families.

#### SOME

As a RPHN with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- As a member of the multidisciplinary team take an active role in key events in individual care, such as family meetings and advance care planning
- Be able to refer the person with a life-limiting condition and their family members to other health care professionals to assess, treat and manage individual and family care issues outside the scope of palliative care practice.

#### **PSYCHIATRIC NURSING**

#### SOME

#### As a RPN you should:

- Demonstrate ability to work collaboratively with the individual, family, carers and other residents and different care teams
- Demonstrate ability to jointly develop and implement care plans and anticipatory care pathways for individuals with serious mental health difficulties who have a life-limiting condition.

#### **FEW**

As a RPN working with people with enduring mental illness and life-limiting conditions you should:

- Understand and respond to the scope and capacity for anticipating and managing deteriorating health in a palliative care context in community, acute and residential mental health care settings
- Provide psychological and therapeutic interventions as appropriate throughout care episodes.





#### INTELLECTUAL DISABILITY NURSING

#### SOME

#### As a RNID you should:

- Demonstrate leadership through the develop of innovative services that will meet the needs of individuals with an intellectual disability who have a life-limiting condition
- Understand the importance of engaging with the individual who has an intellectual disability and a life-limiting condition, and their national network of support in a timely fashion
- Advocate for the use of appropriate guidelines for life-limiting conditions in individuals with an intellectual disability
- Demonstrate an understanding of the importance of timely referral to the specialist palliative care team.

#### **FEW**

As a RNID working with people with an Intellectual disability and life-limiting conditions you should:

- Be able to engage in end-of-life decision making and planning whilst respecting the individuality of the person with an intellectual disability and remain open to potential change
- Be able to recognise when the individual's care needs are complex and warrant referral to specialist palliative care.
- Demonstrate clinical leadership in specialist palliative care nursing practice to enhance the quality of care of the person with an intellectual disability who has a life-limiting condition and their family
- Be able to develop effective relationships with other health care providers, managers and those responsible for governance and quality management
- As a member of the multidisciplinary team take an active role in key events in care, such as family meetings and advance care planning
- Be able to refer the person with an intellectual disability with a life-limiting condition and their family members to other health care professionals to assess, treat and manage individual and family care issues outside the scope of palliative care practice

#### CHILDREN'S NURSING

#### SOME

#### As a RCN you should:

- Demonstrate an understanding of inter-professional collaborative working with parents/professionals/other agencies in all settings when planning care for the child
- Liaise with the appropriate agencies to ensure the provision of seamless care.

#### FEW

As a RCN working with children and young people with life-limiting conditions you should:

- Demonstrate the ability to work collaboratively with parents/professionals/other agencies, putting in place the necessary support mechanisms to care for the child in all settings
- When appropriate act as the key worker in the care of the child or young person and their family.









#### 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
- 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.

#### **ALL NURSES**

#### As a registered nurse caring for people with life-limiting conditions you should:

• Demonstrate an understanding of normal and pathological responses to the diagnosis/prognosis of a life-limiting condition and an ability to address the immediate management of such issues or make appropriate referral.

#### **GENERAL NURSING**

#### SOME

#### As a RGN vou should:

- Understand the strategies to identify the losses that persons with cognitive and sensory impairment encounter and utilise appropriate interventions to address these when managing their palliative care needs
- Demonstrate an ability to identify those experiencing complicated grief and utilise resources to support them
- Appreciate the nature of disenfranchised grief in individuals, families, and carers and appropriate methods of addressing this grief.

#### **FEW**

#### As a palliative care nurse specialist you should

 Be able to act as a resource to support colleagues in the management of loss, grief and bereavement.



#### PUBLIC HEALTH NURSING

#### ALL

#### As a RPHN caring for people with life-limiting conditions you should:

- Be able to identify the additional losses that persons with cognitive and sensory impairment encounter and use appropriate interventions when managing their palliative care needs
- Be able to support individuals who are experiencing loss as a result of their lifechanging circumstances
- Understand advocacy and supporting families and building their resilience to deal with grief and loss
- Demonstrate an ability to identify those experiencing complicated grief and utilise resources to support them
- Appreciate the nature of disenfranchised grief in individuals, families, and carers and appropriate methods of addressing this grief.

#### SOME

As a RPHN with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- Understand the strategies to identify the losses that persons with cognitive and sensory impairment encounter and utilise appropriate interventions to address these when managing their palliative care needs
- Demonstrate an ability to identify those experiencing complicated grief and utilise resources to support them
- Appreciate the nature of disenfranchised grief in individuals, families, and carers and appropriate methods of addressing this grief.

#### **PSYCHIATRIC NURSING**

#### **SOME**

#### As a RPN you should:

- Be able to recognise and manage the bereavement, grief and loss process which individuals and families experience before, during and after death
- Be able to recognise and manage the psychological impact of death and dying on individuals with increased stress vulnerability
- Be able to provide clinical interventions including bereavement support and counselling as appropriate
- Understand the impact of a person/client's death on other client's, family and staff
- Enable cultural, religious and belief processes within care settings such as 'month's mind' to acknowledge residents' experiences of loss, grief and bereavement.

#### FEW

As a RPN working with people with enduring mental illness and life-limiting conditions you should:

- Respond to the impact of loss, grief and bereavement among staff caring for persons over a long period of time
- Be able to provide clinical interventions including family psycho-education, bereavement support and counselling as appropriate.

#### INTELLECTUAL DISABILITY NURSING

#### SOME

#### As a RNID you should:

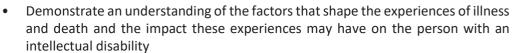
- Be able to recognise that there are a variety of psychological responses to diagnosis and illness
- Understand the impact of a person/resident's death on their family, other residents and staff











- Understand the various approaches to managing grief and loss in people with an intellectual disability
- Be able to recognise the roles of the various members of the multidisciplinary team in providing bereavement support to people with an intellectual disability
- Appreciate the needs of other service users and residents with regard to expression and management of grief
- Appreciate the need to recognise the significance of special remembrance (e.g. birthdays, anniversaries) for individuals with an intellectual disability
- Appreciate the nature of disenfranchised grief in individuals, families, and carers and appropriate methods of addressing this grief
- Develop an awareness of unresolved loss in the person with an intellectual disability.

#### **FEW**

As a RNID working with people with an Intellectual disability and life-limiting conditions you should:

• Demonstrate an ability to meet the needs of bereaved parents, siblings, extended family and other residents.

#### CHILDREN'S NURSING

#### SOME

#### As a RCN you should:

- Be able to recognise the variety of psychological responses to diagnosis and illness
- Demonstrate an understanding of the factors that shape the child's or young persons experience of illness and death and the impact these experiences may have on the child or young persons and their family
- Appreciate the impact of anticipatory grief for the family when living with a child or young persons with a life-limiting condition
- Understand the various approaches to managing grief and loss in children and young people
- Be able to recognise the roles of the various members of the multidisciplinary team in providing bereavement support to children, young people and their families.

#### FEW

As a RCN working with children and young people with life-limiting conditions you should:

- Demonstrate an ability to meet the needs of bereaved parents/guardians, siblings and extended family
- Demonstrate an ability to implement strategies including referral to support for bereaved parents/guardians and families
- Identify and support the child or young persons own concerns, including anticipatory grief, range of losses and relationship issues mindful of the individuals cognitive ability.



#### 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:
  - Recognising 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

#### **ALL NURSES**

As a registered nurse caring for people with life-limiting conditions you should:

- Be aware of and act according to the current code of professional conduct for Nurses and Midwives, as it applies to the care of people with life-limiting conditions
- Demonstrate an understanding of the difference between managing a life-limiting condition and providing end-of-life care.

#### **GENERAL NURSING**

#### FEW

As a palliative care nurse specialist you should:

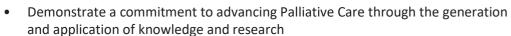
- Demonstrate a commitment to working in partnership with health care managers and providers to assess, coordinate, promote and improve safety in the context of palliative care
- Demonstrate an understanding of the process of quality improvement in the context of palliative care











- Demonstrate leadership through advocating for on-going and continuous service development
- Facilitate appropriate engagement of service users in the development of palliative care services
- Communicate and advance the distinct contribution of palliative nursing
- Participate in the discussion and resolution of ethical dilemmas that may arise in palliative care

#### PUBLIC HEALTH NURSING

As a RPHN caring for people with life-limiting conditions you should:

• Be able to recognise when active management is no longer appropriate and engage in dialogue with family members and the multidisciplinary team members in decisions regarding the withdrawal of treatment.

#### **PSYCHIATRIC NURSING**

#### SOME

#### As a RPN you should:

- Demonstrate the ability to negotiate the principles of palliative care with the comprehension and decision-making capacity of persons with serious mental health problems
- Demonstrate the ability to engage palliative care and other health care teams with the specific communication and comprehension challenges affecting the individual's mental health and decision-making capacity
- Negotiate the implementation of the principles of palliative care with the comprehension and decision-making capacity of persons with mental health problems.

#### FEW

As a RPN working with people with enduring mental illness and life-limiting conditions you should:

- Demonstrate ability to intervene as an advocate for the person when there are specific challenges affecting the individuals interaction with others and decisionmaking on end of life issues
- Demonstrate capacity to meet the individuals wishes in the context of the mental health setting
- Negotiate between existing policies within a given setting and the capacity to respond to an individual's wishes relating to end of life care.

#### INTELLECTUAL DISABILITY NURSING

#### SOME

#### As a RNID you should:

• Understand issues of capacity and consent that may affect practice in the area of intellectual disability.

#### FEW

As a RNID working with people with an Intellectual disability and life-limiting conditions you should:

- Demonstrate understanding of assessment of capacity and obtaining consent for the person with an intellectual disability and a life-limiting condition
- Be able to engage in discussion as it relates to capacity and consent for the person with an intellectual disability and a life-limiting condition





 Demonstrate leadership in identifying and addressing the barriers that exist for people with an intellectual disability who have a life-limiting condition and require palliative care

#### CHILDREN'S NURSING

#### SOME

#### As a RCN you should:

- Demonstrate an awareness of ethical issues specific to children's palliative care
- Be able to recognise when active management is no longer appropriate and engage in dialogue with parents/guardians and the multidisciplinary team members in decisions regarding the withdrawal of treatment.

#### FF\//

#### As a RCN working with children and young people with life-limiting conditions you should:

• Demonstrate a commitment to participate in the discussion and resolution of ethical dilemmas that may arise in the context of palliative care for children and young people and support parents/guardians in their outcomes.







# **DISCIPLINE SPECIFIC COMPETENCES**

**MIDWIFERY** 



#### 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 be eavement.

#### **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 onyou.

#### **MIDWIFERY**

#### ALL

#### As a RM you should:

- Understand the impact of psychological responses to loss, of social stressors and of the spiritual dimensions on the mental health and decision making of individuals and families and take this into account when planning care
- Understand, recognise and address pathological responses to loss which may impact on mental health and decision-making of parents and families
- Take cognisance of the role of specialist palliative care services in supporting staff when providing care using a palliative care approach

#### SOME

As a RM with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

 Understand the principles of palliative care applicable to maternity and neo-natal practice









#### 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 and their family differ. 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

#### **MIDWIFERY**

#### ALL

#### As a RM you should:

- Understand that the communication of information which fundamentally changes the person's understanding of their situation and/or influences their decisionmaking or planning is an on-going process and not a single event
- Be able to assess the person's current understanding of their health status
- Recognise and contribute to the management of potential conflict in decisionmaking.

#### SOME

As a RM with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- Communicate effectively with women and families throughout pregnancy, birth and the post-natal period
- Facilitate effective communication using professional interpretation services when necessary.





#### 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.

#### **Indicators**

As a health care professional you should:

- Understand the significance of anticipating and responding to the needs of people with lifelimiting 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

#### **MIDWIFERY**

#### ALL

#### As a RM you should:

- Be able to assess a person with a life-limiting condition and recognise the role of palliative care in enhancing that person's care
- Be able to assess and manage uncomplicated symptoms associated with lifelimiting conditions using guidelines and standard protocols of care and in the context of current scope of practice
- Be able to instigate the planned care and management of potentially reversible causes of clinical deterioration
- Recognise the need for a change in the focus of care and treatment goals across time
- Be able to help the person with a life-limiting condition and their family adapt to a transition from life prolonging treatment to a focus on palliative care
- Be able to anticipate, recognise and respond effectively to signs and symptoms of imminent death
- Be able to guide the family in the final hours
- Ensure last offices are attended to in the context of the individuals beliefs, culture and where appropriate religious practice.

#### **SOME**

As a RM with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- Be able to recognise the need for a change in the focus of care and treatment goals
- Support parent(s) involvement in optimising comfort and quality of life of a new born with a life-limiting condition
- Involve multidisciplinary team members in parent /sibling support.











As a RM with a specific role providing care to women, neonates and their families with life-limiting conditions you should:

- In the context of scope of practice provide advice on the appropriate pharmacological management of symptoms
- In the context of scope of practice, registration and locally agreed policy prescribe medication for the management of symptoms





#### 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.

#### ALL MIDWIVES

#### As a RM you should:

- Understand the importance of timely referral to primary care and palliative care teams in the management of the person with palliative care needs
- Demonstrate an awareness of the need for communicating with primary care teams and other teams that may impact on the delivery of care to people with life-limiting conditions and their families.









#### 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
- 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.



#### **SOME**

As a RM with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- Understand the impact of pre-natal, intra-natal and early maternity loss on parents, family and health professionals
- Be able to recognise the impact of pregnancy related loss on maternal, paternal and family health outcomes
- Understand the potential long-term impact that peri-natal loss may have on the mother, father and family/ or the maternal and paternal family
- Be able to recognise the need to provide culturally sensitive care and support during times of bereavement to women and their families
- Demonstrate the ability to anticipate the needs of the woman and her family during a time of bereavement, responding with kindness and empathy to provide physical and emotional support.





#### PROFESSIONAL AND ETHICAL PRACTICE IN THE CONTEXT OF PALLIATIVE CA

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.

#### **MIDWIFERY**

#### **SOME**

As a RM with additional preparation for professional practice and increased clinical engagement with people with life-limiting conditions you should:

- Be aware of and act according to the code of professional conduct, as it applies to the care of people with life-limiting conditions
- Demonstrate an understanding of ethical principles and their application in midwifery and neonatal care.

#### FEW

As a RM with a specific role providing care to women, neonates and their families with life-limiting conditions you should:

 Demonstrate an ability to support parents/families in their decision making process relating to ethical issues that may arise.







# **DISCIPLINE SPECIFIC COMPETENCES**

**Health Care Asssistants** 



#### 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 be eavement.

#### **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 onyou.

#### 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.









#### 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.

- 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.





#### 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 lifelimiting 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.

- 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.









#### 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.

- 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.



#### 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.

- 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.











