

FT/1788: Received – 12th April 2016 Responded – 22nd April 2016

Key words – Services for children with life shortening conditions

Do you commission any of the following services for children with life-shortening conditions between the ages of 0 and 25? If yes, do these services provide care out of hours and at weekends?

- Children's hospice services (yes/no)?
- Emotional and psychological support - including bereavement care (yes/no)?
- Equipment - including wheelchairs (yes/no)?

Definitions:

We define children and young people with life-shortening conditions as those with conditions for which there is no reasonable hope of cure and from which they are expected to die. They may also have conditions for which curative treatment may be feasible but can fail. Children and young people with life-shortening conditions need continuing palliative care throughout the trajectory of their illness.

Life-shortening conditions in children and young people can be defined by the following four categories:

1. Life-shortening conditions for which curative treatment may be feasible but can fail - such as cancer or congenital heart disease.
2. Conditions where premature death is inevitable but where there may be prolonged periods where the child is well - such as Duchenne muscular dystrophy.
3. Progressive conditions without curative treatment options, such as Batten disease.
4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death – such as severe brain injury.

The City of York Council commissions a range of services for children and young people with life-shortening conditions working with Continuing Health Care to jointly fund packages of support. Support may include Hospice services, emotional and psychological support and equipment – provision based on assessed need.