

Referral Criteria

November 2023

Contents

1. Introduction

2. General Criteria – including Age and Geography and Map

3. Additional Criteria – Palliative Care only (not Bereavement Care)

3.1. Oncology

3.2. Epilepsy

3.3. Acquired Neurodisability

3.4. Respiratory

3.5. System Failure

3.6. Duchenne Muscular Dystrophy

4. Palliative Care Criteria Diagram

5. Bibliography

1. [Introduction](#)

Shooting Star Children's Hospices is a leading children's hospice charity caring for babies, children and young people with life-limiting conditions, and their families.

Whether lives are measured in days, weeks, months or years, we are here to make every moment count. We support families from diagnosis to end of life and throughout bereavement with a range of nursing, practical, psychosocial, and medical care.

Our bespoke support is free of charge to families and available 365 days a year. Our care service includes overnight short breaks, community nursing, symptom management, end-of-life care, bereavement care and a comprehensive range of therapies and support groups for the whole family.

2. [General Criteria](#)

2.1 [Palliative Care](#)

Young people with a life-limiting condition/diagnosis who are unlikely to reach their 18th birthday.

In order to be accepted babies, children and young people must meet the general criteria above and the age and geography criteria and also the additional condition specific criteria at 3-8 below.

2.2 [Bereavement Support](#)

Any baby, child or young person whose birth has been registered and who has died before their 18th birthday who meets the geography criteria below. *

* At this point in time we are not able to accept referrals for families whose child died by suicide, homicide, or other circumstances where an arrest has been made.

2.3. [Age Criteria](#)

- Aged from pre-birth to 18th birthday. (If a child is referred before birth with a life-limiting condition/diagnosis then if they are "stillborn" the family would be eligible for bereavement support).
- Young people who are 18 years and already receive a service from Shooting Star Children's Hospices can continue to have a service until the day before their 21st birthday as long as they meet criteria at each annual review. Transition work should be in progress. However if the young person is assessed as nearing end of life at this time, then careful consideration should be given as to whether Shooting Star Children's Hospices continue to provide this service.
- Referrals for bereavement support for the family of a child who has died must be made within 18 months of the child's death.

- New referrals for young people aged over 16 years will be assessed sensitively according to life expectancy and needs. Every effort will be made to investigate options for on-going support after 19 years should this be required.