#### 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.









# DISCIPLINE SPECIFIC COMPETENCES Social Work



## MEMBERSHIP OF DISCIPLINE SPECIFIC WORK GROUP SOCIAL WORK



#### David McEvoy (Chair)

Medical Social Worker, Specialist Palliative Care Services, Meath

#### Karen Breen

Senior Medical Social Worker in Palliative Care, Our Lady's Hospice and Care Services

#### **Pauline Carbery**

Senior Medical Social Worker, Specialist Palliative Care Team Child and Family Centre, Portlaoise

#### **Louise Casey**

Principal Medical Social Worker, Director of Bereavement Counselling and Family Support Services, Our Lady's Hospice and Care Services

#### Karen Charnley

Programme Manager (Education), All Ireland Institute of Hospice and Palliative Care

#### Liz Coogan

Psychosocial and Bereavement Care Co Ordinator, Specialist Palliative Care Services, Dochas Centre, Our Lady of Lourdes Hospital

#### Julia Costelloe

Senior Medical Social Worker, Our Lady's Children's Hospital, Crumlin

#### Katherine Dilworth

Senior Medical Social Worker, Specialist Palliative Care Team, Kerry General Hospital

#### Aisling Kearney

Senior Medical Social Worker, Galway Hospice Foundation

#### Irene Murphy

Director of Bereavement and Family Support Services, St. Patrick's Hospital/Marymount Hospice

#### Ciara Savage

Senior Medical Social Worker, Beaumont Hospital

#### Eileen Scott

Senior Medical Social Worker, Palliative Care Team, HSE West, Roscommon.







#### 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 be eavement.

#### **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 onyou.



#### ΔΙΙ

As a social worker you should:

- Understand and recognise common trajectories of life-limiting conditions
- Understand the impact that psychological responses, social stressors and spiritual dimensions to loss may have on the mental health and decision making of the person with a life-limiting condition and their family and take this into account when planning care
- Take cognisance of the potential role of specialist palliative care services in supporting staff in other agencies to provide a palliative care approach to persons with a life-limiting condition.

#### SOME

As a social workers with an added level of engagement with people with life-limiting conditions you should:

- Identify and address the specific barriers which impact on people with life-limiting conditions and their families' ability to access and utilise palliative care
- Support the multidisciplinary team to reflect on and manage the influence of their own values and practice on individuals and families facing life-limiting conditions, within the context of your role
- Advocate for responsive services for people with life-limiting conditions and their families.





#### FEW

As a social worker working primarily with people with life-limiting conditions you should:

- Understand and recognise significant changes at end of life and help indiviudals and their families plan appropriately
- Demonstrate leadership in the development and delivery of palliative care policy and provision
- Be able to recognise the potential for extending the ethos and practice of palliative care beyond formal health care settings, and work to build the capacity of communities and promote social inclusion
- Demonstrate leadership in the development and delivery of palliative care education
- Lead, facilitate and engage in research in the field of palliative care in order to improve practice









#### 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.

#### **SOCIAL WORK**

#### ALL

#### As a social worker you should:

- Be able to assess the person's current understanding of their health status
- In the context of your current role, be able to support colleagues to address questions regarding diagnosis and likely prognosis in an empathic manner, taking account of the person's needs and wishes
- Understand that the communication of information which changes the person's understanding of their situation and/or influences their decision-making or planning is an on-going process and not a single event
- Contribute to and support discussions between individuals, their families and staff members and recognise potential differences in decision making in the context of palliative care
- Support people with life-limiting conditions to adjust to illness and to understand its potential impact on their welfare and that of their families
- Understand the different styles of communication which can be adapted and used to enhance communication in complex situations at end of life.





#### SOME

As a social workers with an added level of engagement with people with life-limiting conditions you should:

- Support people with life-limiting conditions, their families and health care professionals to use developmental and age appropriate communication with children and vulnerable adults
- Assist in the mediation of conflict in decision-making in the palliative care setting and work towards consensus building in care planning
- Support Parents/Guardians/Families in sharing difficult or bad news, relating to illness or death, with children and vulnerable adults; facilitating direct supportive communication with them, where appropriate.

#### FFW

As a social worker working primarily with people with life-limiting conditions you should:

- Communicate the social workers role and demonstrate leadership in relation to complex and high risk cases which may arise in palliative care, identifying appropriate interventions that may be of help, from within the service or from other agencies
- Explore and engage with issues of a private and sensitive nature which may arise when caring for a person with life-limiting condition, offering support and guidance to colleagues in managing these situations.









#### 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 how the palliative care approach can enhance the assessment and management of symptoms
- Understand the significance of anticipating and responding to the needs of people with lifelimiting conditions and their families (e.g. physical, psychological, social and spiritual) in a proactive and timely manner
- 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
- Demonstrate professional awareness of the scope of, and benefits of timely, and appropriate access to specialist palliative care services
- 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.
- Be aware of the uniqueness of a good death and facilitate the achievement of this as much as possible.

#### **SOCIAL WORK**

#### ΔΙΙ

#### As a social worker you should:

- Engage in psychosocial assessment with a person with a life-limiting condition and recognise the role of palliative care in enhancing that person's care
- Demonstrate an ability to analyse appropriate knowledge and information to inform decision making in end of life care
- Recognise how the changing nature of symptoms can impact on the life of the person with a life-limiting condition and their family
- Be able to recognise that there can be practical, social and cultural aspects of the dying process
- Be able to recognise and address the socio-economic impact of a life-limiting diagnosis on the individual and their family and possess a knowledge of supports and interventions which may ease economic and social distress
- Provide therapeutic interventions based on assessment or refer on where appropriate.

#### SOME

As a social workers with an added level of engagement with people with life-limiting conditions you should:

- Recognise how disease progression may impact on the capacity of the person with a life-limiting condition to engage in meaningful discussion
- Support families with complex relationships in order to facilitate the on-going provision of care, whilst prioritising the wishes of the person with a life-limiting condition, where appropriate





• In the context of your current role, support the team when considering the care and treatment options for the person with a life-limiting condition and with due regard to the persons wishes.

#### FFW

As a social worker working primarily with people with life-limiting conditions you should:

- Be able to recognise and at times anticipate the need to change and adapt the focus of social work intervention at critical points during a life-limiting condition, supporting the person with a life-limiting condition and their family through times of transition
- Provide specialist therapeutic interventions based on going assessment of palliative and end of life needs.









#### 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.

#### **SOCIAL WORK**

#### ALL

#### As a social worker you should:

- Work collaboratively with the person with a life-limiting condition, their family and other professionals, including co-ordinating family meetings, team meetings, mediating discussions and planning for future care
- Recognise that the person with a life-limiting condition may lose capacity to make decisions towards end-of-life
- In situations where a person lacks capacity to make decisions, the Social Worker acts as an advocate for the person and/or their family/carers and within their current Code of Professional Conduct and Ethics
- Understand the centrality of relationships for people, based on the theories of attachment, separation, loss, change and resilience
- Identify and coordinate the input of multiple care agents to support a range of differing care needs of people with life-limiting conditions, their carers and families at end of life.





#### SOME

As a social workers with an added level of engagement with people with life-limiting conditions you should:

- Share professional knowledge and expertise regarding psychosocial issues in palliative care and at end of life, with the multidisciplinary team or with colleagues
- Support and advise the multidisciplinary team to interpret, use and access relevant policy, legal and administrative processes during times of illness, loss and bereavement, within the context of your current role.

#### FEW

As a social worker working primarily with people with life-limiting conditions you should:

- Carry out bereavement risk assessment in collaboration with the family and multidisciplinary team
- Demonstrate leadership role by drawing on in-depth psychosocial assessment and integrating multiple sources of knowledge and experience in order to contribute to care planning
- Demonstrate leadership in identifying complex psychosocial issues and facilitate the appropriate team response through family meetings involving other team members and services as appropriate
- Demonstrate leadership in the development and maintenance of effective relationships with health care providers, managers of services and the public in the context of palliative care.









#### 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
- 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.

#### **SOCIAL WORK**

#### ALL

#### As a social worker you should

- Work in partnership with parents, guardians and other family members in order to prepare and support children and vulnerable adults for the loss of loved ones and refer on where appropriate
- Facilitate the person with a life-limiting condition and their carers to express their thoughts and feelings relating to illness and loss
- Be able to recognise that there are a variety of psychological responses to diagnosis and illness
- Demonstrate an understanding the theories of loss, grief and bereavement.

#### SOME

As a social workers with an added level of engagement with people with life-limiting conditions you should:

- Provide supports and interventions to carers and families after the death of a loved one, as appropriate
- Demonstrate knowledge of available networks and supports across a range of family needs into bereavement
- Provide bereavement support in individual and group settings, with referral to other agencies, where appropriate.





#### **FFW**

As a social worker working primarily with people with life-limiting conditions you should:

- Understand and share knowledge of theories and research evidence relevant to loss and bereavement including anticipatory grief and risk indicators for complicated grief
- In the context of your practice setting provide multidisciplinary team debriefing and support the development of self-care strategies for colleagues working in end of life care
- Provide bereavement risk assessment and counselling in individual or group settings, with referral on to other agencies, where appropriate
- Provide expert guidance on adult and childhood grief within complex family situations
- Promote research and development of bereavement care, including audit of own agency practice and forge appropriate links with external agencies.









#### 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.

#### **SOCIAL WORK**

#### ALL

#### As a social worker you should:

• Engage in reflective practice to promote greater self- awareness and ability to critically evaluate one's own practice within end of life care.

#### SOME

As a social workers with an added level of engagement with people with life-limiting conditions you should:

- Utilise supervision to ensure best practice in end of life care and to meet organisational and professional requirements
- Have a commitment to anti-oppressive practice in relation to end of life care and service delivery
- Raise awareness within the multidisciplinary team of the factors or practices which may be considered oppressive.





#### **FFW**

As a social worker working primarily with people with life-limiting conditions you should:

- Demonstrate a commitment to working in partnership with health care managers and providers to assess, coordinate, promote and improve individual safety in the context of palliative care
- Demonstrate an understanding of the process of quality improvement in the context of palliative care
- Demonstrate a commitment to advancing Palliative Care through the generation and application of knowledge and research
- Demonstrate leadership through advocating for on-going and continuous service development
- Facilitate appropriate engagement of service users in the development of palliative care services
- Be able to facilitate the discussion and resolution of ethical issues that may arise in palliative care
- Communicate and advance the distinct contribution of social work to palliative care.







## DISCIPLINE SPECIFIC COMPETENCES

Occupational Therapy



## MEMBERSHIP OF DISCIPLINE SPECIFIC WORK GROUP OCCUPATIONAL THERAPY

#### Deirdre Rowe (Chair)

Occupational Therapy Manager / Deputy Head of Clinical Services, Our Lady's Hospice and Care Services, Harold's Cross

Joint Therapy Lead to the HSE National Clinical Programme for Palliative Care Discipline lead for the Occupational Therapy Competency Working Group

#### Leonora Carey

Occupational Therapist Manager, Milford Care Centre, Limerick

#### Lisa Churchward

Chairperson of the Occupational Therapy Advisory Group for Palliative Care & Oncology, Association of Occupational Therapists of Ireland

#### Dr Deirdre Connolly

Assistant Professor and Head of Discipline of Occupational Therapy, TCD Trinity Centre for Health Sciences, St. James' Hospital

#### Sarah Delaney

Senior Occupational Therapist, St. Francis Hospice, Raheny

#### Linda Gormley

Acting Occupational Therapist Manager, St. Francis Hospice, Raheny

#### Angeline Ingram

Senior Occupational Therapist, HSE SPC Services, Dochás Centre, Drogheda, Co.Louth

#### Claire O'Herlihy

Senior Occupational Therapist, Cork University Hospital

#### Carol Reynolds

Senior Occupational Therapist, HSE Primary Care, Dublin South West













#### 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 be eavement.

#### **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 lifelimiting 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 onyou.

#### OCCUPATIONAL THERAPY

#### ALL

#### As an occupational therapist you should:

- Understand and be able to recognise common trajectories of life-limiting conditions, including common symptoms and problems
- Understand the impact that psychological responses, social stressors and spiritual
  dimensions to multiple loss, including loss of occupational roles and functional
  independence, may have on the behaviour and decision making of individuals
  with life-limiting conditions and their families and take this into account when
  planning care
- Understand, recognise and address the management of pathological responses
  to loss of occupational roles and functional independence which may impact on
  behaviour and decision-making of individuals with life-limiting conditions and
  families, referring to specialist palliative care where appropriate
- Provide education to individuals with life-limiting conditions, their carers and colleagues in the context of your role and at an appropriate level
- Take cognisance of the role of specialist palliative care services in supporting staff when providing a palliative care approach to the person with a life-limiting condition.

#### SOME

As an occupational therapist with increased clinical engagement with people with lifelimiting conditions you should:

 Be able to demonstrate in-depth understanding of the full spectrum of trajectories of life-limiting conditions in the context of your current clinical practice.



- Undertake additional study relevant to the needs of individuals with life-limiting conditions to advance knowledge and enhance competence through the integration of on-going learning into practice
- Be able to identify and engage in research that will lead to effective clinical practice.

#### FEW

As an occupational therapist whose core role is the provision of palliative care, you should:

- Demonstrate an advanced knowledge, and understanding of the full spectrum of trajectories of life-limiting conditions when responding to complex and multidimensional care needs
- Undertake study and continuously develop a knowledge base at an advanced level to improve the quality and standard of therapy outcomes and service delivery in palliative care
- Develop, facilitate and provide education, leadership, mentorship and professional support for colleagues and generalist providers of palliative care
- Demonstrate leadership that encourages colleagues to foster a caring environment that supports all staff working in sensitive situations with people with life-limiting conditions and their families
- Lead, facilitate and engage in further education and research in palliative care.
- Design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues
- Act as an expert resource providing and advising on undergraduate and postgraduate education in the domain of Occupational Therapy Practice in Palliative Care.















#### 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.

#### OCCUPATIONAL THERAPY

#### ALL

#### As an occupational therapist you should:

- Be able to assess the person's current understanding of his/her health, roles & functional status identifying their occupational performance in the context of the person's life-limiting condition
- Be able to communicate current occupational performance status and likely progression in an accurate and compassionate manner, taking account of the patient's needs and wishes
- Understand that the communication of information which fundamentally changes the future of the person living with a life-limiting condition is an on-going collaborative process and not a single event
- Be able to recogniseand contribute to the management of potential conflict in decision-making in the palliative care setting.

#### SOME

As an occupational therapist with increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate an understanding of the multidimensional communication challenges that arise when working with people with life-limiting conditions, responding with sensitivity and compassion to the needs of individuals and carers
- Demonstrate an increased level of confidence in utilising and modifying effective communication strategies to support the changing needs and wishes of individuals with life conditions and their families
- Be able to enlist the skills of the multidisciplinary team or colleagues to enhance and support communication with the person with a life-limiting condition and their family.

#### **FEW**

As an occupational therapist whose core role is the provision of palliative care, you should:

- Demonstrate the ability to use a variety of strategies to engage in highly skilled, compassionate, individualised and timely communication with individuals with life-limiting conditions, their carer's and members of the interdisciplinary team
- Demonstrate expertise as a mediator and advocate for the patient and the family to enable them to access appropriate and timely palliative care intervention and other relevant essential services
- Demonstrate self-awareness of own responses to communication challenges and remain in meaningful contact with individuals and carers even in the most complex, intense and changing circumstances
- Be able to act as an expert that supports and facilitates multidisciplinary teaching of communication skills, as they pertain to occupational therapy practice
- Demonstrate expertise in the assessment of cognitive and functional capacity to enable individuals with life-limiting conditions to communicate their needs and engagement with others through the identification and modification of assistive technology.













#### 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 lifelimiting 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.

