



Referral Guidelines for Children and Young People with Epilepsy

Shooting Star Chase children's hospice service aims to offer equitable acceptance criteria and service to all families with a life-limited young person (0-19 years), living within our geographical area.

These guidelines have been developed to assist referrers in ensuring appropriate children and young people are referred to Shooting Star Chase.

Definition of Epilepsy

A group of neurological disorders characterised by recurrent episodes of convulsive seizures, sensory disturbances, abnormal behaviour, loss of consciousness or all of these. Common to all types of epilepsy is an uncontrolled electrical discharge from the nerve cells of the cerebral cortex (Mosby 2002).

Background

Most children who have epilepsy have a normal life expectancy. However, studies have shown that people with epilepsy, including children, have an increased mortality rate compared with the general population (Appleton 2003, WHO 2001).

The reasons for this include:

1. A complication of epilepsy or its treatment (For example, traumatic or burn related injury, drowning, suffocation, aspiration of stomach contents).
2. A consequence of convulsive status epilepticus.
3. As a result of an underlying static or progressive neurological or anatomical cause for death. (For example, cerebral dysgenesis, late infantile neuronal ceroid lipofuscinosis or brain tumour).

However, there are a proportion of young people with epilepsy whose death cannot be adequately explained. The term Sudden Unexpected Death due to Epilepsy (SUDEP) has been identified (Nashef 1997).

Acceptance Criteria

Shooting Star Chase children's hospice service will consider Children/Young People with epilepsy for support if they have one or more of the following criteria present:

- Poor seizure control without/despite optimum Anti Epileptic Drug Therapy
- The young person is under 2 years old (e.g. Severe myoclonic epilepsy of infancy)
- The young person experiences or is at risk of unacceptable side effects from anti-epileptic therapy.
- The young person's epilepsy is a consequence of a Life-limiting condition (e.g. tumours, neurological conditions)
- There is diagnostic doubt as to the nature of the seizures and/or seizure syndrome.
- A Consultant Paediatrician or Neurologist considers the young person to be particularly vulnerable and likely to have a shortened life-expectancy (i.e. unlikely to survive beyond their 19th birthday)

(NICE 2004)

If at a later date through our review process the young person is no longer considered life limited the service Shooting Star CHASE offered will be withdrawn following discussion with the family and referrer.

REFERENCES:

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WHO (World Health Organisation). Epilepsy: aetiology, epidemiology and prognosis (2001) www.who.int/mediacentre/factsheets. (accessed 30/01/2006)

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