



STANDARD POLICY

Ref: POL/HH/CC/019/02

Referral Criteria (ACT categories 1-4) for Children and Families Attending Haven House for short breaks, day care and respite care from North East London – Redbridge, Waltham Forest, Havering, Barking and Dagenham, under specialist Palliative Care block contract

Care Quality Commission Outcome 1 and 4	Copy Number 001
	Approved <i>Christine Twomey</i>
Summary of Significant Changes Updated Criteria from ACT	

The aim of Haven House Foundation is to provide support to children with life threatening conditions through the provision of short stay breaks; day care, respite and palliative care services. The age range of infants, children and young people is 0-19 years. For planned respite we will endeavour to admit children and young people of similar ages. For emergency admissions where age groups may be mixed, our care areas will be designated age specific. Please read the "Our Services" leaflet which is available in six languages to view the full range of services to children, young people and families.

Process

All families will be offered 20 nights per full year, in year referrals will receive a pro rata allocation. All parents and carers will book their child's admission with care administration and will be expected to attend all appointments. Choice will be offered wherever possible as availability allows.

Author: Christine Twomey
Implementation Date: July 2007
Updated: October 2012
Next Review Date: October 2015
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Emergency care will also be considered on a case by case basis. The criteria for this care include family breakdown and illness of main carer. This could also include safeguarding procedures.

Responsibility

It is the responsibility of The Director of Nursing to ensure that the policy and procedure regarding treatment and care, and access to services is adhered to; and that services are provided which are non-discriminatory, appropriate and timely.

The Director of Nursing will also audit access to services against the admissions criteria. The Director of Nursing will ensure that the care team are appropriately trained in all aspects of assessment across all domains, and skilled in determining when to refer the child and family to other members of the multidisciplinary team external to Haven House or statutory organisations.

Care Team

It is the responsibility of the care team to follow all internal procedures regarding access to services ensuring that access is non-discriminatory, appropriate and timely. They are required to assess the needs of children and carers across all domains prior to accessing services, using reported information and ensuring that on acceptance of referral the multidisciplinary team will be required to provide timely and up to date care and treatment plans. The referrer is always communicated with to explain whether acceptance to our service is deemed appropriate or inappropriate.

Haven House is a nurse led unit and therefore the Nurse Team members must work within the limits of their own clinical competence and seek advice where appropriate. All nurses are registered with the Nursing and Midwifery Council. The unregistered staff work under the supervision of the registered staff. The skill mix is approximately 50:50

The ACT categories of life-limiting and life threatening conditions (criteria for referral to Haven House)

ACT (2009) recognises that four broad groups of life threatening and life limiting conditions may be delineated. Categorisation is not easy and the examples used below are not exclusive.

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Diagnosis is only part of the process: the spectrum of the disease, severity of the disease and the subsequent complications as well as the needs of and the impact on the child and the family, need to be taken into account.

These four categories outline the four types of illness trajectory which will require children's palliative care provision. The categorisation is important for the purpose of planning and needs assessment. The need for palliative care should always be assessed on an individual basis.

Group 1

Life- threatening conditions for which curative treatment may be feasible but can fail

Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of the threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services.

(Examples: cancer, irreversible organ failures of heart, liver or kidney)

Group 2

Conditions where premature death is inevitable

There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities.

(Examples: cystic fibrosis, muscular dystrophy)

Group 3

Progressive conditions without curative treatment options

Treatment is exclusively palliative and may commonly extend over many years.

Examples (: Battens disease, mucopolysaccharidosis)

Group 4

Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death

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(Examples: severe cerebral palsy, neurodegeneration, and multiple disabilities e.g.: following brain or spinal cord injury, complex health needs, high risk of an unpredictable life threatening event or episode.

Additional criteria for children within category 4

Definition of Group 4 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 3 of the following criteria:

- Total body involvement with poor head control
- Severe scoliosis that compromises respiratory function
- Ongoing need for interventions to maintain respirations e.g. ventilatory support, oxygen 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.

Acceptance Criteria

The panel which includes the Director of Nursing, Clinical Nurse Manager and the Palliative Care Consultant will sit once per week and consider all of the referrals against the ACT criteria. Children in Groups 1-4 will automatically be accepted for care at Haven House at Panel. Parent will be offered the opportunity to view the house either in person or online before they choose to take up the service. All referrers have the right to appeal.

Provision of Service

- There is no charge for this service. The age range for children (boys and girls) is 0-19 years
- Haven House offers practical help and emotional support to the whole family, and as no two families are the same, we have the flexibility to respond to the particular needs of mothers, fathers, brothers, sisters, as well as the extended family.

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- The child will not be discriminated against on the grounds of race, colour, ethnic background, or religious belief.
- A member of the nursing staff will assess the child, and the child will be allocated to a team. The care will be tailored to the individual needs of that child.
- Where possible normal home routine will be followed.
- Each child will have an individualised plan of care, as well as a play and activity assessment, which will be fully discussed with the child and parents. Any decisions concerning the child's care will be documented in the care plan.
- The child and family will be fully involved in any decision-making and changes in treatment.
- Siblings with parents will also be allowed to stay and be involved in care.

Referrals to Haven House

A referral to Haven House can be made by:

- The child's GP
- A paediatrician
- Hospital nursing staff
- The child's Community Children's Nurse
- A Social Worker
- Health visitor
- School nurse
- The referral can be made by telephone, fax, e-mail or a written referral. All confidential information will be protected by the Caldicott guidance
- We ask for recent medical information to accompany the referral and that the person making the referral has discussed this with the family.
- The family will then be contacted within 1 week of a decision being made. An assessment visit will then be arranged which either can be held at Haven House or at the child's home.
- We will ask the family's permission to contact their child's GP or hospital consultant in order to obtain medical details.
- The Clinical Nurse Manager at Haven House will also feedback to the person who has made the initial referral with the outcome of the referral meeting.
- All staff will be experienced in assessment skills and in determining appropriate referral routes to alternative health and/or social care agencies, should the referral to Haven House be inappropriate.
- The outcome of the referral meeting will be documented in the child's care plan and also on the referral form.

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- The child's GP will receive a formal letter informing him/her of acceptance for Palliative Care Services.

This referral policy will be made accessible to GP'S in the geographical area, social workers, community children's nurses, school nurses, and health visitors. It will also be made available at the various child development centres and local children's wards in the areas covered by Haven House.

Reference:

ACT, 2009. A Guide to the Development of Palliative Care Services, 3rd Edition. Bristol: ACT

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