#### OCCUPATIONAL THERAPY

#### ALL

#### As an occupational therapist you should:

- Be able to assess a person with a life-limiting condition and manage uncomplicated symptoms whilst recognising the role of palliative care in enhancing that person's care
- Be able to recognise potentially reversible causes of functional deterioration in occupational performance areas of self-care, productivity and leisure employing a palliative rehabilitation approach that is appropriate to promote optimal independence and safety
- Be able to help the person with a life-limiting condition and their family to adapt to a transition from life prolonging treatment to a focus on palliative care, where appropriate.

#### SOME

As an occupational therapist with increased clinical engagement with people with life-limiting conditions you should:

- Be able to recognise a need for change in the focus of care and treatment goals at critical decision points in the course of a life-limiting condition
- In the context of current scope of practice, be able to recognise and take appropriate action to address emergencies that may arise in palliative care (e.g. spinal cord compression)
- Be able to recognise and utilise non-pharmacological interventions for the management of symptoms, including but not limited to fatigue, dyspnoea, anxiety and pain that can impact on functional engagement in occupational performance activities and quality of life



- Provide education, advice and practical strategies for energy conservation, activity analysis, pacing and prioritisation to support the management of fatigue and dyspnoea symptoms
- Provide education, advice and practical strategies for managing anxiety and pain including education in relaxation techniques for symptom reduction
- Demonstrate increased awareness of the impact of multiple losses, including loss
  of occupational performance roles & functional independence, when formulating
  relevant and realistic treatment programmes appropriate to the needs of the
  individual with a life-limiting condition
- Be able to provide appropriate assessment and intervention for the management of cognitive and perceptual disorders associated with primary or secondary brain disease
- Be able to identify adaptive or compensatory strategies and /or environmental modifications that will enhance and support the safety, occupational performance & functional independence of the individual
- Demonstrate knowledge and competence in equipment prescription and provision to enable the functional independence and /or facilitate the care needs of the individual with a life-limiting condition within the hospital and/ or home environment
- Demonstrate an ability to consider the benefits, burdens and risks of occupational therapy interventions and make decisions regarding the appropriateness of these for each person living with a life-limiting condition
- Demonstrate the ability to manage decisions about withdrawing or withholding intervention, while recognising when to re-engage if appropriate
- Be able to assess caregivers' skills and need for skill training and support and as required, effectively and sensitively educate carers in the practical skills required to assist with personal care and transfer methods within the home environment.

#### **FEW**

As an occupational therapist whose core role is the provision of palliative care, you should:

- Apply advanced clinical knowledge and understanding of complex symptoms associated with progressive disease in order to comprehensively identify current and prospective clinical issues in palliative care
- Demonstrate advanced knowledge of patient clinical presentations and disease trajectories in Specialist Palliative Care and respond in a proactive and timely manner to identified needs
- Through advanced clinical reasoning and experiential learning, be able to recognise clinical limitations and professional boundaries and refer to other colleagues appropriately in a timely manner
- Be able to act as an expert resource to other staff on the role of Occupational Therapy and rehabilitation in symptom management and optimising quality of life
- Be able to recognise and value individuals and their roles within the family and community, proactively supporting individuals with life-limiting conditions to adapt to on-going changes in their occupational performance and roles
- Demonstrate expertise in enabling individuals to identify meaningful occupations in which they want to engage and adapting these activities to support continued engagement, and promote quality of life
- Demonstrate expert knowledge of the impact of fatigue, dyspnoea, lymphoedema, anxiety and pain on occupational performance, utilizing non – pharmacological and palliative rehabilitation approaches to alleviate and manage distressing symptoms and promote functional independence
- Be able to assess and prescribe specialised seating for complex palliative care seating and pressure care needs to provide comfort and enable engagement in occupational performance
- Demonstrate expertise in assessing individuals with life-limiting conditions for assistive technology, outlining recommendations for devices/modifications that will promote functional independence, comfort and safety in occupational performance for the individual within their environment.













#### 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.

#### OCCUPATIONAL THERAPY

#### ALL

#### As an occupational therapist you should:

- As a member of the interdisciplinary team be able to participate in key events in patient care, including family meetings
- Demonstrate ability to recognise that the person with a life-limiting condition may lose cognitive and functional capacity to make decisions towards end of life. In such circumstances decisions must be made in the best interest of the person and follow Occupational Therapy professional ethical guidelines in respect to decision making
- Understand the importance of referral to the specialist palliative care team for the management of complex needs.



#### SOME

As an occupational therapist with increased clinical engagement with people with life-limiting conditions you should:

- Be able to work collaboratively and effectively within the inter-professional team and with other stakeholders to manage positive working relationships that will support the wellbeing of the patient and carer and promote patient centred care planning
- Be able to facilitate individuals and their families towards active involvement in decision making and goal setting to support best outcomes and quality of life
- Be able to collaborate with the individual and their family to agree individualised goal based treatment programmes that are realistic, meaningful and responsive to the changing needs of the individual with a life-limiting condition
- Demonstrate flexibility in relation to care planning, acknowledging that a person's priorities can alter with a change in their condition and disease advancement
- Be able to facilitate discharge planning, carrying out in depth functional and risk assessments to facilitate the discharge to preferred place of care whilst recognising the complexities and challenges involved for individuals with lifelimiting conditions and their carers
- Be able to facilitate the individual to make an informed decision regarding place of care whilst identifying potential and actual functional & environmental risks in a supportive manner, and at all times keeping the team informed.

#### FEW

As an occupational therapist whose core role is the provision of palliative care, you should:

- Demonstrate expertise in developing therapeutic relationships with individuals/ families to assist their informed choices for care planning and therapy treatment options.
- Be able to act as an expert clinical resource, as required, to generalist and other specialist providers of palliative care, role modelling advanced clinical skills when assessing and managing individuals with complex life -limiting conditions
- Demonstrate advanced understanding of the roles of the wider multidisciplinary team, show leadership through building partnerships and utilise the strengths of the team to facilitate optimal palliative care therapy outcomes for the individual and their family
- Demonstrate a high level of clinical expertise in supporting the individual in adapting to changing clinical presentation creating a holistic and person centred plan that acknowledges the psychosocial impact of diminishing levels of function and roles in occupational performance, and sets realistic goals that are continually adapted to individual need and expectations
- Be able to critically evaluate outcomes of interventions against established standards and guidelines to further develop own practice and that of professional colleagues in specialist palliative care.
- Demonstrate an advanced level of clinical expertise and sensitivity in facilitating
  a safe, smooth and seamless transition of care for individuals with complex
  discharge planning needs who choose to be cared for at home rather than in
  hospital or hospice.











#### 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
- 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.

#### OCCUPATIONAL THERAPY

#### ALL

#### As an occupational therapist you should:

- Have knowledge of theories of loss and grief and know when to refer to other palliative care professionals for complex case issues.
- Demonstrate greater sensitivity and engagement with the different stages of grief and loss, including loss related to occupational roles, and functional independence in occupational performance (self-care, productivity & leisure activities), utilising this awareness to inform care planning and treatment interventions.

#### SOME

As an occupational therapist with increased clinical engagement with people with life-limiting conditions you should:

 Be able to appreciate the nature of disenfranchised grief in individual, families and carers and appropriate methods of addressing this grief.

#### **FEW**

As an occupational therapist whose core role is the provision of palliative care, you should:

- Demonstrate advanced knowledge of the grieving process and reactions to actively support individuals with life-limiting conditions and their families throughout the disease trajectory.
- Demonstrate the ability to proactively respond to complex grief reactions and processes using own skills and/ or referral to appropriate disciplines or agencies.
- Mentor and educate colleagues to understand the personal impact of loss, grief and bereavement, supporting them to recognise their own loss responses and encouraging engagement in activities to maintain their resilience on an on-going basis.



#### 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.

#### OCCUPATIONAL THERAPY

#### ALL

#### As an occupational therapist you should:

- Be aware and act according to the Code of Ethics and Professional Conduct of the Association of Occupational Therapists of Ireland, and any requirements as stipulated by CORU for the state registration of Occupational Therapists.
- Demonstrate an understanding of the difference between managing a lifelimiting condition and providing end of life care to an individual with a life-limiting condition.

#### **SOME**

As an occupational therapist with increased clinical engagement with people with lifelimiting conditions you should:

- Participate in processes of clinical governance and quality assurance to maintain and improve clinical practice
- Provide and participate in professional supervision and peer review processes to









monitor personal and professional responses to clinical situations.

#### FFW/

As an occupational therapist whose core role is the provision of palliative care, you should:

- Apply an advanced understanding of contemporary legal, ethical and professional standards to the provision of quality palliative care services
- Lead and develop clinical governance and quality assurance programmes that are specific to palliative care
- Design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues
- Actively influence and promote strategic initiatives and policy development for palliative care services at local, regional and national levels
- Act as an expert resource contributing to palliative care service development and delivery across all clinical settings including primary, acute, tertiary and residential care.











## **DISCIPLINE SPECIFIC COMPETENCES**

Physiotherapy



## MEMBERSHIP OF DISCIPLINE SPECIFIC WORK GROUP PHYSIOTHERAPY

#### Deirdre Rowe (Chair)

Occupational Therapist Manager / Deputy Head of Clinical Services, Our Lady's Hospice and Care Services, Harold's Cross

Joint Therapy Lead to the HSE National Clincial Programme for Palliative Care

#### **Shirley Real**

Physiotherapist Manager, Milford Care Centre, Limerick Joint Therapy Lead to the HSE National Clincial Programme for Palliative Care Discipline lead for the Physiotherapy Competency Working Group

#### Jide Afolabi

Senior Physiotherapist, Our Lady's Hospice and Care Services, Harold's Cross

#### Ailish Daly

Clinical Specialist Physiotherapist, Oncology Care, UPMC Beacon Hospital, Dublin

#### Bernadette Doohan

Clinical Specialist Physiotherapist, Meath Palliative Care, Navan, Co. Meath

#### Mary Hickey

Senior Physiotherapist, Kerry Palliative Care

#### Lisa McGirr

Physiotherapist Manager, St. Francis Hospice, Raheny













#### 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 be eavement.

#### **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 lifelimiting 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 onyou.

#### **PHYSIOTHERAPY**

#### ALL

#### As a physiotherapist you should:

- Understand and be able to recognise common trajectories of life-limiting conditions, including common symptoms and problems
- Understand the impact of psychological responses to loss of role and functional independence, social stressors and the spiritual dimensions on the behaviour and decision making of individuals and families and take this into account when planning care
- Understand, recognise and address the management of pathological responses to loss of role and functional independence, which may impact on behaviour and decision making of individuals and families, referring to specialist palliative care where appropriate
- Provide education to individuals with life-limiting conditions, their carers and colleagues in the context of your role and at an appropriate level
- Take cognisance of the potential role of specialist palliative care services in supporting staff in other agencies to provide a palliative care approach to persons with a life-limiting condition.

#### **SOME**

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate in-depth understanding of the full spectrum of trajectories of lifelimiting conditions in the context of your current clinical practice
- Undertake additional study relevant to the needs of individuals with life-limiting conditions to further knowledge and enhance application in practice.
- Be able to identify and engage in research that will lead to effective clinical practice.

#### FEW

#### As a physiotherapist whose core role is the provision of palliative care you should:

- Demonstrate an advanced knowledge and understanding of the full spectrum of trajectories of life-limiting conditions when responding to complex and multidimensional care needs.
- Undertake study and continuously develop a knowledge base at an advanced level to improve the quality and standard of therapy outcomes and service delivery in palliative care.
- Develop, facilitate and provide education, leadership, mentorship and professional support for colleagues and generalist providers of palliative care
- Demonstrate leadership, initiating strategies that will encourage colleagues to foster a caring environment that supports all levels of staff working in challenging situations with people with life-limiting conditions and their families
- Lead, facilitate and engage in further education and research in palliative care
- Design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues
- Be able to act as an expert resource providing and advising on undergraduate and postgraduate education in the domain of Physiotherapy Practice in Palliative Care.













#### 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.

#### **PHYSIOTHERAPY**

#### ALL

#### As a physiotherapist you should:

- Be able to assess the person's current understanding of his/her health, role and functional status in the context of the person's life-limiting condition
- Be able to communicate current functional status and likely progression in an accurate and compassionate manner, taking account of the individual's needs and wishes
- Understand that the communication of information which fundamentally changes the person's understanding of their situation and/or influences their decisionmaking or planning is an on-going collaborative process and not a single event
- Be able to recogniseand contribute to the management of potential conflict in decision-making in the palliative care setting.



#### **SOME**

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate an understanding of the multidimensional communication challenges that arise when working with people with life-limiting conditions, responding with sensitivity and compassion to the needs of individuals and carers
- Demonstrate an increased level of confidence in utilising and modifying effective communication strategies to support the changing needs and wishes of individuals with life-limiting conditions and their families
- Be able to enlist the skills of the multidisciplinary team or colleagues to enhance and support communication with the person with a life-limiting condition and their family.

#### FEW

#### As a physiotherapist whose core role is the provision of palliative care you should:

- Demonstrate the ability to use a variety of strategies to engage in highly skilled, compassionate, individualised and timely communication with individuals with life-limiting conditions, their carer's and members of the multidisciplinary team
- Demonstrate expertise as a mediator and advocate for the individual and the family to enable them to access appropriate and timely palliative care intervention and other relevant essential services
- Demonstrate self-awareness of own responses and remain in meaningful contact with individuals and carers even in the most complex, intense and changing circumstances
- Be able to act as an expert that supports and facilitates multidisciplinary teaching of communication skills as these pertain to physiotherapy practice.













#### 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 lifelimiting 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.

#### **PHYSIOTHERAPY**

#### ALL

#### As a physiotherapist you should:

- Be able to assess a person with a life-limiting condition and manage uncomplicated symptoms whilst recognising the role of palliative care in enhancing that person's care
- Recognise potentially reversible causes of physical deterioration and employ a palliative rehabilitation approach that is appropriate to promote optimal independence
- Be able to help the person with a life-limiting condition and their family to adapt to a transition from life prolonging treatment to a focus on palliative care, where appropriate.

#### SOME

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

- Recognise a need for change in the focus of care and treatment goals at critical decision points in the course of a life-limiting condition.
- In the context of current scope of practice, be able to recognise and take appropriate action to address emergencies that may arise in palliative care (e.g. spinal cord compression)
- Recognise and utilise non-pharmacological symptom management to promote comfort and quality of life
- Demonstrate an ability to consider the benefits, burdens and risks of physiotherapy interventions and make decisions regarding the appropriateness of these for each person living with a life-limiting condition
- Demonstrate the ability to manage decisions about withdrawing or withholding interventions, whilst recognising when to reengage if appropriate.

#### **FEW**

#### As a physiotherapist whose core role is the provision of palliative care you should:

- Be able to apply advanced clinical knowledge and understanding of complex symptoms associated with progressive disease in order to comprehensively identify current and prospective clinical issues in palliative care
- Demonstrate advanced knowledge of individual clinical presentations and disease trajectories in Specialist Palliative Care and respond in a proactive and timely manner to identified needs
- Through advanced clinical reasoning and experiential learning, be able to recognise clinical limitations and professional boundaries and refer to other colleagues appropriately in a timely manner
- Be able to act as an expert resource to other staff on the role of physiotherapy and rehabilitation in symptom management and optimising quality of life
- Demonstrate knowledge to alleviate and manage distressing symptoms whilst attempting to maximise the individual's ability to function, to promote their independence and to adapt to changes that occur due to their life-limiting condition
- Ensure that the emphasis of treatment is on physical performance and symptom management: expertise and advanced knowledge is required to identify the complex interplay of factors that impact on physical function
- Have expert and advanced knowledge in the management of symptoms, functional changes and interventions which include but are not limited to: function, exercise tolerance, respiratory care, fatigue, lymphoedema, neurological, orthopaedic, palliative rehabilitation and pain.













