



Deaths in Children with Life-Limiting Conditions

Estimates indicate that there are around 20,000 children and young people in England living with conditions likely to require palliative care. This is based upon a prevalence rate for life-limiting conditions of 16 per 10,000 children aged 28 days to 17 years. It is suggested that each year in a health district of 250,000 people, with a child population of 50,000, there are likely to be eight children and young people who will die from a life-limiting condition (with the possibility of three of these deaths being from cancer, two from heart disease and three from other life-limiting conditions). In addition there will be approximately 60 – 85 children and young people living with a life-limiting condition, about half of whom will require active palliative care at any one time.

Whilst it is to be expected that children with life-limiting conditions will die at some time, it is not always easy to predict when, or in what manner they may die. Professionals responding to the death of a child with a life-limiting condition should ensure that the response to these families is appropriate and supportive, and does not cause them any additional unnecessary distress at a time when they are dealing with the tragic but anticipated, natural death of their child, and that their child's expected death can be dignified and peaceful. The lives of children with life-limiting conditions are as valued and important as those of any other children, and hence the unexpected, unexplained death of a child with a life-limiting condition will be managed so as to determine the cause of death and any contributory factors, as it would in any other unexpected death, out of respect for that child and family, as well as to fulfil any statutory requirements.

Life-Limiting Conditions

Life Limiting conditions are those for which there is no reasonable hope of cure and from which young people are likely to die. They cover a wide spectrum of conditions. Four broad groups may be identified²:

- 1** Life threatening conditions for which treatment may be feasible but can fail, (e.g. cancer, irreversible organ failure of heart, liver, kidney).
- 2** Conditions where premature death is inevitable but where there may be long periods of intense treatment aimed at prolonging life and allowing participation in normal activities (e.g. cystic fibrosis).

- 3** Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. (e.g. Batten's disease, mucopolysaccharidoses, muscular dystrophy)

- 4** Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and the likelihood of premature death (e.g. severe cerebral palsy, multiple disabilities such as following brain or spinal cord injuries).

Palliative Care

Children's palliative care is concerned with the treatment of children with life-limiting or life-threatening conditions. It aims to maintain and improve quality of life, not just in the dying stages, but also in the weeks, months and years before death¹.

Palliative care for children and young people 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 management of distressing symptoms, provision or respite and care through death and bereavement.²

Children's palliative care services are at differing stages of development throughout England – some services are well developed with co-ordinated provision of care, whilst others are still embryonic. Services aim to provide care in the place of choice for the child or young person and their family, and aim to enable the child and family to lead as normal a life as possible, ideally within the home environment.

To enable these services to be planned and delivered in a co-ordinated manner, most areas will have a core palliative care team, with a lead clinician. Children's Community Nursing Teams are key to this provision of care in the community, working alongside the child's hospital team. The core team will work alongside the child's local team of GP, school nurse, teacher, social worker, dietician, play therapist and hospital team, as well as specialists in their condition, who may be based at a distant hospital. At the appropriate stage, this team will help prepare both the child and the family for the child's death, and to support them through the death and afterwards.

¹ *Palliative Care Services for Children and Young People in England; an independent review for the Secretary of Health; Professor Sir Alan Craft and Sue Killen; April 2007*

² *ACT/RCPCH, A Guide to the Development of Children's Palliative Care Services, 2003*

Unexpected Deaths in Children with Life-Limiting Conditions

Some children with a life-limiting condition will die at an expected time, in an expected manner and in the expected place of care of hospital, home or hospice. However, some deaths may occur at an unexpected time or in an unexpected manner. It can be very difficult to 'predict' when a child with a life-limiting condition will die – they may suffer from recurrent severe infections, appear to be dying each time, yet recover again only to then die later from an apparently more minor event. During this stage however, the child and family are likely to be well known to their palliative care and primary care team, who will be aware that the child or young person is now in an end of life phase and is likely to die. The family may have an end-of life care plan, a written summary outlining the child's condition and plans for their death, prepared as part of their anticipatory planning in partnership with the family and their clinical team.

Alongside this, children with life-limiting conditions are also susceptible to all the extrinsic factors that may cause death in other children. They may be even more vulnerable to some circumstances and may die of causes unrelated to their underlying life-limiting condition. It is recognised that disabled children may be more vulnerable to abuse and neglect, and the possibility exists that a young person with a life-limiting condition might try to take their own life. It is therefore important that in all circumstances, consideration is given to the cause of death and any contributory factors, and whether the death fits the expected pattern. In this respect, liaison with child's palliative care and primary care team is essential.

Responding to Unexpected Deaths in Children with Life Limiting Conditions

Where it is recognised that a child or young person has reached an end-of-life stage and is likely to die, plans will have been put in place to enable the family to access support should their child's condition deteriorate. It is therefore possible that one of the child's clinical team will be with the family at the time of the child's death or would have been visiting regularly. In these circumstances, where the death is expected and the cause apparent, the attending doctor should be able to complete a medical certificate of the cause of death, and the multi-agency rapid response will not be triggered. Some families will have agreed plans for the place of care of their child's body after death, some choosing to keep their child's body at home until the funeral, and others choosing to use a 'special bedroom' at their hospice. Whatever the decisions at this time, the family will be supported through their bereavement by the palliative care and primary care team who they know well, and the staff will be supported and offered debriefing.

Where, however, the death appears to occur unexpectedly, but the child is known to have a life-limiting condition, the

first step should be for liaison between the palliative care team, primary care team, and the multi-agency rapid response team to consider: was this death actually expected?

1 If it was expected, then further involvement of the rapid response team would be filtered out at this stage. Ensure that appropriate services are in place to support the family, that practical arrangements are made for issuing the Medical Certificate of the Cause of Death and for registering the death. Referral to the coroner and further investigation into the cause of death will not be needed. Information will be gathered for the purposes of the Child Death Overview Panel, enabling an overview of all deaths of children with life-limiting conditions.



2 If, after liaison between the teams, the death remains unexpected or unexplained, then a multi-agency response as for any other unexpected child death will be required. The palliative care team will need to work sensitively with the family, the coroner, police team, children's social care and other health professionals to provide:

- a. Immediate care in hospital
- b. An initial information sharing and planning meeting
- c. A home visit to review the circumstances of death and provide ongoing support to the family
- d. A post-mortem examination as directed by the coroner
- e. Further checks with all agencies

f. A final case discussion to collate and review all the information, establish the cause of the child's death and any contributory factors, review the previous and ongoing support needs of the family and to provide support and debriefing for the professionals involved.

At all times, whether the death was expected or not, it is essential that the child and family are treated with the utmost respect and sensitivity as they deal with their grief and bereavement at such a tragic time.

Reviewing Deaths in Children with Life-Limiting Conditions

Responding to unexpected deaths in children with life-limiting conditions should therefore ensure sensitive support to the family, a thorough investigation into the causes and circumstances of death, and allow review by the Child Death Overview Panel. This will then provide an opportunity to learn from each of the deaths, to audit factors involved and to improve services and support for families with children with life-limiting conditions.

