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# Glossary of Terms

Palliative Care Programme, Clinical Strategy and Programmes Directorate

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Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive



PALLIATIVE  
CARE

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# Introduction

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The Palliative Care Programme is pleased to present the first 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 the stakeholder advisory groups to the Palliative Care 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 and review will be essential to this ongoing process. Please send any comments or suggestions for improvement to Brian Lee, Programme Manager, Palliative Care Programme at [brianlee@rcpi.ie](mailto:brianlee@rcpi.ie).



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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 patient's condition with loss of capacity to make decisions and communicate these to others. <sup>1</sup>

## B

### **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. <sup>2</sup>

## C

### **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. <sup>3</sup>

### **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. <sup>4</sup>

## E

### **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. <sup>5</sup> The discipline of palliative care helps patients to “live until they die” whenever that occurs.<sup>6</sup> 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. <sup>7</sup> 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 patients and their families facing the problems associated with life-threatening illness.*

## F

Family:

In the context of palliative care, the family is defined as any person who is significant to the patient.<sup>8</sup>

## G

### **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 is often used to describe the care offered to patients 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.

## L

### **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. <sup>9</sup>



## M

### **Most Responsible Physician:**

The physician who has final responsibility and is accountable for the medical care of a patient. <sup>10</sup>

## P

### **Palliative Care:**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. <sup>11</sup>

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 patients 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 patients 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 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. <sup>12</sup>

### **Palliative Care Rehabilitation:**

- Helps patients 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. <sup>13</sup>

### **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 patients 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 patient's death. <sup>12</sup>

## **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. <sup>8</sup>

## **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. <sup>14</sup>

## **U**

### **Unstable:**

Unstable is where the patient 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. <sup>15</sup>

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