# 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.

# **PHYSIOTHERAPY**

# ALL

# As a physiotherapist you should:

- As a member of the multidisciplinary team be able to participate in key events in individual care, including family meetings
- Demonstrate ability to recognise that the person with a life-limiting condition may lose capacity to make decisions towards end of life. In such circumstances decisions must be made in the best interest of the person and follow Physiotherapy professional ethical guidelines in respect of decision making
- Understand the importance of referral to palliative care teams for the management of the person with palliative care needs.

# SOME

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

Be able to work collaboratively and effectively within the inter-professional team

- and with other stakeholders to manage positive working relationships that will support the wellbeing of the individual and carer and promote individual centred care planning
- Be able to facilitate individuals and their families towards active involvement in decision making and goal setting to support best outcomes and quality of life
- Demonstrate flexibility in relation to care planning, acknowledging that a individual's priorities can alter with a change in their condition and disease advancement
- Be able to facilitate discharge planning, carrying out in depth functional and risk assessments to facilitate the discharge to preferred place of care whilst recognising the complexities and challenges involved for individuals with life-limiting conditions and their carers
- Be able to facilitate the individual to make an informed decision regarding place of care whilst identifying potential and actual risks in a supportive manner, and at all times keeping the team informed.

## FEW

## As a physiotherapist whose core role is the provision of palliative care you should:

- Demonstrate expertise in developing therapeutic relationships with individuals/ families to assist their informed choices for care planning and therapy treatment options.
- Be able to act as an expert clinical resource, as required, to generalist and other specialist providers of palliative care, role modelling advanced clinical skills when assessing and managing individuals with complex life -limiting conditions
- Demonstrate advanced understanding of the roles of the wider multidisciplinary team (MDT), show leadership through building partnerships and utilise the strengths of the team to facilitate optimal palliative care therapy outcomes for the individual and their family
- Demonstrate a high level of clinical expertise in supporting the individual in adapting to changing clinical presentation and functional levels
- Be able to critically evaluate outcomes of interventions against established standards and guidelines to further develop own practice and that of professional colleagues in specialist palliative care
- Demonstrate an advanced level of clinical expertise and sensitivity in facilitating a safe, smooth and seamless transition of care for individuals with complex discharge planning needs who choose to be cared for at home rather than in hospital or hospice
- Create a holistic and person centred plan that acknowledges the psychosocial impact of diminishing function and sets realistic goals that have to be continually adapted to individual need.















# 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
- 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.

## **PHYSIOTHERAPY**

# ALL

# As a physiotherapist you should:

- Have knowledge of theories of loss and grief and know when to refer to other palliative care professionals for complex case issues
- Demonstrate greater sensitivity and engagement with the different stages of grief and loss, including loss of functional independence utilising this awareness to inform care planning and treatment interventions.

#### **SOME**

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

• Appreciate the nature of disenfranchised grief in individual, families and carers and appropriate methods of addressing this grief.

#### **FEW**

As a physiotherapist whose core role is the provision of palliative care you should:

- Demonstrate advanced knowledge of the grieving process and reactions to actively support individuals and their families throughout the disease trajectory
- Demonstrate the ability to proactively respond to complex grief reactions and processes using own skills and/ or referral to appropriate disciplines or agencies
- Mentor and educate colleagues to understand the personal impact of loss, grief and bereavement, supporting them to recognise their own loss responses and encouraging engagement in activities to maintain their resilience on an on-going basis.

# 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.

# **PHYSIOTHERAPY**

# ALL

# As a physiotherapist you should:

- Be aware and act according to the code of professional conduct of the Irish Society of Chartered Physiotherapists, and any requirements stipulated by CORU for the state registration of Physiotherapists
- Demonstrate an understanding of the difference between managing a lifelimiting condition and providing end of life care to an individual with a life-limiting condition.

# **SOME**

As a physiotherapist with increased clinical engagement with people with life-limiting conditions you should:

- Participate in processes of clinical governance and quality assurance to maintain and improve clinical practice
- Provide and participate in professional supervision and peer review processes to monitor personal and professional responses to clinical situations.













# FEW

# As a physiotherapist whose core role is the provision of palliative care you should:

- Apply an advanced understanding of contemporary legal, ethical and professional standards to the provision of quality palliative care therapy services
- Lead and develop clinical governance and quality assurance programmes that are specific to palliative care
- Actively influence and promote strategic initiatives and policy development for palliative care services at local, regional and national levels
- Act as an expert resource contributing to palliative care service development and delivery across all clinical settings including primary, acute, tertiary and residential care
- Design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues.







# **DISCIPLINE SPECIFIC COMPETENCES**

Speech and Language Therapy



# MEMBERSHIP OF DISCIPLINE SPECIFIC WORK GROUP SPEECH AND LANGUAGE THERAPY



Occupational Therapist Manager / Deputy Head of Clinical Services, Our Lady's Hospice and Care Services, Harold's Cross

Joint Therapy Lead to the HSE National Clincial Programme for Palliative Care

#### Claire Parkes

Clinical Specialist Speech and Language Therapist in Radiation Oncology, St. James's Hospital Discipline lead for the Speech & Language Therapy Competency Working Group

## Suzanna Dooley

Senior Speech and Language Therapist, Outreach Service, St. Columcille's Hospital, Loughlinstown Co. Dublin

#### Deirdre Kidnev

Senior Speech and Language Therapist, Neurology Service, St. Vincent's University Hospital, Dublin

#### Aideen Lawlor

Chairperson of Speech and Language Therapy Manager's Group Speech and Language Therapy Manager, St. Mary's Hospital, Dublin

# Maeve Murphy

Speech and Language Therapy Managers Advisory Group Speech and Language Therapy Manager, AMNCH, Tallaght

## Noreen O'Regan

Senior Speech and Language Therapist in Head and Neck Surgery, St. James's Hospital

# **Frances Shinkins**

Senior Speech and Language Therapist, Mid-Western Regional Hospital, Limerick

# **Dr Martine Smith**

Head of Discipline, Clinical Speech and Language Studies, Associate Professor in Speech and Language Pathology, Trinity College Dublin











# 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 be eavement.

#### **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 lifelimiting 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 onyou.

# SPEECH AND LANGUAGE THERAPY

#### **ALL**

As a speech and language therapist you should:

- Understand and be able to recognise common trajectories of life-limiting conditions, including common symptoms and problems
- Understand the impact of psychological responses to multiple loss including loss of social participation, social stressors and the spiritual dimensions on the behaviour and decision making of individuals with life-limiting conditions and families and take this into account when planning care
- Understand, recognise and address the management of pathological responses to
  multiple loss, social participation and functional communication which may impact
  on behaviour and decision-making of individuals with life-limiting conditions and
  families, and refer individuals and/or their families to specialist palliative care
  where appropriate
- Provide education to individuals with life-limiting conditions, their carers and colleagues in the context of your role and at an appropriate level
- Take cognisance of the role of specialist palliative care services in supporting staff when providing a palliative care approach to the person with a life-limiting condition.

#### SOME

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

Demonstrate in-depth understanding of the full spectrum of trajectories of lifelimiting conditions in the context of your current clinical practice





- Undertake additional study relevant to the needs of individuals with life-limiting conditions to enhance application in practice
- Be able to identify and engage in research that will lead to effective clinical practice.

#### **FEW**

As a speech and language therapist whose core role is the provision of palliative care, you should:

- Demonstrate an advanced knowledge, and understanding of the full spectrum of trajectories of life-limiting conditions when responding to complex and multidimensional care needs
- Undertake study and continuously develop a knowledge base at an advanced level to improve the quality and standard of therapy outcomes and service delivery in palliative care
- Develop, facilitate and provide education, leadership, mentorship and professional support for colleagues and generalist providers of palliative care
- Demonstrate leadership that encourages colleagues to foster a caring environment that supports all staff working in sensitive situations with people with life-limiting conditions and their families
- Lead, facilitate and engage in further education and research in palliative care
- Design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues
- Act as an expert resource providing and advising on undergraduate and postgraduate education in the domain of Speech and Language Therapy Practice in Palliative Care.









# 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

# SPEECH AND LANGUAGE THERAPY

#### ALI

#### As a speech and language therapist you should:

- Be able to assess the person's current understanding of his/her health, role and functional FEDS (feeding, eating, drinking and swallowing) and communication status in the context of the person's life-limiting condition
- Be able to optimise effective communication for the person with a life-limiting condition who presents with receptive and/or expressive speech and language impairment, cognitive-communication difficulties, and/or alaryngeal communication, accessing expertise in assistive communication when appropriate
- Be able to educate and facilitate members of the multidisciplinary team in optimising
  effective communication with the person with a life-limiting condition who presents
  with receptive and/or expressive speech and language impairment, cognitivecommunication difficulties, and/or alaryngeal communication





- Be able to communicate current functional status in relation to communication and disorders of FEDS and likely progression in an accurate and compassionate manner, taking account of the patient's needs, wishes and possible changes in communicative function
- Understand that the communication of information which fundamentally changes the future of the person living with a life-limiting condition is an on-going collaborative process and not a single event
- Recogniseand contribute to the management of potential conflict in decisionmaking in the palliative care setting.

## **SOME**

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate an understanding of the multidimensional communication challenges that arise when working with people with life-limiting conditions, responding with sensitivity and compassion to the needs of individuals and carers
- Demonstrate an increased level of confidence in demonstrating, utilising and modifying effective communication strategies including the use of assistive communication, to support the changing needs and wishes of individuals with life-limiting conditions and their families
- Be able to facilitate assessment of decision making capacity in individuals with communication or cognitive-communication impairment
- Be able to enlist the skills of the multidisciplinary team or colleagues to enhance and support communication with the person with a life-limiting condition and their family.

#### **FEW**

As a speech and language therapist whose core role is the provision of palliative care you should:

- Demonstrate the ability to use a variety of strategies to engage in highly skilled, compassionate, individualised and timely communication with individuals with life-limiting conditions, their carers and members of the interdisciplinary team
- Demonstrate expertise as a mediator and advocate for the patient and the family to enable them to access appropriate and timely palliative care intervention and other relevant essential services
- Demonstrate expertise as a mediator and advocate for the patient and family with regard to decision making related to initiating, withdrawing or withholding artificial hydration and nutrition as a consequence of advanced oropharyngeal dysphagia
- Demonstrate self-awareness of own responses to communication challenges and remain in meaningful contact with individuals and carers even in the most complex, intense and changing circumstances
- Be able to act as an expert that supports and facilitates multidisciplinary teaching
  of communication skills, as they pertain to speech and language therapy practice
  including but not limited to the management of individuals with receptive and
  and/or expressive language impairment, cognitive-communication difficulties
  and/or alaryngeal communication.











# 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 lifelimiting 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.

# SPEECH AND LANGUAGETHERAPY

#### ALL

#### As a speech and language therapist you should:

- Be able to assess a person with a life-limiting condition and manage uncomplicated symptoms whilst recognising the role of palliative care in enhancing that person's care
- Be able to recognise potentially reversible causes of functional deterioration in the
  patient's FEDS and communication abilities, identifying adaptive or compensatory
  strategies and /or employing a palliative rehabilitation approach that is appropriate
  to promote optimal independence and safety in these areas
- Be able to assess caregivers' skills and need for skill training and support, to assist with safe swallow techniques within the context of life-limiting condition.
- Promote and educate carers on optimising effective communication with the individual who presents with communication or cognitive-communication impairment
- Be able to help the person with a life-limiting condition and their family to adapt to a transition from life prolonging treatment to a focus on palliative care, where appropriate.

#### SOME

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

Be able to recognise critical junctures in care and thereby identify a need for change in the focus of care and treatment goals in the course of a life-limiting condition





- Be able to recognise and access multidisciplinary expertise and non –
  pharmacological interventions to support the management of symptoms including
  fatigue, dyspnoea, secretion management and anxiety that can impact on safe
  and/ or pleasurable engagement in FEDS, communication activities and quality of
  life
- Demonstrate increased awareness of the impact of multiple loss (e.g. communicative autonomy, ability to eat/drink), when formulating relevant and realistic treatment programmes appropriate to the needs of the individual with a life-limiting condition
- Be able to recognise the need to seek expertise in seating and other equipment
  which may promote autonomy in communication and enhance safety and
  independence in eating, drinking and swallowing in the individual with a lifelimiting condition within the hospital and/ or home environment.
- Demonstrate an advanced ability to consider the benefits, burdens and risks of speech and language therapy interventions (including instrumental assessment) in individualising management for each person living with a life-limiting condition
- Demonstrate the ability to manage decisions about withdrawing or postponing speech and language therapy intervention, while recognising when to reengage if appropriate.

#### **FFW**

As a speech and language therapist whose core role is the provision of palliative care, you should:

- Be able to apply advanced clinical knowledge and understanding of complex symptoms associated with progressive disease in order to comprehensively identify current and prospective clinical issues in palliative care
- Demonstrate advanced knowledge of patient clinical presentations and disease trajectories in Specialist Palliative Care and respond in a proactive and timely manner to identified needs
- Through advanced clinical reasoning and experiential learning, be able to recognise clinical limitations and professional boundaries and refer to other colleagues appropriately in a timely manner
- Be able to act as an expert resource to other staff on the role of speech and language therapy and rehabilitation, in symptom management and optimising quality of life
- Be able to identify the psychosocial impact of diminishing communication and/ or swallow function as a consequence of life-limiting condition providing timely person centred modifications to facilitate continued social participation
- Demonstrate expertise in facilitating individuals and their families to identify personally significant functional communication activities and empowering continued participation through supported conversation and total communication approaches
- Demonstrate expert knowledge of the impact of pain, dyspnoea and other symptoms on swallow function and/or communication performance, utilizing compensatory and palliative rehabilitation approaches to alleviate symptoms, and optimise effective, pleasurable and safe participation in these activities
- Be able to access MDT expertise in the pharmacological management of secretions, dyspnoea and anxiety which may impact upon safe and/or pleasurable engagement in eating drinking, swallowing and/or communication
- Demonstrate expertise in assessing individuals with life-limiting conditions for assistive communication technology, outlining recommendations for devices/ modifications that will promote communicative autonomy for the individual within their environment.









# 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 caresettings
- 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.

# SPEECH AND LANGUAGETHERAPY

#### ALL

# As a speech and language therapist you should:

- As a member of the interdisciplinary team be able to participate in key events in patient care, including family meetings
- Demonstrate the ability to recognise and promote the importance of communication, supporting the individual's ability to make and communicate decisions in all ways possible
- Demonstrate ability to recognise that the person with a life-limiting condition may lose communicative competency to make decisions towards end of life. In such circumstances decisions must be made in the best interest of the person and must adhere to speech and language therapy professional ethical guidelines in respect to decision making
- Understand the importance of referral to the specialist palliative care team for the management of complex needs.





