

## Children's palliative care definitions

### Children's palliative care

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

### 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.

### Child

A child is defined as a young person aged up to their 19th birthday.

### Children's hospice services

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services take a holistic approach to care, aiming to meet the needs of both child and family - physical, emotional, social and spiritual - through a range of services. These include:

- 24 hour end of life care.
- Support for the entire family (including siblings, grandparents and the extended family).
- Bereavement support.
- 24 hour access to emergency care.
- Specialist short break care.
- 24 hour telephone support.
- Practical help, advice and information.
- Provision of specialist therapies, including physiotherapy, play and music therapy.
- Provision of information, support, education and training to carers, where needed.

Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose built building.

## Children's palliative care networks

Children's palliative care networks are linked groups of multi-agency professionals and organisations from primary, secondary and tertiary care, social services, education and other statutory and voluntary services working together in a co-ordinated manner. They provide the forum in which:

- Better integrated and more effective commissioning models can be developed and shared.
- Statutory and voluntary agencies will work together to provide an agreed and comprehensive range of services.
- Local needs can be assessed, through mapping of affected children and young people and available services (this would be via children's trust arrangements).
- Skills, knowledge and expertise can be exchanged.
- Local service users can be involved and included in service development.

## Commissioner

A commissioner is a person with responsibility for commissioning services from service providers in either the public, private or voluntary sector.

## Commissioning

Commissioning is the process of improving outcomes and meeting the needs of the population within the local health community with the resources available.

## Complex care/continuing care

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

## End of life

The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health/social care professional or team responsible for the care of the patient, but it is often the child/young person or family who first recognises its beginning.

## 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 child/young person and the 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 and support for the family into bereavement.

## 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 the 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.

## Family

The term 'family' includes parents, other family members involved in the care of the young person, or other carers who are acting in the role of parents. Family includes informal carers and all those who matter to the child/young person.

## Hospice at Home

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, families and other carers.

## Key working

Key working or care co-ordination is a service, involving two or more agencies, that provides 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. (Care Co-ordination Network UK, 2006).

## Life-limiting/life-shortening conditions

Life-limiting /life-shortening 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 cancer. Children in long-term remission or following successful curative treatment are not included.

## Needs-led

Need-led is the term used to describe how services should be provided on the basis of the needs of the patient and family and not as a result of assessing the resources that are available. To deliver a needs-led service it is important to assess and thoroughly understand the needs of the children, young people and families first.

## Parents

The term 'parents' is used to mean any carer for a child whether that is a married or unmarried couple, a single parent, guardian or foster parent.

## Primary care organisation

A primary care organisation is the NHS body responsible for providing primary health services and improving health within a local community through commissioning. Primary care organisations have taken on many of the responsibilities of planning and purchasing health services that were formerly undertaken by health authorities and in addition they can also provide services themselves e.g. Primary care trusts and local health boards.

## Primary healthcare team

A primary healthcare team comprises the general practitioner (GP), practice nurse and community staff (such as community children's nurses or physiotherapists) who work with the practice staff.

## Service level agreement

A service level agreement is an agreement between the commissioner and any organisation providing a service. They specify standards to which the service should be provided, for what sum of money and for how long.

## Short breaks

Short break care has three main functions:

- To provide the child or young person with an opportunity to enjoy social interaction and leisure facilities.
- To support the family in the care of their child in the 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 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.

## Specialist short break care

Specialist short break care refers to a setting of care, a programme of care or a service that provides additional care for highly complex or technology dependent children who may otherwise be excluded from short breaks provided by social care. 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 short break care provides the support required to meet the child's holistic care needs and enables children and families to access short break services. Specialist short breaks will often address some aspects of symptom management. Specialist short breaks should also meet the functions described under general short breaks.

## **Supportive care**

Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to improve the quality of life for people with life-threatening illnesses. It recognises that people need some forms of care that are not directed towards cure from the time that the possibility of a life-threatening condition is raised.

## **Symptom management**

Symptom management is the management of common symptoms associated with life-limiting conditions. It is often used to refer to symptoms that are primarily physical, but in palliative care symptom management also includes attention to psychosocial and spiritual aspects of symptoms where appropriate.

## **Technology dependent children**

Technology dependent children are those who need both a medical device to compensate for the loss of a vital bodily function and substantial and on-going nursing care to avert death or further disability (Kirk and Glendinning 1999; Glendinning et al 2001).

## **Young adult**

The term young adult describes a person from their 19th birthday.

## **Young person**

The term young person describes a person from their 13th – 19th birthday.