

Children's Palliative Care: Descriptions and Definitions

"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."

ACT and the Royal College of Paediatrics and Child Health (RCPCN) 1993

The aim of palliative care is to achieve quality of life and a dignified death, preferably in a place of the child and family's choosing. All children with palliative care needs require an individual package of care including variable components of both generic and specialist palliative care provided in a planned, coordinated, timely and flexible manner as directed by need.

Definitions

● Children's palliative care

Children's palliative care 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 whole family and includes the management of distressing symptoms, provision of respite and care from diagnosis through death and bereavement.

● Symptom management

Symptom management is the control of the physical aspects of symptoms combined with attention to the psychosocial and spiritual aspects of symptoms.

● Short breaks/respite care

Short breaks/ Respite care is care where the three main functions are:

- To provide the child or young person an opportunity to enjoy social interaction and leisure facilities.
- To support the family in the care of their child in home or an alternative community environment such as a children's hospice.
- To provide opportunities for siblings to have fun and receive support in their own right.

Short breaks/Respite care may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.

Children's Palliative Care: Descriptions and Definitions (continued)

● Specialist respite care

Specialist respite care refers to a setting of care, a programme of care or a service that provides additional services. It may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist respite care provides the support required to meet the child's holistic care needs and enables children & families to be able access short break services. Specialist respite care will often incidentally address some aspects of symptom management

● Hospice

This term is often used interchangeably to describe a philosophy, a program of care or a site of care. The term is commonly used to refer to an organisation or programme of care that provides, arranges, coordinates and advises on a wide range of clinical and supportive services for dying patients and those close to them.

● Children's Hospice

A children's hospice is an organisation which provides palliative care for a child or young person with a life-limiting condition and their family and aims to meet all needs - physical, emotional, social and spiritual through a range of services including children's palliative care, specialist respite care, terminal and emergency care, 24-hour telephone support, practical help, advice and information and bereavement support for all family members.

● Hospice at Home

Hospice at Home is an integral component of children's palliative care. Hospice at home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment. Hospice at Home works in partnership with parents and families and provides hands-on expert nursing care, on up to a 24-hour basis, along with other elements of palliative care including:

- Emotional, psychological and social support, counselling, and spiritual care.
- Access to specialist colleagues in other disciplines, such as physiotherapy, as required.
- Provision of information, support, education and training where needed to all carers both lay and professional.
- Close collaboration and communication with the primary care team, the child's acute hospital specialists if appropriate, and other agencies.
- Specialist respite care.
- 24 hour End of life care.
- Bereavement support.

● End of life

The phase 'end of life' ends in death. Definition of its beginning is variable according to individual child/young person and professional perspectives. In some cases it may be the child/young person or family who first recognises its beginning. In other cases the principal factor may be the judgement of the health/social care professional/team responsible for the care of the patient.

Children's Palliative Care: Descriptions and Definitions (continued)

● End of life care

End-of-life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition, this includes care during and around the time of death - and immediately afterwards. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

● End of life care services

End of life care services are services to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive and end of life care needs of both child/young person and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.

● Supportive care

Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to support people with life-threatening illness. It is not a response to a particular disease or its stage, but is based on an assumption that people have needs for supportive care from the time that the possibility of a life-threatening condition is raised.

● Care of the dying

Care of the dying is the care of the patient and family in the last hours and days of life. It incorporates four key domains of care, physical, psychological, social and spiritual and supports the family at that time and into bereavement.

● Key working

Key working/care co-ordination is a service, involving two or more agencies that provide disabled children and young people and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels, and a named key worker for the child and their family. Families with disabled children should only have a key worker if they want one. (CCNUK (Care Co-ordination Network UK), 2006

● Complex care/continuing care

Continuing care is a bespoke package of care beyond what is available through core and universal health services. It is provided to children with high levels of complexity or intensity of nursing care needs.

Children's Palliative Care: Descriptions and Definitions (continued)

- **Life-limiting conditions**

Life-limiting conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

- **Life-threatening Conditions**

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as children with cancer. Children in long-term remission or following successful curative treatment are not included.

- **Family**

Family includes informal carers and all those who matter to the patient.