## **SOME**

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

- Be able to work collaboratively and effectively within the inter-professional team and with other stakeholders to manage positive working relationships that will support the wellbeing of the patient and carer and promote patient centred care planning
- Be able to facilitate individuals and their families towards active involvement in decision making and goal setting to support best outcomes and quality of life
- Be able to collaborate with the multidisciplinary team to ensure that information regarding care decisions and consent is accessible to the individual's level of cognitive –communication capacity
- Be able to optimise the ability of individuals with communication or cognitivecommunication difficulties to be involved in decisions and consent processes regarding their care, including enabling the individual to understand the information provided, to identify the consequences of making a care decision and to communicate his/her decision
- Be able to collaborate with the individual and their family to agree individualised goal based treatment programmes that are person centred and responsive to the changing needs of the individual with a life-limiting condition
- Demonstrate flexibility in relation to care planning, acknowledging that a person's priorities can alter with a change in their condition and disease advancement
- Be able to facilitate discharge planning, carrying out in depth swallowing and communication assessments and risk assessments to facilitate the discharge to preferred place of care whilst recognising the complexities and challenges involved for individuals with life-limiting conditions and their carers.

#### **FEW**

As a speech and language therapist whose core role is the provision of palliative care, you should:

- Demonstrate expertise in developing therapeutic relationships with individuals/ families to assist their informed choices for care planning and therapy treatment options
- Be able to act as an expert clinical resource, as required, to generalist and other specialist providers of palliative care, role modelling advanced clinical skills when assessing and managing individuals with complex life -limiting conditions
- Demonstrate advanced understanding of the roles of the wider multidisciplinary team, show leadership through building partnerships and utilise the strengths of the team to facilitate optimal palliative care therapy outcomes for the individual and their family
- Demonstrate a high level of clinical expertise in supporting the individual in adapting to changing clinical presentation and functional communication ability
- Be able to critically evaluate outcomes of interventions against established standards and guidelines to further develop own practice and that of professional colleagues in specialist palliative care
- Demonstrate an advanced level of clinical expertise and sensitivity in facilitating
  a safe, smooth and seamless transition of care for individuals with complex
  communication, cognitive-communication and FEDS needs who choose to be
  cared for at home rather than in hospital or hospice.









# 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
- 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.

# SPEECH AND LANGUAGE THERAPY

#### ALL

## As a speech and language therapist you should:

- Have knowledge of theories of loss and grief and know when to refer to other palliative care professionals for complex case issues
- Demonstrate sensitivity and engagement with the different stages of grief and loss, including multiple loss related to role and functional independence in communication and swallowing, utilising this awareness to inform care planning and treatment intervention.

#### SOME

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

• Be able to appreciate the nature of disenfranchised grief in individuals, families and carers and appropriate methods of addressing this grief.

#### FFW

As a speech and language therapist whose core role is the provision of palliative care, you should:

- Demonstrate advanced knowledge of the grieving process and reactions to actively support individuals with life-limiting conditions and their families throughout the disease trajectory
- Demonstrate the ability to proactively respond to complex grief reactions and processes using own skills and/ or referral to appropriate disciplines or agencies.
- Mentor and educate colleagues to understand the personal impact of loss, grief and bereavement, supporting them to recognise their own loss responses and encouraging engagement in activities to maintain their resilience on an on-going basis





# 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:
  - Recognising 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

# SPEECH AND LANGUAGE THERAPY

#### ALL

#### As a speech and language therapist you should:

- Be aware of and act according to the Code of Professional Conduct of the Irish Association of Speech and Language Therapists and any requirements stipulated by CORU for the state registration of Speech and Language Therapists
- Demonstrate an understanding of the difference between managing a lifelimiting condition and providing end of life care to an individual with a life-limiting condition
- Be aware of the limitations of role, practice and expertise in end of life decision making related to artificial hydration and/or nutrition as a consequence of severe oropharyngeal dysphagia in advanced life-limiting condition, referring to relevant specialist palliative care expertise as appropriate.









# **SOME**

As a speech and language therapist with increased clinical engagement with people with life-limiting conditions you should:

- Participate in processes of clinical governance and quality assurance to maintain and improve clinical practice
- Provide and participate in professional supervision and peer review processes to monitor personal and professional responses to clinical situations.
- Use recognised ethical, legal and professional frameworks to guide speech and language therapy intervention in end of life decision making related to initiating/ withdrawing/withholding artificial hydration and/or nutrition as a consequence of severe oropharyngeal dysphagia in advanced life-limiting condition.

#### FF\//

As a speech and language therapist whose core role is the provision of palliative care you should:

- Apply an advanced understanding of contemporary legal, ethical and professional standards to the provision of quality palliative care services
- Lead and develop clinical governance and quality assurance programmes that are specific to palliative care
- Actively engage in building the evidence base to support interventions with persons with a life-limiting condition, in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues
- Actively influence and promote strategic initiatives and policy development for palliative care services at local, regional and national levels
- Act as an expert resource contributing to palliative care service development and delivery across all clinical settings including primary, acute, tertiary and residential care.











# **DISCIPLINE SPECIFIC COMPETENCES**

**Dietetics/Clinical Nutrition** 



# MEMBERSHIP OF DISCIPLINE SPECIFIC WORK GROUP DIETETICS / CLINICAL NUTRITION



## Deirdre Rowe (Chair)

Occupational Therapist Manager / Deputy Head of Clinical Services, Our Lady's Hospice and Care Services, Harold's Cross

Joint Therapy Lead to the HSE National Clincial Programme for Palliative Care

# Claire Molloy

Senior Dietitian working in Specialist Palliative Care, Milford Care Centre, Limerick Joint Discipline lead for the Dietetics/ Clinical Nutrition Competency Working Goup

# Helena McCloskey

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Joint Discipline lead for the Dietetics/ Clinical Nutrition Competency Working Goup

## Sandra Brady

Clinical Nutrition Manager, St. James's Hospital Dublin

#### Liz Barnes

Dietitian Manager, St. Vincent's University Hospital, Dublin

## Diarmuid Duggan

Senior Dietitian, Bon Secours Hospital Cork

## Sinead Glover

Senior Community Dietitian, Limerick Health Promotion, Limerick

## Sinead Knox

Senior Oncology Dietitian, St. Vincent's Private Hospital Dublin

#### Paula O'Connor

Dietitian Manager / Senior Oncology Dietitian, Beaumont Hospital Dublin











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 be eavement.

# **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.



#### ALL

# As a dietitian/clinical nutritionist you should:

- Understand and be able to recognise common trajectories of life-limiting conditions, including common symptoms and problems
- Understand and be able to recognise the physical, psychological, social and spiritual issues that may precipitate dietary concerns for people with life-limiting conditions and their families throughout the continuum of care
- Understand, recognise and address the management of pathological responses to loss which may impact on behaviour and decision-making of individuals with life-limiting conditions and families, referring to specialist palliative care where appropriate
- Provide education to individuals with life-limiting conditions, their carers and colleagues in the context of your role as a Dietitian / Clinical Nutritionist and at an appropriate level
- Take cognisance of the role of specialist palliative care services in supporting self and staff when providing a palliative care approach to the person with a life-limiting condition.

#### SOME

As a dietitian/clinical nutritionist with increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate in-depth understanding of the full spectrum of trajectories of lifelimiting conditions in the context of your current clinical practice
- Undertake additional study relevant to the needs of individuals with life-limiting conditions to further knowledge and enhance application in practice
- Be able to identify and engage in research that will lead to effective clinical practice.





#### **FEW**

As a dietitian/clinical nutritionist whose core role is the provision of palliative care, you should:

- Demonstrate an advanced knowledge, and understanding of the full spectrum of trajectories of life-limiting conditions and their impact on nutritional management when responding to complex and multidimensional care needs
- Be able to provide empathetic patient centred care that recognises a person's individuality of concerns, goals, beliefs and culture
- Develop, facilitate and provide education, leadership, mentorship and professional support for colleagues and generalist providers of palliative care
- Demonstrate leadership that encourages colleagues to foster a caring environment that supports all staff working in sensitive situations with people with life-limiting conditions and their families
- Undertake study and continuously develop a knowledge base at an advanced level to improve the quality and standard of nutrition and dietary intervention and outcomes and service delivery in palliative care
- Lead, facilitate and engage in further education, research and audit in palliative care
- Design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues
- Act as an expert resource providing and advising on undergraduate and postgraduate education in the domain of Dietetics/ Clinical Nutrition in Palliative Care.











# 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.

# **DIETITIAN / CLINICAL NUTRITIONIST**

#### ALL

# As a dietitian/clinical nutritionist you should:

- Be able to assess the person's current understanding of his/her health, in the context of the person's life-limiting condition
- Understand that the communication of information which fundamentally changes the future of the person living with a life-limiting condition is an on-going collaborative process and not a single event
- Effectively communicate with individuals with life-limiting conditions, their families and carers to devise appropriate nutrition care plans for the patient's needs and communicate these to the multidisciplinary team
- Recogniseand contribute to the management of potential conflict in decisionmaking in the palliative care setting.





#### **SOME**

As a dietitian/clinical nutritionist with increased clinical engagement with people with life-limiting conditions you should:

- Demonstrate an understanding of the multidimensional communication challenges that arise when working with people with life-limiting conditions, responding with sensitivity and compassion to the needs of individuals and carers
- Demonstrate an increased level of confidence in utilising and modifying effective communication strategies to support the changing needs and wishes of individuals with life-limiting conditions and their families
- Be able to enlist the skills of the multidisciplinary team or colleagues to enhance and support communication with the person with a life-limiting condition and their family.

#### **FEW**

As a dietitian/clinical nutritionist whose core role is the provision of palliative care you should:

- Demonstrate the ability to use a variety of strategies to engage in highly skilled, compassionate, individualised and timely communication with individuals with life-limiting conditions, their carer's and members of the multidisciplinary team
- Demonstrate expertise as a mediator and advocate for the patient and the family to enable them to access appropriate and timely palliative care intervention and other relevant essential services
- Demonstrate self-awareness of own responses and remain in meaningful contact with individuals with life-limiting conditions and carers even in the most complex, intense and changing circumstances
- Be able to act as an expert that supports and facilitates multidisciplinary teaching of communication skills as these pertain to Dietetic/ Clinical Nutrition practice.











# 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 lifelimiting 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.

# **DIETITIAN / CLINICAL NUTRITIONIST**

#### ALL:

#### As a dietitian/clinical nutritionist you should:

- Be able to assess a person with a life-limiting condition and manage uncomplicated symptoms whilst recognising the role of palliative care in enhancing that person's care
- Be able to help the person with a life-limiting condition and their family to adapt to a transition from life prolonging treatment to a focus on palliative care, where appropriate
- Be able to recognise potentially reversible causes of dietary issues and employ appropriate dietary and nutrition support strategies
- Be able to recognise a need for change in the focus of care and treatment goals at critical decision points in the course of a life-limiting condition
- Be able to provide individualised Dietetic counselling to individuals with palliative care needs.

## SOME:

As a dietitian/clinical nutritionist with increased clinical engagement with people with life-limiting conditions you should:

- Be able to recognise and utilise non-pharmacological symptom management to promote comfort and quality of life
- Be able to assess the individual, their family and carers' skills and need for dietary education and support
- Demonstrate an ability to consider the benefits, burdens and risks of Dietetic/
   Clinical nutrition interventions and make decisions regarding the appropriateness





- of these for each person living with a life-limiting condition as part of the MDT
- Provide education, advice and practical strategies to the individual, their family and carers for the dietary management of symptoms which include but are not limited to: poor appetite, nausea, vomiting, constipation, diarrhoea and taste changes
- Provide education, advice and practical strategies for the management of individual, family and carer concerns relating to diet and nutrition
- Provide education, advice and practical strategies to the individual, their family and carers in relation to aspects and management of artificial nutrition support
- Demonstrate increased awareness of the impact of role change when formulating relevant and realistic nutrition care plans for the individual with a life-limiting condition
- Be able to contribute in decision making about withdrawing or withholding interventions as part of the multidisciplinary team with the patient and family, whilst recognising when to reengage if appropriate.

#### FEW:

As a dietitian/clinical nutritionist whose core role is the provision of palliative care you should:

- Be able to apply advanced clinical knowledge and understanding of complex symptoms associated with progressive disease in order to comprehensively identify current and prospective clinical issues in palliative care
- Demonstrate advanced knowledge of patient clinical presentations and disease trajectories in Specialist Palliative Care and respond in a proactive and timely manner to identified needs
- Through advanced clinical reasoning and experiential learning, be able to recognise clinical limitations and professional boundaries and refer to other colleagues appropriately in a timely manner
- In the context of current scope of practice, be able to recognise emergencies that may arise in palliative care (e.g. spinal cord compression, superior vena cava obstruction) and refer for appropriate intervention
- Act as an expert resource to other staff on the role of dietary / nutritional interventions in symptom management and optimising quality of life
- Have expert and advanced knowledge in the management of symptoms and interventions which include but are not limited to poor appetite, nausea, vomiting, constipation, diarrhoea, taste changes and artificial nutrition support
- Provide support and counselling to the individual, their family and carers regarding irreversible weight loss and anorexia that may occur as end of life approaches.











# 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 caresettings
- 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.

# DIETITIAN / CLINICAL NUTRITIONIST

#### ALL

## As a dietitian/clinical nutritionist you should:

- As a member of the interdisciplinary team be able to participate in key events in patient care, including family meetings
- Demonstrate ability to recognise that the person with a life-limiting condition may lose capacity to make decisions towards end of life and that in these situations decisions must be made in the best interests of the person and should follow professional ethical guidelines in respect of decision making
- Understand the importance of referral to palliative care teams for the management of the person with palliative care needs.

# SOME

As a dietitian/clinical nutritionist with increased clinical engagement with people with life-limiting conditions you should:

Be able to work collaboratively and effectively within the inter-professional team





- and with other stakeholders to manage positive working relationships that will support the wellbeing of the patient and carer and promote patient centred care planning
- Be able to facilitate individuals and their families towards active involvement in decision making and goal setting to support best outcomes and quality of life
- Demonstrate flexibility in relation to care planning, acknowledging that a patient's priorities can alter with a change in their condition and disease advancement
- Be able to facilitate discharge to preferred place of care whilst recognising the complexities and challenges involved for individuals with life-limiting conditions and their carers
- Be able to facilitate the individual to make an informed decision regarding place of care whilst identifying potential and actual risks in a supportive manner, and at all times keeping the team informed
- Be able to actively participate in advance care planning regarding nutrition support.

## FEW

As a dietitian/clinical nutritionist whose core role is the provision of palliative care you should:

- Demonstrate expertise in developing therapeutic relationships with individuals with life-limiting conditions and their families to assist their informed choices for nutrition care planning
- Be able to act as an expert clinical nutrition resource, as required, to generalist and other specialist providers of palliative care
- Demonstrate advanced understanding of the roles of the wider multidisciplinary team, show leadership through building partnerships and utilise the strengths of the team to facilitate optimal palliative care therapy outcomes for the individual and their family
- Demonstrate a high level of clinical expertise in supporting the individual in adapting to changing clinical presentation
- Be able to critically evaluate outcomes of interventions against established standards and guidelines to further develop own practice and that of professional colleagues in specialist palliative care
- Create a holistic and person centred plan that acknowledges the psychosocial impact of changing nutritional requirements and/or dietary intake and sets realistic goals that have to be continually adapted to individual need and expectations.