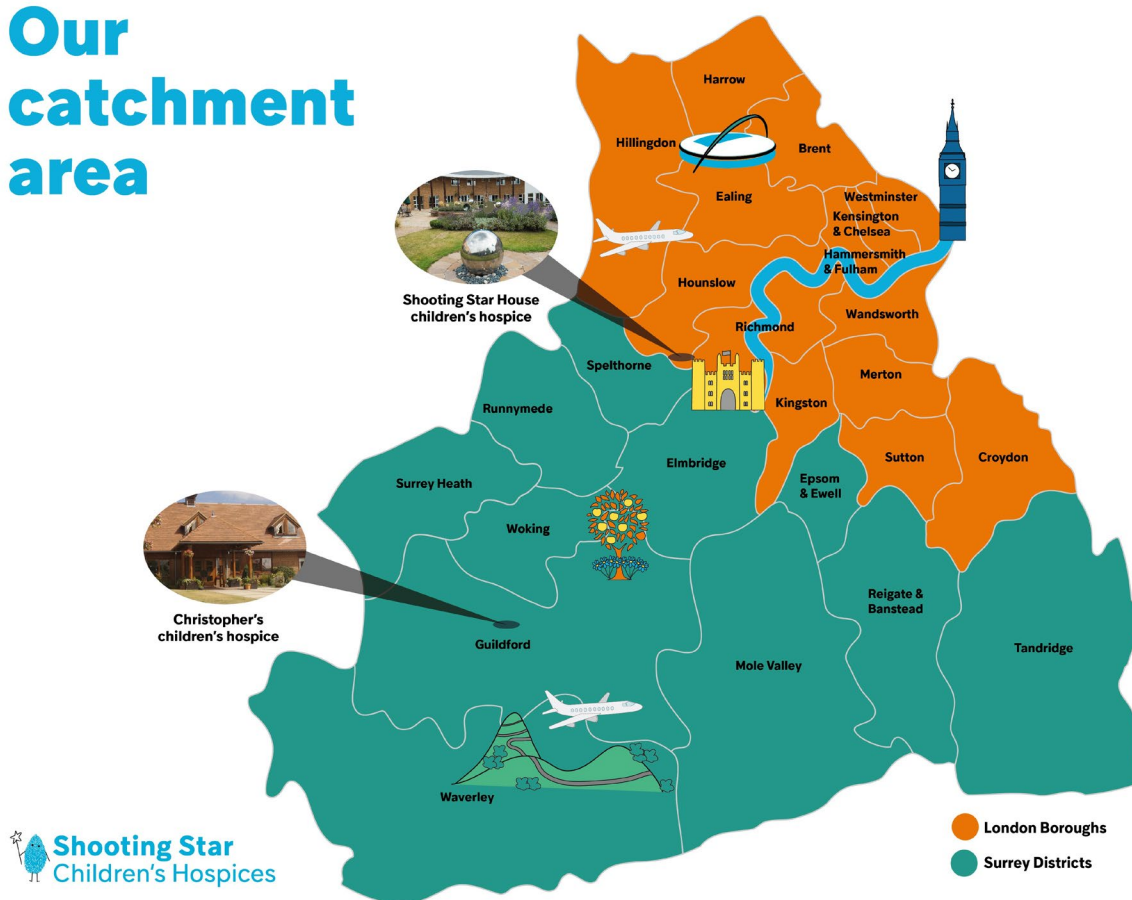
2.4. Geographic Criteria

- Families **must** reside in one of the 14 London Boroughs listed below or the Local Authority area Surrey and registered with a GP practice in one of the 4 ICB areas that we cover listed below
- Bereavement Support only – referral after a child's death. From Nov 23 – Mar 24 we are prioritising families from NW London ICB as a pilot phase.
- If a child does not have access to a Children's hospice facility in their locality and they require end of life care they will automatically be accepted.

• List of Boroughs and ICBs covered:

Hammersmith and Fulham, Kensington and Chelsea, Wandsworth, Westminster, Brent, Croydon, Ealing, Harrow, Hillingdon, Hounslow, Kingston upon Thames, Merton, Richmond upon Thames, Sutton, the County of Surrey

Our catchment area



3. Additional Criteria – Palliative Care only (not Bereavement Care)

3.1. Oncology Criteria

- Any child who has a Palliative or poor prognosis
- Any child who has relapsed and has refractory or recurrent disease including a bone marrow/stem cell transplant. They would then be reviewed 2 years post transplant.
- Any child with a cancer that is known not to be curable at diagnosis

3.2. Epilepsy Criteria

- Complex and/or poorly controlled seizures - or seizure disorder that is life limiting
- A Consultant Paediatrician or Neurologist considers the young person to be unlikely to reach their 18th birthday due to their epilepsy.
- Epilepsy disorder that is considered to be progressive in nature despite no formal diagnosis.
- The young person's epilepsy is a consequence of a life-limiting condition (e.g. tumours, neurological conditions)

3.3. Acquired Neurodisability Criteria

Definition

A non-progressive condition caused by an insult to the brain, acquired in utero, at birth, or some time after birth, resulting in a disorder of posture and movement. This will include young people with Cerebral Palsy, in addition to those who suffer an insult following illness such as meningitis, encephalitis or injury, including near drowning, head injury.

The above acquired neurodisability and any of the following:-

- Vulnerable unsupported airway, eg. Stridor, apnoea, requiring airway repositioning or jaw thrust.
- Severe scoliosis that compromises respiratory function
- Repeated prolonged and severe chest infections requiring intervention/antibiotics
- Ongoing need for oxygen therapy or ventilatory support
- Frequent, unplanned hospital admissions
- Escalating medical interventions
- Neuro-genic gut failure
- Central shut down

Babies and Young Children aged 0-24 months with Acquired Neurodisability

- Since the longer-term prognosis is not always clear for younger children with acquired neuro-disability, Shooting Star Children's Hospices will accept referrals for vulnerable babies and young children, aged 0-24 months with acquired neurodisability, without one the additional criteria. Between 24-36 months they will be reviewed using the above criteria and may be discharged if they do not have one of the additional criteria.

