



Glossary of Terms

National Clinical Programme for Palliative Care, Clinical Strategy and Programmes Division

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Introduction

The national clinical programme for palliative care is pleased to present the second edition of the palliative care Glossary of Terms (the palliative care glossary). This document was developed as part of a process to promote clarity and consistency in the way in which we speak about palliative care and the services that are provided to people with palliative care needs. It was developed in consultation with stakeholder advisory groups to the programme.

The diverse membership of the palliative care community provides a rich and vibrant environment in which we strive to continually improve the quality of care that we provide to people with life-limiting conditions and their families. The broad array of characteristics, experiences, backgrounds and perspectives provides a fertile ground for challenging assumptions, testing ideas and broadening our understanding of how we can best meet patient needs. However, in recent years there has been increasing confusion associated with use of palliative care terminology and the meanings attached to certain words.

Communication is a cornerstone of healthcare provision; a lack of consistency in use of terminology can lead to challenges in service development and provision when terms come to represent different things to different people. It is therefore important to stimulate reflection and discussion about current use of terminology and move towards developing common understanding between stakeholders in order to provide a firm basis for dialogue and engagement.

The importance of ongoing review and revision of the glossary is acknowledged and feedback will be essential to this ongoing process. Please send any comments or suggestions for improvement to clinicalprogrammeadmin@rcpi.ie.



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Glossary of Terms

In the interests of clarity, accuracy and consistency, the Palliative Care Programme has adopted the following definitions for use:

A

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 person's condition with loss of capacity to make decisions and communicate these to others (The Scottish Government, 2009).

B

Bereavement:

The term bereavement, takes account of the unique individual grief experience of the bereaved person, through the anticipation of death and the subsequent adjustment to living following the death, of someone significant (Stroebe et al, 2008; Strada, E.A. 2013; Christ et al, 2003).

C

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" (Association for Children with Life Threatening or Terminal Conditions and Their Families and Royal College of Paediatrics and Child Health Child Health, 2003).

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 patient/carer/family (National Institute for Clinical Excellence, 2004).

E

End of Life Care:

End of life care is the term used to describe care that is provided during the period when death is imminent, and life expectancy is limited to a short number of hours or days. The term has been used to describe the last 12 months of life. The clinical programme does not use the term in this way.

F

Family:

A family is defined as those closest to the patient in knowledge, care and affection who are connected through their common biological, legal, cultural, and emotional history.

G

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/education 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 life-limiting illness 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.

H

Hospice Care:

Hospice care is a "term that may be used to describe both a place of care (i.e. institution) and a philosophy of care, which may be applied in a wide range of care settings". The term is often used interchangeably with 'palliative care' (Department of Health & Children, 2001).

L

Life-limiting Condition:

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

- a) is progressive and fatal; and
- b) the progress of which cannot be reversed by treatment.

(The Scottish Parliament, 2010)

M

Most Responsible Physician:

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

P

Palliative Care:

Palliative care is an approach that improves the quality of life of persons 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 patient care;
- offers a support system to help persons live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of persons 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, retrieved on January 9th 2014)

Palliative Care Approach:

The palliative care approach aims to promote both physical and psychosocial well-being. 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 (National Council for Hospice and Specialist Palliative Care Service, 1995).

Palliative Care Competence Framework:

The palliative care competence framework is a document that describes competences required of healthcare professionals who provide care to people with life-limiting conditions.

Palliative Medicine:

Palliative medicine is the appropriate medical care of persons with active, progressive and advanced disease, for whom the prognosis is limited, and the focus of care is the quality of life (National Council for Hospice and Specialist Palliative Care Service, 1995).

Palliative Care Rehabilitation:

Palliative rehabilitation attempts to maximise a patients' ability to function, to promote their independence and to help them adapt to their condition (NICE, 2004).

The focus of palliative rehabilitation is on enhancing function, adaptive coping and independence within progressive disease constraints. Tailoring rehabilitation goals to the stage of the disease, prognosis and personal meaning of quality of life allows for the establishment of realistic, attainable and often short term goal. This is achieved through a multidisciplinary, patient and family centered approach to the provision of rehabilitation care encompassing open communication, continual review and adjustment of therapeutic goals.

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.

S

Specialist Palliative Care Services:

Specialist palliative care services are those services with palliative care as their core speciality and which are provided by an inter-disciplinary team, under the direction of a consultant physician in palliative medicine (Department of Health & Children, 2001).

R

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 (Department of Health, New South Wales, 2010).

U

Unstable:

Unstable is where the person's 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 (Department of Health & Human Services, Tasmania, 2008).

References

Association for Children with Life Threatening or Terminal Conditions and Their Families and Royal College of Paediatrics and Child Health Child Health (2003) *A Guide to the Development of Children's Palliative Care Services* 2nd edn. Retrieved from http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/11895/act_pathway.pdf on January 9th 2014

Christ, G., Bonanno, G., Malkinson, R., Rubin, S. (2003) Bereavement experiences after the death of a child. In Institute of Medicine. *When children die: improving palliative and end of life care for children and their families*. Washington DC, National Academy Press.

College of Physicians and Surgeons of Ontario, (2011) *Professional Responsibilities in Postgraduate Medical Education*. Retrieved from <http://www.cpso.on.ca/policies/policies/default.aspx?ID=1846> on January 9th 2014

Department of Health and Children (2001) *Report of the National Advisory Committee on Palliative Care*. Brunswick Press, Dublin.

Department of Health and Human Service, Tasmania (2008) *Palliative Care Service Delivery Model*. Retrieved from http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0003/37542/DHHS_PC_model_-_explained_22_May_2008.pdf on January 9th 2014.

Department of Health, NSW (2010) Policy Directive *Children and Adolescents - Guidelines for Care in Acute Care Setting*. Retrieved from http://www.health.nsw.gov.au/policies/pd/2010/pdf/PD2010_034.pdf on 9 January 2014

National Council for Hospice and Specialist Palliative Care Services (1995) *Specialist Palliative Care: A Statement of Definitions*. National Council for Hospice and Specialist Palliative Care Services, London.

National Institute for Clinical Excellence (2004) *Guidance on Cancer Services. Improving Supportive and Palliative Care for Adults with Cancer. The Manual*. National Institute for Clinical Excellence. London
Retrieved from <http://www.nice.org.uk/nicemedia/pdf/csgspmanual.pdf> on 9 January 2014.

Palliative Care Australia (2008) *Palliative and End of Life Care. Glossary of Terms*. Retrieved from <http://www.palliativecare.org.au/Portals/46/PCA%20glossary.pdf> on 9 January 2014.

The Scottish Government: Long Term Conditions Collaborative (2009) *Improving Complex Care 3. Introduce advanced/anticipatory care plans*. Retrieved from <http://www.scotland.gov.uk/Publications/2009/03/06140257/4> on 9 January 2014

Strada, E. A. (2013) *Grief and Bereavement in the Adult Palliative Care Setting*. OUP, USA.

Stroebe, M., Hansson, R., Schut, H., Stroebe, W., (eds) (2008) *Handbook of bereavement research and practice: Advances in theory and intervention*. American Psychological Association, Washington.