# 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
- 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.

# DIETITIAN / CLINICAL NUTRITIONIST

# As a dietitian/clinical nutritionist you should:

- Have knowledge of theories of loss and grief and know when to refer to other palliative care professionals for complex case issues
- Demonstrate greater sensitivity and engagement with the different stages of grief and loss, utilising this awareness to inform care planning and treatment interventions.

#### **SOME**

As a dietitian/clinical nutritionist with increased clinical engagement with people with life-limiting conditions you should:

Appreciate the nature of disenfranchised grief in individual, families and carers and appropriate methods of addressing this grief.

As a dietitian/clinical nutritionist whose core role is the provision of palliative care you

- Demonstrate advanced knowledge of the grieving process and reactions to actively support individuals with life-limiting conditions and their families throughout the disease trajectory
- Demonstrate the ability to proactively respond to complex grief reactions and processes using own skills and/or referral to appropriate disciplines oragencies
- Mentor and educate colleagues to understand the personal impact of loss, grief and bereavement, supporting them to recognise their own loss responses and encouraging engagement in activities to maintain their resilience on an on-going basis.





# 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:
  - Recognising 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.

# DIETITIAN / CLINICAL NUTRITIONIST

#### ALL

## As a dietitian/clinical nutritionist you should:

- Be aware and act according to the Irish Nutrition & Dietetic Institute Code of Professional Practice and the Irish Nutrition & Dietetic Institute Professional Competencies, and any requirements stipulated by CORU for the state registration of Dietitians/Clinical Nutritionist
- Be aware of ethical and legal issues that may arise regarding artificial nutrition support in the palliative population
- Demonstrate an understanding of the difference between managing a lifelimiting condition and providing end of life care to an individual with a life-limiting condition.











As a dietitian/clinical nutritionist with increased clinical engagement with people with life-limiting conditions you should:

- Be able to actively participate in the discussion and resolution of ethical and legal issues in conjunction with the multidisciplinary team, individuals with life-limiting conditions and families that may arise in relation to artificial nutrition support in the palliative population
- Participate in processes of clinical governance and quality assurance to maintain and improve clinical practice.

#### **FEW**

As a dietitian/clinical nutritionist whose core role is the provision of palliative care you should:

- Apply an advanced understanding of contemporary legal, ethical and professional standards to the provision of quality palliative care therapy services
- Be able to facilitate discussion and resolution of ethical and legal issues in conjunction with the multidisciplinary team, individuals with life-limiting conditions and families that may arise in relation to artificial nutrition support in the palliative population
- Lead and develop clinical governance and quality assurance programmes that are specific to palliative care
- Actively influence and promote strategic initiatives and policy development for palliative care services at local, regional and national levels
- Act as an expert resource contributing to palliative care service development and delivery across all clinical settings including primary, acute, tertiary and residential care
- Design research projects in line with palliative care service needs, collaborating with all relevant stakeholders in respect of research issues.













# MEMBERSHIP OF DISCIPLINE SPECIFIC WORK GROUP PHARMACY

# Cliona Hayden (Chair)

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# Aisleen Haughey

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# Karen Hodgson

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#### Fiona McGrehan

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# Marie Wright

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#### 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 be eavement.

#### 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 onyou.

#### **PHARMACY**

#### ALL

#### As a pharmacist you should:

- Integrate the principles of palliative care into pharmacy practice
- Demonstrate knowledge and understanding of the trajectories of common lifelimiting conditions
- Demonstrate knowledge of symptoms commonly experienced by people with lifelimiting conditions and their treatments
- Demonstrate an ability to locate, assess and interpret information about medicines used in palliative care
- Demonstrate an awareness of physical, psychological, social and spiritual needs of people with life-limiting conditions and understand how these may impact on their pharmaceutical care needs
- Be able to provide individualised pharmaceutical care and support for people with life-limiting conditions and their families
- Recognise and understand the changing pharmacological and pharmaceutical care needs of people with life-limiting conditions throughout the disease trajectory
- Be able to identify and actively respond to the medicines information needs of people living with life-limiting conditions and their families
- Be able to identify and actively respond to the medicines information needs of other health care professionals
- Demonstrate an understanding of the role of specialist palliative care services in supporting health care professionals to provide a palliative care approach to persons with a life-limiting condition
- Maintain individual confidentiality, privacy and autonomy throughout the disease trajectory.

As a pharmacist with training in palliative care and regular clinical engagement with individuals with life-limiting conditions you should:

- Demonstrate an understanding of a broad spectrum of life-limiting conditions and the associated symptoms and treatments
- Integrate the physical, psychological, social and spiritual needs of a person with life-limiting conditions into the provision of pharmaceutical care and pharmacy practice
- Be able to identify and actively respond to medicines information needs of health care professionals and support the provision of evidence-based practice in a variety of care settings
- Demonstrate leadership in the delivery of palliative care provision in your local health care network
- Demonstrate leadership in the delivery of palliative care education in your local health care network.

#### FEW

#### As a pharmacist whose core role is the provision of palliative care you should:

- Demonstrate an in-depth understanding of the full spectrum of life-limiting conditions, the associated complex symptoms and treatments
- Be able to identify and actively respond to complex medicines information needs of health care professionals and support the provision of evidence-based practice in a variety of care settings
- Demonstrate an in-depth knowledge of the use of specialist resources providing information about medicines used in palliative care and adapt this information for use in clinical settings
- Demonstrate leadership in the identification, development and delivery of medicines-related palliative care guidance and policy
- Actively influence and promote strategic initiatives and policy development for palliative care services at local, regional and national levels
- Demonstrate leadership in the development and delivery of palliative care education at a national level.
- Be able to lead, facilitate and engage in audit and research in the field of palliative care in order to improve practice.

#### 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.

#### **PHARMACY**

#### ALL

#### As a pharmacist you should:

- Be caring, empathetic and sensitive to the needs and rights of people with lifelimiting conditions when communicating with them, their family and/or carer(s) about medication issues
- Recognise that individuals with life-limiting conditions have varying levels of health literacy and medication information should be delivered at an appropriate level for the person, their family and carers
- Endeavour to ensure that the person with a life-limiting condition, their family and carers understand the information they receive regarding medication
- Communicate recommendations regarding appropriate use of medicines to other health care professionals in order to inform decision-making about medications used in palliative care
- Understand the importance of communicating with health care professionals in various care settings to ensure the seamless delivery of pharmaceutical care to people with life-limiting conditions and their families.

As a pharmacist with training in palliative care and regular clinical engagement with individuals with life-limiting conditions you should:

- Demonstrate an understanding of the communication challenges that may arise in the context of engaging with people with life-limiting conditions
- Be able to utilise the skills of the multidisciplinary team or colleagues to enhance and support communication with the person with a life-limiting condition and their family/carer.

#### **FEW**

As a pharmacist whose core role is the provision of palliative care you should:

- Demonstrate the ability to use a variety of strategies to engage in highly skilled, empathic, individualised and timely communication with individuals with lifelimiting conditions, their families and other health care professionals
- Demonstrate expertise in medicines management issues that individuals with lifelimiting conditions may experience and communicate their needs and opinions to other health care professionals
- Demonstrate expertise as a mediator and advocate for the individual with lifelimiting conditions and the family in issues related to pharmaceutical care and decision making regarding pharmaceutical care
- Be able to facilitate the multidisciplinary teaching of communication skills with regards to pharmaceutical care.

#### **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 lifelimiting 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.

#### **PHARMACY**

#### ALL

#### As a pharmacist you should:

- Understand the importance of the timely provision of medication for symptom control and disease management
- Demonstrate knowledge of treatment choices for symptoms experienced by people with life-limiting conditions and the pharmaceutical care issues associated with these treatments
- Demonstrate an ability to provide pharmaceutical care for the management of symptoms throughout the disease trajectory and at the end-of-life
- Demonstrate an ability to counsel individuals with life-limiting conditions and their families regarding the identification and management of common adverse effects of medications
- In the context of the scope of practice, undertake individual-specific monitoring
  for medication therapy outcomes, recommend alternative medicines or dosage
  forms, identify duplicative medications, identify medication omissions, provide
  management strategies for interacting medications, and provide advice regarding
  the prevention or control of medication related adverse effects
- Recognise and if appropriate respond to psychosocial issues which may impact on compliance and concordance with medications
- Demonstrate an ability to address and resolve any issues and concerns that the individual or family member may have about medications being used to treat symptoms at the end-of-life
- Demonstrate an awareness of factors relating to the dispensing and supply of medicines, particularly unlicensed medicines, off-label usage of medicines and expensive medicines
- Recognise when it is appropriate to refer the person with a life-limiting condition to other health care professionals.

As a pharmacist with training in palliative care and regular clinical engagement with individuals with life-limiting conditions you should:

- Demonstrate advanced knowledge and clinical application of pharmacological treatment options for symptoms in people with life-limiting conditions
- Provide expert advice on compatibility and stability when using multiple drugs being administered subcutaneously (SC) or intravenously (IV).

#### **FEW**

As a pharmacist whose core role is the provision of palliative care you should:

- Support and advise prescribers making decisions to modify the pharmacological management of co-morbidities
- Demonstrate expert knowledge and clinical application of pharmacological treatment options for the management of complex and non-complex symptoms in palliative care
- Be able to provide leadership, expertise and guidance to colleagues on the pharmacological management of complex and non-complex symptom control strategies in individuals with life-limiting conditions.

#### 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.

#### **PHARMACY**

#### ALL

#### As a pharmacist you should:

- Understand that in situations where a person lacks capacity to make decisions, decisions must be made in the best interests of the person, in collaboration with the family and other members of the multidisciplinary team
- Demonstrate an ability to collaborate with individuals, family members, carers and other health care professionals in monitoring medicines used for symptom control at the end-of-life
- Demonstrate an ability to individualise pharmaceutical care to address the physical and psychosocial needs of persons with life-limiting conditions
- Demonstrate an ability to identify any potential medication safety risks and educate persons with life-limiting conditions and their family members on the correct use of medications used in palliative care and liaise with other health care professionals where appropriate

- Demonstrate flexibility in medication related care planning, acknowledging that the persons priorities can alter with a change in their condition and disease advancement
- Demonstrate an ability to recommend strategies for medication recalls or medication/ dosage formulation shortages in order to avoid any disruption to care at the end-of-life
- Be able to provide advice to other health care professionals regarding commonly used difficult to source or expensive medications.

As a pharmacist with training in palliative care and regular clinical engagement with individuals with life-limiting conditions you should:

- Be able to provide advice to other health care professionals regarding specialised and difficult to source medications.
- Demonstrate an ability to collaborate with individuals, family members, carers and other health care professionals in designing, implementing, and monitoring a pharmaceutical plan for symptom control throughout the disease trajectory and at the end-of-life
- Demonstrate an in-depth understanding of medication related issues that may develop over the disease trajectory and plan accordingly
- Demonstrate an ability to perform a structured, critical examination of prescribed medication in order to optimise the impact of medicines and minimise the number of medication related problems
- Demonstrate knowledge of the medication safety risks that arise with the use of medicines in palliative care and an ability to advise other health care professionals on methods to minimise the risk of harm to individuals.

#### FEW

As a pharmacist whose core role is the provision of palliative care you should:

- Demonstrate the ability to collaborate with specialist palliative care teams and provide expert pharmaceutical care for people with life-limiting conditions with complex symptoms
- Demonstrate an ability to act as an expert clinical resource, as required, to generalist providers of palliative care with regard to the use of medicines in palliative care
- Be able to promote the safe use of medicines in palliative care by encouraging the reporting of errors, improving medication use processes and developing and implementing medication safety strategies for high risk medications.

#### 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
- 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.

#### **PHARMACY**

#### ALL

#### As a pharmacist you should:

- Demonstrate an understanding of the impact a life-limiting diagnosis may have on a individual and their family
- Demonstrate understanding of normal and pathological responses to the diagnosis/prognosis of a life-limiting condition and an ability to address the immediate management of such responses
- In context of your role appreciate the needs of family and carers with regard to expression and management of grief
- Facilitate the safe, efficient and traceable removal of drugs from the home of individuals with life–limiting conditions as required
- Reflect on experiences with persons with life-limiting conditions and bereaved family members to enhance professional practice.

#### 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:
  - Recognising 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.

#### **PHARMACY**

#### ALL

#### As a pharmacist you should:

- Be aware of and act according to the Pharmaceutical Society of Ireland Code of Conduct for Pharmacists and its application to the care of people with life-limiting conditions
- Be aware of and act according to the Pharmaceutical Society of Ireland Core Competency Framework for Pharmacists in Ireland (CCF)
- Demonstrate an understanding of the difference between managing a life-limiting condition and providing end-of-life care
- Demonstrate an awareness of the importance of maintaining professional boundaries when working with individuals with life-limiting conditions.

As a pharmacist with training in palliative care and regular clinical engagement with individuals with life-limiting conditions you should:

- Demonstrate an understanding of the process of quality improvement in the context of palliative care
- Participate in professional supervision and peer review processes to monitor personal and professional responses to clinical situations
- Demonstrate a commitment to working with pharmacy colleagues and other health care professionals to assess, co-ordinate, promote and improve medication safety in the context of palliative care.

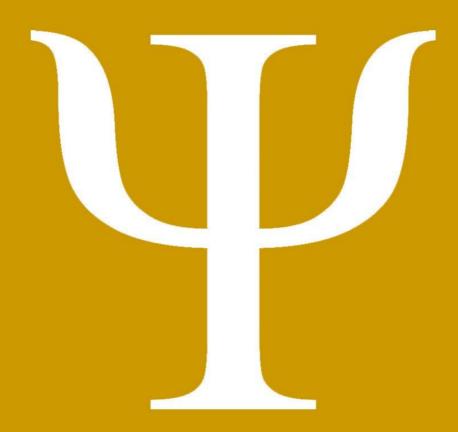
#### FFW

#### As a pharmacist whose core role is the provision of palliative care you should:

- Demonstrate an ability to influence processes and behaviours that determines how medicines are used in palliative care at a national level
- Demonstrate a commitment to working in partnership with health care managers and providers to assess, coordinate, promote and improve individual safety in the context of palliative care
- Demonstrate an understanding of the process of quality improvement and risk management in the context of palliative care
- Demonstrate a commitment to advancing Palliative Care through the generation and application of knowledge and research
- Demonstrate leadership through advocating for continuous service development and professional practice
- Facilitate appropriate engagement of service users in the development of palliative care services
- Participate in the discussion and resolution of ethical dilemmas that may arise in palliative care
- Communicate and advance the distinct contribution of palliative pharmacy.

# **DISCIPLINE SPECIFIC COMPETENCES**

**Psychology** 



# MEMBERSHIP OF DISCIPLINE SPECIFIC WORK GROUP PSYCHOLOGY

#### Dr Paul D'Alton (Chair)

Senior Clinical Psychologist/Head and Clinical Lead of Psycho-oncology Department, St. Vincent's University Hospital

#### **Ursula Bates**

Head of Psychology Our Lady's Hospice and Care Service, Harold's Cross and Blackrock

#### **Dr Susan Delaney**

Clinical Psychologist, Irish Hospice Foundation

#### Dr Louise Kinsella

Clinical Psychologist, Psycho-oncology Department, St. Vincent's University Hospital

#### Dr Aidan McKiernan

Senior Clinical Psychologist, LauraLynn Ireland's Children's Hospice

#### Dee McKiernan

Counselling Psychologist, Psycho-oncology Department, St. Vincent's University Hospital













#### 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 be eavement.

#### **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 lifelimiting 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 onyou.