3.4. Respiratory Criteria

- Up to child's 5th birthday any child on ventilation in the community, until they are weaned and stable
- From 5th birthday children on ventilation in the community will be considered on a case by case basis with consideration for progressive respiratory failure.

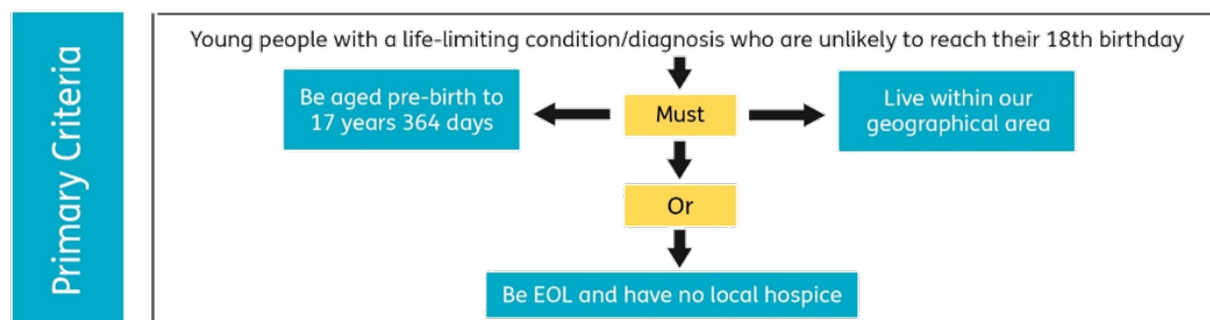
3.5. System Failure

- Any system failure which leads to a life limiting condition ie: System failure before a solid organ transplant; chronic lung disease leading to oxygen dependency; severe gut failure potentially leading to total parenteral nutrition.

3.6. Duchenne Muscular Dystrophy

- This criteria uses the "Stages of disease and care considerations" diagram from "Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and pharmacological and psychosocial management" Bushby et al The Lancet 2009. This is on the next page.
- Children who are at stages 1, 2 and 3 (without additional cardiac symptoms) as confirmed by their neurologist will be accepted onto the service and they and their families will be able to access all therapy and activity groups and the hydrotherapy pool.
- Children who are at Stage 3 and have additional cardiac symptoms and children and young people at stage 4 and 5 as confirmed by their neurologist will be able to access the whole service.

4. Palliative Care Criteria – Diagram (NOT Bereavement Care)



If the young person meets the above and has one of the conditions below, they must also meet the secondary criteria.

Secondary Criteria	Cancer	Does the child/young person have cancer ? If so are they: <ul style="list-style-type: none"> • Palliative/poor prognosis? • Relapsed with refractory or recurrent disease including a bone marrow/stem cell transplant?
	Seizures	Does the child/young person have seizures ? If so are they: <ul style="list-style-type: none"> • Complex, poorly controlled or life-limiting? • Is the disorder progressive in nature, despite no formal diagnosis? • Are the seizures a consequence of a life-limiting condition?
	Acquired neuro-disability	Does the child/young person have acquired neuro-disability ? Do they also have any of the following: <ul style="list-style-type: none"> • Vulnerable unsupported airway, eg. Stridor, apnoea, requiring airway repositioning or jaw thrust? • Severe scoliosis that compromises respiratory function? • Repeated prolonged and severe chest infections requiring intervention/antibiotics? • Ongoing need for oxygen therapy or ventilatory support? • Frequent, unplanned hospital admissions? • Escalating medical interventions? • Neuro-genic gut failure? • Central shut down? • Aged 0-24 months?
	Long term ventilation	Is the child/young person on oxygen/ventilation in the community? Are they: <ul style="list-style-type: none"> • Under 5? • Over 5 (a case by case basis with consideration for progressive respiratory failure)?
	System failure	Does the child/young person have a system failure ? <ul style="list-style-type: none"> • Any system failure which leads to a life-limiting condition i.e. system failure before a solid organ transplant; chronic lung disease leading to oxygen dependency; and/or severe gut failure potentially leading to total parenteral nutrition.
	DMD	Does the child/young person have Duchenne muscular dystrophy (DMD) ? <ul style="list-style-type: none"> • All will be accepted but access to services will be dependant on the stage of the condition.

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