

guidance for referral

Richard House accepts children and young people up to the age of 19 years old who have life-limiting, life-threatening or complex health care conditions, living within the Greater London area. Parental/guardian consent is needed before making a referral.



Richard House bases its referral criteria in line with Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT). All referrals need to fit into one of the four groups outlined on page five.

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referral criteria

Life-threatening conditions

These are serious conditions or diseases for which treatment aimed at cure is available. While these children endure distressing and sometimes painful treatment that disrupts normal life for a considerable period of time, a proportion of them will achieve long-term remission. Some examples are cancer and leukaemia that may respond to surgery, chemotherapy, radiotherapy or bone marrow transplant; heart defects that may be corrected with surgery; and kidney, liver or heart disease that may be successfully treated by a transplant.

Life-limiting conditions

These are diseases and conditions for which there can be no hope of cure and from which children will die within a matter of months or, more usually, years. Many of these conditions cause progressive degeneration rendering the child increasingly dependent on parents and carers. Their need for nursing skills and personal care will gradually increase over a period of time until they may require 24-hour care and complex medical procedures.

Complex healthcare conditions

Included in this group of children are those with profound multiple disabilities who have become extremely weak and vulnerable to health complications. This means they have a very poor prognosis and examples include severe cerebral palsy, an acquired brain injury following birth, an accident or a childhood illness. It does not include diabetes, autistic spectrum disorder etc.

referral criteria

Palliative care needs

Palliative care is the alleviation of symptoms of a progressive disease or condition from which a person will not recover. In a strictly clinical sense, the symptoms referred to are physical and will usually require some form of medical intervention. It is now accepted that modern palliative care involves the emotional, psychological, physical and spiritual care of both the child with the illness and their family and carers.

In many children for whom there is no hope of a cure, palliative care may begin at an early point after the initial diagnosis. In others, palliative care may not become the sole form of care until months or years of specialist medical treatment have finally proved unsuccessful. The term 'palliative care' is significant since this is care that is offered when it is acknowledged that a child's illness is likely ultimately to cause death. Thus, palliative care involves the relief of physical, emotional, psychological and spiritual symptoms or distress not only in the sick child themselves but also in their immediate families and carers.

End-of-life care needs

This is the specialised care given when the end of a person's life is imminent. It is usually the time when those around the ill person recognise that life is slipping away and death will happen soon. Special care is taken to make the patient as comfortable and pain free as possible.

It is also important to the child's relatives that the death happens with as much dignity and respect as possible. Those experienced in terminal

referral criteria

care can help relatives prepare for death and ensure that, if at all possible, it is a 'good' death. In children, this final stage is not easy to predict and there is often no recognisable entry into a 'terminal phase'. Children can make remarkable recoveries from what might appear to be imminent death. The terminal phase in a child's life is often measured in days or hours rather than months or weeks.

Reference: Taken from ACT (Association for Children with Life-Threatening or Terminal Conditions and their Families)



referral categories

Category One

Life-threatening conditions for which curative treatment may be feasible, but can fail. Palliative care may be necessary during periods of prognostic uncertainty and when treatment fails. Children in long-term remission or following successful curative treatment are not included.

Examples: Cancer, irreversible organ failure

Category Two

Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible.

Examples: Cystic fibrosis, muscular dystrophy

Category Three

Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.

Example: Batten's disease

Category Four

Conditions with severe neurological disability, which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably but are not usually considered progressive. Additional criteria apply to this group.

Examples: Severe multiple disabilities such as following brain or spinal cord injuries. Includes severe cerebral palsy

Reference: A Guide to the Development of Children's Palliative Care Services

Report of joint working party of: The Association for Children with Life-Threatening or Terminal Conditions and their Familiars and the Royal College of Paediatrics and Child Health. January 1997.

category four

All children's hospices strive to offer equitable acceptance criteria and services to all life-limited and life-threatened young people aged up to 19-years-old living within their geographical catchment area. With this aim in mind, these specific guidelines have been developed to assist the referrers in ensuring appropriate referrals are made within Category Four.

Definition of Category Four conditions

Irreversible, but non-progressive conditions, causing severe disability leading to susceptibility to health complications that are likely to cause premature death.

These include acquired neurodisability such as cerebral palsy, birth injury and those who suffer an insult following illnesses such as meningitis, encephalitis or head injury. Children/young people being referred under this category need to fulfil at least three of the following criteria:

- Total body involvement with poor head control.
- Severe scoliosis that compromises respiratory function.
- Ongoing need for interventions to maintain respirations, for example ventilatory support and O₂ therapy.
- Regular apnoeic episodes.
- Poorly controlled seizures despite optimum treatment.
- Frequent unplanned hospital admissions (please state number of admissions, reason and length of stays).
- Underlying complex nutritional condition, which requires accurate assessment, without which would be life-threatening.



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