#### ALL

#### All applied psychologists should:

- Assess the person's subjective experience and meaning of their illness trajectory
- Recognise dying as a normal process in life
- Have an awareness of the psychological aspects of life-limiting conditions and potential mental health needs arising from these
- Be aware of the importance of empathic and responsive relationships between those experiencing life-limiting conditions and their health care team
- Demonstrate an understanding of palliative care issues, which may impact on subsequent interactions with individuals and their families
- Be aware of the role of specialist palliative services in supporting staff when providing a palliative care approach to a person with a life-limiting condition

#### SOME

All applied psychologists whose work involves increased engagement with people with lifelimiting conditions and their families should:

- Demonstrate an understanding of the mental health needs of those with life-limiting conditions and by virtue of the scientist-practitioner framework ensure that clinical practice is both informed by and informs this understanding
- Maintain a thorough understanding of psychological theories of death, dying and living with life-limiting conditions
- Maintain a thorough understanding of specific psychological issues pertaining to the clinical practice of palliative care, such as impact of integrating palliative care with active treatment and the significance of transition periods
- Demonstrate an understanding of and capacity to work in a self-reflective way with existential issues that impact upon people with life-limiting conditions, their families and psychologists themselves

- Engage in psychological assessment, formulation and intervention with people with lifelimiting conditions and their families within personal competency limits, referring on as appropriate
- Critically evaluate the effectiveness of any psychological intervention and modify or refer on for more specialist support, as appropriate
- Engage in research pertaining to palliative care within the context of the local work environment
- Identify and critically appraise research evidence relevant to practice as it pertains to living with life-limiting conditions
- Demonstrate cultural competence in academic or applied practice, for example maintain a critical understanding of the dominant discourses in palliative care
- Understand the relevant national policy, practice, and legislation pertaining to palliative care
- Raise awareness of a psychological perspective on death and dying and mental health needs of people with life-limiting conditions at all levels including but not limited to: among people with life-limiting conditions, caregivers, within teams and work organisations
- Be involved as team members, or leaders, in the design and conduct of staff support and training programmes in issues pertaining to life-limiting conditions.
- Demonstrate understanding and competence to plan and engage in service audit

#### FEW

All applied psychologists whose core role is the provision of care to people with life limiting conditions and their families should:

- Engage in specialist psychological assessment, formulation and intervention with people with life-limiting conditions and their families presenting with complex and often multiple clinical conditions
- Work with and consult on various psychological protective functions such as death denial and death anxiety, as appropriate to palliative care
- Consult with teams in the management of people with life-limiting conditions with complex needs such as organic brain damage, toxicity, dual mental health diagnosis and personality difficulties, which may interfere with their ability to engage with services
- Possess a knowledge of the historical development and role of psychology in palliative care nationally and internationally and the challenges associated with the adoption of a holistic model of care within dynamic health care systems
- Lead and facilitate research addressing issues pertaining to palliative care
- Provide leadership in the development and delivery of palliative care policy at local and national levels
- Demonstrate a commitment to continuous professional training centred on that pertaining to the evolving field of palliative care
- Provide leadership in the psychology of palliative care by contributing to the knowledge base of society via talks, conferences, media
- Demonstrate leadership in palliative care education as it pertains to psychology up to and including 3rd level post-graduate programmes
- Provide a board range of evidence-based therapeutic interventions (e.g. Cognitive Behavioural Therapy (CBT), Meaning Centred Therapy) to service users and family members.













#### 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 differ. 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 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 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 her/his families 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

#### ALI

#### All applied psychologists should:

- Demonstrate awareness that effective communication is a fundamental underpinning of applied psychological practice
- Be able to assess a person's current understanding of their life-limiting condition
- Cultivate and support effective communication skills among individuals with life-limiting conditions, their families and other health care providers
- Provide compassionate communication, general psychological support to individuals with life-limiting conditions and their carers, including individual, family and group
- Demonstrate a working knowledge of the therapeutic alliance and the importance of building rapport with individuals with life-limiting conditions, their carers and family members
- Recognise communication challenges in individuals with life-limiting conditions and refer on for further clinical assessment and intervention as appropriate
- Proactively communicate to the individual with a life-limiting conditions and their family, the limits of confidentiality and the need for a joint patient record and team

communication about care planning

• Have an awareness of specialist palliative supports in relation to communication: professional interpreters, sign language and assistive technology.

#### SOME

All applied psychologists whose work involves increased engagement with people with lifelimiting conditions and their families should:

- Support parents/guardians/families in sharing difficult or bad news relating to illness or death and facilitate direct supportive communication, where appropriate
- Demonstrate competence in communication with individuals with life-limiting conditions, displaying a wide range of cognitive ability, sensory acuity and modes of communication
- Communicate effectively with individuals with life-limiting conditions and their families from diverse cultures and different backgrounds, using professional interpreters and/or assistive communication technology where necessary
- Demonstrate an ability to communicate sensitively and clearly about advance care planning with the individuals with life-limiting conditions, their family and the range of professionals and agencies involved
- Demonstrate awareness of the different levels of communication (such as verbal and non-verbal; conscious and unconscious) of individuals with life-limiting conditions
- Demonstrate theoretical knowledge of evidence-based models of psychotherapeutic intervention and outcome measures appropriate to individuals with life-limiting conditions
- Facilitate effective intra and interdisciplinary communication among individuals with life-limiting conditions, their families and other health care providers within the multidisciplinary team.

#### **FEW**

All applied psychologists whose core role is the provision of care to people with life limiting conditions and their families should:

- Provide training and support to enable health and social care staff working in palliative care to communicate with people with life-limiting conditions clients and their families sensitively and effectively
- Communicate clinical and non-clinical information from a psychological perspective in a style appropriate to a variety of different audiences; including professional colleagues, individuals with life-limiting conditions and their carers
- Demonstrate an understanding of and clinical ability to work with the broader aspects of psychological theory; including but not limited to; the unconscious, the intra-psychic and other non-verbal communication as it applies to individuals with life-limiting conditions
- Demonstrate an understanding and awareness of medications, physical pain, organic or cognitive impairment and its impact on the individual with a life-limiting condition
- Provide additional training and consultation with regard to the normal and complicated adjustment and systemic processes
- Demonstrate leadership in communication, such as facilitating team communication, staff support, debriefing and case reviews.



Ψ









#### 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 lifelimiting 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

#### ALL

#### All applied psychologists should:

- Demonstrate an understanding that psychological assessment and treatment should take place in the context of multidisciplinary care team
- Have a working knowledge of the factors underpinning psychosocial adjustment to lifelimiting condition and recognise the potential role of palliative care in enhancing the care of the individual and their family
- Have the ability to pre-empt potential problems and apply psychological approaches, such as Cognitive Behaviour Therapy (CBT), Brief Solution Focused Therapy based on assessment or refer on as appropriate

#### SOME

All applied psychologists whose work involves increased engagement with people with life-limiting conditions and their families should:

- Recognise how disease progression and associated medical treatments can adversely
  affect the quality of life of a person with a life-limiting condition by virtue of their
  potential to impact on the person's emotional wellbeing, interpersonal relationships,
  material wellbeing, personal development, physical well-being, self-determination,
  social inclusion and human rights
- Support people with life-limiting conditions to psychologically process the implication and impact of moving from curative care to palliative care
- Knowledge and understanding of the diagnosis and treatment of mental health difficulties, with onward referral for more specialist assessment as appropriate
- Conduct standardised assessment of the psychological adjustment of an individual with a life-limiting condition
- Develop psychological formulations based on assessment findings and communicating

- these formulations, as appropriate, to relevant stakeholders in order to shape and support patient care pathways
- Deliver evidence-based psychotherapeutic interventions to people with life-limiting conditions and their families
- Provide education to people with life-limiting conditions, their families and carers and the wider health professional network on the psychological aspects of pain, fatigue, anxiety and other presentations associated with the experience of end of life.

#### **FEW**

All applied psychologists whose core role is the provision of care to people with life limiting conditions and their families should:

- Demonstrate advanced clinical knowledge of complex mental health presentations through assessment, diagnosis and treatment
- Demonstrate competence in the use of classification systems for mental health disorders such the Diagnostic and Statistical Manual of Mental disorders (DSM) and in treating mental health disorders in people with life-limiting conditions
- Support and educate individuals with life-limiting conditions and their families on quality of life decisions and the psychological implications of decisions
- Provide specialist evidence-based psychotherapeutic interventions based on on-going psychological assessment
- Support teams in the management of individuals with life-limiting conditions who
  present with organic brain damage, toxicity, dual mental health diagnosis and personality
  disorders which may interfere with their engagement with services
- Provide consultation to the team when considering the care and treatment options for a person with a life-limiting condition, with due regard to the persons wishes and how their psychological state may influence this.
- Provide consultation and direct support to families with complex dynamics and staff to facilitate care provision
- Support health and social care professionals as appropriate such as debriefing, supervision, case management









# Y



# **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 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.

#### ALL

#### All applied psychologists should:

- Demonstrate understanding of the relationship between medical illnesses and treatment of mental health presentations in palliative care
- Demonstrate an ability to build empathic, responsive relationships and maintain physical and emotional presence with individuals with life-limiting conditions
- Demonstrate an ability to gather and analyse information from a variety of sources and evaluate this information to make well-founded decisions with respect to care planning and communicate samethrough compassionate communication
- Have awareness of the essential multidisciplinary nature of care in palliative care and therefore, the need for consultation with other agencies caring for the person
- Have knowledge and understanding of how to resource and refer an individual with a life-limiting conditions or their carer or family member, for support and guidance on contemporary issues in palliative care
- Understand that the person with a life-limiting condition may lose (sometimes temporally)
   capacity to make decisions towards end-of-life

• Have awareness of the Pharmaceutical Society of Ireland Guidelines on Equality and Inclusive Practice (2008) and the impact that membership of minority groups may have on care plan formulation.

#### SOME

All applied psychologists whose work involves increased engagement with people with lifelimiting conditions and their families should:

- Recognise that psychological care planning takes place in a dynamic field of changing health and care where care plans have regularly be revised and reformulated
- Be able to refer a person with a life-limiting condition or their family members to other mental health professionals for issues outside the scope of palliative care practice (such as family therapy)

#### FEW

All applied psychologists whose core role is the provision of care to people with life limiting conditions and their families should:

- Demonstrate psychological formulation and re-formulation of care planning in the context of changing health status of the patient
- Consult and support conversations about Advanced Care Planning, capacity, and contemporary end-of-life issues in line with current Irish policies
- Demonstrate awareness of reputable on-line resources and assist individuals with lifelimiting conditions and their families to inform themselves and appropriately use selfhelp resources and support groups
- Demonstrate understanding that psychological assessment and treatment takes place inthe context of multidisciplinary care team. Pro actively communicate to individuals with life-limiting conditions and their families the limits of confidentiality and the need for a joint patient record and team communication about care planning
- Work collaboratively with other professional to ensure a realistic care plan so that services do not place an undue burden on the individual with a life-limiting condition
- Model and provide consultation with regard to building empathic, responsive relationships and maintain physical and emotional presence with individuals with lifelimiting conditions
- Consult on the application of the international best practice guidelines on end-of life care and demonstrate ability to apply these guidelines in practice
- Awareness of one's own existential issues, as well as those of people with life-limiting conditions and their families and the impact of such issues on counter transference and self-care.



Ψ









#### LOSS, GRIEF AND BEREAVEMENT

The knowledge and skills base which a psychologist brings to end of life and bereavement care is both broad (for example, an ability to understand and apply different approaches to care) and deep (for example, an ability to be expert in specific models of therapy, research and clinical areas) Psychologists approach each service user and situation from a discipline which is firmly rooted in research and theoretical understanding. Psychologists bring a detailed understanding of human development across the lifespan including cognitive functioning, personality development, behaviour and group dynamics and utilise this information to ensure best service delivery.

#### **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.

#### ALL

#### All applied psychologists should:

- Be familiar with contemporary theories and models of loss and grief (for example; Dual Process, Continuing Bonds, Meaning Making)
- Provide culturally competent bereavement support to individuals with life-limiting conditions and their family members
- Use appropriate referral pathways for individuals and family members requiring more specialised psychological interventions
- Be aware of appropriate supports and resources for people with life-limiting conditions and their family members
- Utilise supervision and other support strategies to maintain well-being and effective practice.

#### SOME

All applied psychologists whose work involves increased engagement with people with lifelimiting conditions and their families should:

- Be proficient in applying contemporary, evidence-based models of bereavement support
  and counselling across a broad range of individuals with life-limiting conditions; adjusting
  for differences in cognitive level and learning style and demonstrating sensitivity to
  gender, sexual orientation, religious and cultural differences
- Be able to communicate therapeutically with individuals with life-limiting conditions, and their families, noting normal and pathological loss responses and attending to individual

- styles of coping and grieving
- Stay abreast of published literature in the area of grief, loss and bereavement and disseminate this information to colleagues and individuals with life-limiting conditions as appropriate
- Demonstrate good self-care practice and include an emphasis on work impact on self when giving and receiving supervision.

#### **FFW**

All applied psychologists whose core role is the provision of care to people with life limiting conditions and their families should:

- Apply an in-depth understanding of the grief and loss literature to the care of people with life-limiting conditions and their families and provide consultation and training updates for mental health professionals
- Understand the complexity and dynamic nature of responses to loss, and provide expert input to the multidisciplinary team on the psychological aspects of people with lifelimiting conditions and family care.
- Demonstrate proficiency in using validated assessment tools to diagnose and differentiate between ego-syntonic sadness and mental health issues such as; anxiety, depression and Post Traumatic Stress Disorder
- Formulate and deliver a broad range of evidence-based therapeutic interventions to people with life-limiting conditions and their family members who present with increased stress vulnerability and/or complex grief responses
- Demonstrate ability to use recognised and validated tools to diagnose Post Traumatic Stress Disorder and other pathological grief responses in individuals with life-limiting conditions and family members
- Assess the efficacy of treatment interventions and adjust accordingly
- Provide additional training and consultation with regard to the normal and complicated adjustment and systemic processes
- Provide bereavement intervention to family members and carers.
- Engage in research that adds to the body of literature on psychology, loss, grief and bereavement and disseminate research findings
- Contribute to teaching curricula on loss, grief and bereavement up to and including 3rd level education across a range of disciplines
- Lead and develop strategies and practice that enhance well-being and effective practice amongst individual staff members and teams.













# 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:
  - Recognising 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.

#### ΔΠ

#### All applied psychologists should:

- Be aware and act according to the Code of Ethics and Professional Conduct of the Psychological Society of Ireland
- Adopt the Psychological Society of Ireland (PSI) Guidelines on Equality and Inclusive Practice in relation to caring for people with life-limiting conditions

#### SOME

All applied psychologists whose work involves increased engagement with people with lifelimiting conditions and their families should:

- Promote and provide access to psychological therapies for people with a life-limiting condition
- Demonstrate ability to understand and apply the PSI Guidelines on Equality and Inclusive Practice (2008)

- Contribute to education of health care professionals and general public about the psychology of death and dying (such as promote a bio-psycho-social understanding of death promote an understanding of the unconscious mind)
- Provide and participate in professional supervision and peer review processes to monitor
  personal and professional responses to clinical situations and to ensure best practice in
  providing care to people with life-limiting conditions and their families
- Actively participate in the discussion and resolution of ethical and legal issues in conjunction with the multidisciplinary team, individuals with life-limiting conditions and families that may arise in relation to factors which impact on living with a life-limiting condition
- Use recognised ethical, legal and professional frameworks to guide end of life decision making.

#### **FEW**

All applied psychologists whose core role is the provision of care to people with life limiting conditions and their families should:

- Demonstrate a commitment to working to promote the provision of comprehensive palliative care services at local, regional and national levels across all clinical settings including primary, acute, tertiary and residential care
- Demonstrate leadership through advocating for on-going and continuous service development with particular emphasis on the often unmet mental health needs of people with a life-limiting conditions and advocate for the provision of psychological services for people with life-limiting conditions
- Be committed to advancing the role of psychology in palliative care through the application of knowledge and generation and dissemination of research at national and international conferences
- Demonstrate skills in bridging the biomedical and social sciences research paradigm by leading multidisciplinary research projects and publications.
- Facilitate discussion and resolution of ethical issues that may arise in palliative care
- Apply an advanced understanding of contemporary legal, ethical and professional standards in the provision of quality palliative care with particular emphasis on issues such as capacity and euthanasia







# **DISCIPLINE SPECIFIC COMPETENCES**

Chaplaincy/Pastoral Care



# MEMBERSHIP OF DISCIPLINE SPECIFIC WORK GROUP CHAPLAINCY/PASTORAL CARE

#### Brian Gough (Chair)

Head of Chaplaincy Services, St James's Hospital, Dublin Chair of the National Association of Health care Chaplains (NAHC)

#### Marie Gribbon

Chaplain, St Francis Hospice, Raheny, Dublin 5
Executive Member National Association of Healthcare Chaplains

#### Brendan Mc Keever

Chaplain, Our Lady's Hospice, Harold's Cross, Dublin Chair of the Health care Chaplaincy Board (HCB)

#### **Daniel Nuzum**

Chaplain, Cork University Hospital, Cork Member of the Chaplaincy Accreditation Board (CAB)

#### Bruce A. Pierce

CPE Supervisor & Director of Education, St Luke's Education Centre, Cork Chair of the Association of Clinical Pastoral Education (Ireland) Ltd (ACPE (Ireland) Ltd.)

#### Margaret Mulcaire

Chaplain & Coordinator of Chaplaincy Services, St John of God Menni Services, Dublin

#### Bryan Nolan

Communications & Development Coordinator (Final Journeys). Irish Hospice Foundation

#### Jim Owens

Chaplain, St Vincent's Hospital, Fairview, Dublin

#### Nan O Mahony

Chaplain, Marymount University Hospital and Hospice, Cork.

#### Siobhan Quill

Chaplain, Marymount University Hospital and Hospice, Cork.

- 1. The National Association of Health care Chaplains (NAHC) is a professional association whose members serve as chaplains in hospital and health care facilities in Ireland.
- 2. The Health care Chaplaincy Board (HCB) is a sub-committee of the Council for Health care of the Irish Bishops' Conference. The HCB is the certifying and regulating body for Catholic Health care Chaplaincy throughout Ireland.
- 3. The Chaplaincy Accreditation Board (CAB) certifies Health care Chaplains following interview and meeting the standards of CAB. The CAB operates under the auspices of the House of Bishops of the Church of Ireland. As a body it will certify members of other church/faiths groups subject to the support of the relevant authorities of that church/faith.
- 4. Association of Clinical Pastoral Education Ireland (ACPE (I)) Ltd is a professional interfaith association which certifies persons as pastoral educators in the clinical pastoral education (CPE) method. CPE supervisors direct CPE programmes and administer CPE centres













#### 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 be eavement.

#### **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 lifelimiting 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 onyou.

#### ΔΠ

#### As a Chaplain you should:

- Recognise that chaplaincy care is an essential element of holistic care for the person with a life-limiting condition and their family
- Understand the nature of spirituality and recognise that everyone has a spiritual dimension and that for many people this may have a religious component
- Assist the person with a life-limiting condition to discern their spiritual needs and create a safe space where they can name and address them
- Recognise that the opportunity for human development; physical, emotional and spiritual, is an essential component of palliative care
- Understand and appreciate that spiritual and emotional pain often results from a loss of meaning and unmet spiritual needs
- Engage pastorally with persons who are experiencing spiritual distress and pain
- Understand and appreciate that in some cases suffering can be seen as part of the normal, process of living with the profound challenges of having a progressive illness, functional disability, and awareness of impending death
- Demonstrate knowledge and understanding of the main world faiths, philosophies, beliefs, practices, cultures and traditions around life, illness, dying and death
- Offer support and encouragement to the multidisciplinary team in order to promote wellbeing and self-care



As a Chaplain with an additional level of engagement with people with life-limiting conditions you should:

- Have the capacity to integrate spiritual and/or religious care into the appropriate palliative care setting
- Be committed to ongoing development, personally, pastorally and professionally
- Be familiar with research in palliative care and use this to inform practice.

#### **FEW**

As a Chaplain working primarily with people with life-limiting conditions you should:

- Be familiar with family systems practice and its importance within the palliative care setting
- Be committed, involved and take a leadership role in the delivery of spiritual and /or religious care within the context of a multidisciplinary team approach.
- Promote research and development of bereavement care, including audit of own practice.













#### **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 differ. 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 a 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

#### ALL

#### As a Chaplain you should:

- Recognise and appreciate that the quality of pastoral presence is an essential component of spiritual care
- In the course of pastoral ministry be fully attentive to the individual with a life-limiting condition and demonstrate the ability to connect and empathise with them
- Demonstrate sensitivity in pastoral conversations with patients, families and significant others
- Understand that the communication of information which changes the person's understanding of their situation and/or influences their decision-making or planning is an on-going process and not a single event
- Provide person-centred, family-focused chaplaincy care that understands and respects diversity in all its dimensions
- Use pastoral interventions and engage in pastoral conversations, which are ageappropriate
- Apply best practice in spiritual assessment and documentation to help determine and

- communicate interdisciplinary plans of care
- Recognise, understand and be sensitive to the significant changes in the person's condition when moving toward end of life and facilitate the individual, and their family to consider options for spiritual care and support
- Have the skill and capacity to engage respectfully and sensitively with patients around their beliefs, fears, hopes and uncertainties regarding death and afterlife
- Whilst respecting the individual's beliefs and wishes, ensure that spiritual and/or religious rituals and/or sacraments for end of life, are available
- Through spiritual accompaniment, help the individual with a life-limiting condition to make their final journey with dignity, peace and compassion, while also providing support to their family
- Demonstrate the ability to apply knowledge of the key physical, psychological and social principles in palliative care in order to communicate effectively with the multidisciplinary team
- Understand and practice appropriate principles of confidentiality in relation to matters of a private and sensitive nature.

As a Chaplain with an additional level of engagement with people with life-limiting conditions you should:

 Provide spiritually and culturally appropriate chaplaincy support during patient and family conferences and when participating in support groups.

#### **FEW**

As a Chaplain working primarily with people with life-limiting conditions you should:

- Contribute to and support discussions between individuals, their families and staff members and recognise potential differences in decision making in the context of palliative care
- Understand how different styles of communication can be adapted and used to enhance communication in complex situations at end of life
- As part of the multidisciplinary team assist in the mediation of conflict in decision-making in the palliative care setting and work towards consensus building in care planning
- Support the multidisciplinary team, parents/guardians/families in sharing difficult or bad news, relating to illness or death, with children and vulnerable adults; facilitating direct supportive communication with them, where appropriate
- Anticipate and facilitate the distinctive needs of parents, families and colleagues in perinatal palliative care













#### **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 lifelimiting 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 far as possible

#### ALL

#### As a Chaplain you should:

- Be able to help the person living with a life-limiting condition to feel assured that chaplains
  are capable of accompanying persons of all faith traditions, persons who profess no faith,
  persons whose lives are guided by a particular life philosophy
- Demonstrate an ability to assist members of the multidisciplinary team to understand the nature and importance of addressing the spiritual and religious needs of the individual and how these may impact on wellbeing
- Demonstrate an ability to assess the spiritual/religious needs of the person with a lifelimiting condition and share as appropriate with the multidisciplinary team
- At the request of the individual with a life-limiting condition or their family liaise with the individuals parish clergy, faith group, spiritual companions/leaders and/or other community religious/spiritual and cultural resources.

#### **SOME**

As a Chaplain with an additional level of engagement with people with life-limiting conditions you should:

- Demonstrate an ability to analyse appropriate knowledge and information to inform decision making in end of life care
- In the context of your current role, support the team when considering the care and treatment options for the person with a life-limiting condition with due regard to the persons wishes.
- Be able to recognise and at times anticipate the need to change and adapt the focus of pastoral care intervention at critical points during a life-limiting condition, supporting the person with a life-limiting condition and their family through times of transition



#### FEW

As a Chaplain working primarily with people with life-limiting conditions you should:

• Provide specialist pastoral care interventions based on continuing assessment of palliative and end of life care needs.













#### 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 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

#### ALL

#### As a Chaplain you should:

- Demonstrate an ability to assess, plan and communicate the spiritual needs of the patient to the multidisciplinary team
- Be aware and respect professional boundaries when offering and providing spiritual care to patients and when interacting with other members of the multidisciplinary team
- Demonstrate an ability to assess the need to seek professional consultation regarding the effectiveness of pastoral care and the appropriateness of referral to another professional care provider
- Document appropriate referrals following spiritual assessment (e.g. referral to the patients own faith representative if requested)
- Demonstrate an ability for effective engagement in multidisciplinary team meetings, highlighting and addressing spiritual issues and suggesting appropriate responses to identified spiritual need
- Work collaboratively with the person with a life-limiting condition, their family and other
  professionals, including attending family meetings, team meetings, mediating discussions
  and planning for future care.



 Recognise that the person with a life-limiting condition may lose capacity to make decisions towards end-of-life

#### **SOME**

As a Chaplain with an additional level of engagement with people with life-limiting conditions you should:

- Be able to facilitate and integrate collaborative processes and multidisciplinary relationships that respect the principles of holistic care within the wider health care institutional culture
- Demonstrate leadership in identifying spiritual/religious issues and facilitate the appropriate team response through family meetings involving other team members and services as appropriate
- Have the ability to articulate the unique professional role of chaplains as leaders in the provision of spiritual care
- Be able to quantify the benefits and measurable outcomes of pastoral care interventions through reflecting on expressed patient and family satisfaction

#### **FEW**

As a Chaplain working primarily with people with life-limiting conditions you should:

 Provide staff support and guidance around spiritual care issues by sharing professional knowledge and expertise regarding spiritual/religious issues in palliative care and at end of life, with the multidisciplinary team













### 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
- 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.

#### ALL

#### As a Chaplain you should:

- Be able to articulate important spiritual, existential and emotional concepts for patients, families and significant others
- Work in partnership with parents, guardians and other family members in order to prepare and support children and vulnerable adults for the loss of loved ones
- Be able to provide appropriate spiritual care and emotional support to grieving persons of diverse cultural and religious traditions, and to persons with no affiliation to a faith tradition
- Be able to plan and lead appropriate rituals, suitable for the time of dying or after death, which offer hope and comfort to persons from a diversity of cultural and faith traditions, and to persons who represent a diversity of world views
- Be able to plan and lead services suitable for specific faith traditions, and also ecumenical and interfaith services
- Demonstrate an ability to work in partnership with the patient's faith group/leaders and/or other community religious/spiritual and cultural resources to ensure that all sacramental, religious and faith based rituals are met in a timely and appropriate manner



#### **SOME**

As a Chaplain with an additional level of engagement with people with life-limiting conditions you should:

- Demonstrate an understanding of the theories of loss, grief and bereavement
- Be culturally aware of nuances regarding pain, suffering, loss, complicated and anticipatory grief, and life review
- In the context of your current role as an ordained chaplain and appropriate to the faith tradition of the individual with a life-limiting condition, celebrate Mass and the sacraments of the Anointing of the Sick, Reconciliation and others as required
- In the context of your current role as an ordained chaplain and appropriate to the faith tradition of the individual with a life-limiting condition ensure faith based rituals, sacraments and ministry are met in a timely and appropriate manner
- In the context of your role as a Rabbi and appropriate to the faith tradition of the individual with a life-limiting condition ensure faith based rites and rituals are met in a timely and appropriate manner
- In the context of your role as an Imam and appropriate to the faith tradition of the individual with a life-limiting condition ensure faith based rituals are met in a timely and appropriate manner
- In the context of your role as Asacharya and appropriate to the faith tradition of the individual with a life-limiting condition ensure faith based rituals are met in a timely and appropriate manner
- In the context of your role as Sensei and appropriate to the faith tradition of the individual with a life-limiting condition ensure faith based rituals are met in a timely and appropriate manner

#### **FEW**

As a Chaplain working primarily with people with life-limiting conditions you should:

 Provide multidisciplinary team debriefing and support the development of self-care strategies for colleagues working in end of life care.













## 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 people's wishes about their care and options/ preferences.
   This includes: Recognising peoples right to make informed decisions to refuse additional treatment(s)
- Seek, respond to and implement the person'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

#### ΔΠ

#### As a Chaplain you should:

- Respect and uphold the dignity of the person who is receiving palliative or end-of-life care.
- Respect and support the person with a life-limiting condition and their family to be treated with dignity throughout the course of illness, during the dying process, and after death.
- Identify how one's feelings, attitudes, values and assumptions impact on pastoral ministry with the person with a life-limiting condition and their family.
- To recognise and articulate challenging areas of ethical sensitivity and awareness in the hospice and palliative care arena.
- Demonstrate maintaining one's integrity and authenticity in professional practice during the process of assisting others in moral and ethical care decisions, within a diverse and transitioning health care system and patient population.
- Engage in reflective practice to promote greater self- awareness and ability to critically



- evaluate one's own practice within end of life care.
- Utilise professional supervision to ensure best practice in end of life care and to meet organisational and professional requirements.

#### **SOME**

As a Chaplain with an additional level of engagement with people with life-limiting conditions you should:

- Participate in family meetings around ethical decision-making for patients and families honouring diverse ethnic, cultural, religious/faith tradition and philosophical world views.
- Demonstrate leadership through advocating for on-going and continuous service development
- Be able to facilitate the discussion and resolution of ethical issues that may arise in palliative care.

#### **FEW**

As a Chaplain working primarily with people with life-limiting conditions you should:

- Demonstrate an understanding of the process of quality improvement in the context of palliative care
- Communicate and advance the distinct contribution of pastoral care to palliative care.
- Demonstrate a commitment to advancing Palliative Care through the generation and application of knowledge and research







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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  $\pm$  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 <a href="http://www.hse.ie/eng/about/who/clinical/natclinprog/palliativecareprogramme/glossary.pdf">http://www.hse.ie/eng/about/who/clinical/natclinprog/palliativecareprogramme/glossary.pdf</a>

#### **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.	
SBN 978-1-906218-79-9	
Health Services Executive National Clinical Programme Palliative Care	