

statement of purpose

1. Introduction

Richard House is a purpose built 8 bedded children's hospice, situated in East London, in which children and young people (aged from birth to 19 years) with life limiting, life threatening and very complex health care conditions, and their families can come for short breaks, day care and end of life care.

In addition to this we have a social group for young adults, which can be accessed as a stand alone service for young adults aged 16-25yrs who have a life limiting/ life threatening condition.



Living for today, creating positive memories for tomorrow

picture gallery



Living for today, creating positive memories for tomorrow

2. Name and Address of the registered provider is:

Richard House Children's Hospice
Richard House Drive
London
E16 3RG

3. The registered responsible person is:

Peter Ellis
Chief Executive, BA (Hons) RGN

4. The registered manager is:

Vivienne Oram
Director of Care, RGN, RSCN

Implementation: July 2008

Review: July 2009

Reviewed: Feb 2011

Next review: Feb 2012

Responsibility: Director of care

Approved by: Senior management team

5. Core Purpose, Vision and Mission

Core Purpose

The core purpose of Richard House is to accompany families with children and young people with life-limiting or life-threatening conditions during the child or young person's journey through life to death, creating positive experiences along the way which become good memories for the future.

Vision

Richard House has a vision of a world where every child and young person has access to holistic care and support they need to enable them to live full, ordinary lives.

Mission

Richard House has a mission to work in collaboration with others in our locality to provide holistic care for children and young people with life-threatening conditions or complex health care needs.

To help families choose when, where and how they receive care and to

- provide specialist nursing and medical care;
- short breaks and respite care;
- end of life care;
- family support before and after death.

To support individuals, families and communities of all faiths and none with living, dying and death.

To promote education and understanding of issues to do with living, dying and death

Values

Richard House values are that we:

- put children, young people and families first in everything we do;
- welcome and respect all people;
- are passionate about achieving excellence through continual learning and integrity;
- work in partnership to ensure the best for families and children;
- all contribute towards creating a safe and positive environment;
- be responsive, pro-active and caring in all that we do.

6. Referrals

Richard House accepts children and young people between the ages of 0-19 years who have a life-limiting, life-threatening and very complex health care conditions; living within the greater London area. Referrals can be made by anyone so long as Parental/Guardian consent has been granted prior to making referral.

Richard House bases its referral criteria in line with ACT –The Association for children's Palliative care. A summary of this is outlined below:

■ Life-threatening conditions

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

Also included in this group of children are those with profound multi-disabilities who have become extremely weak and vulnerable to health complications, which mean they have a very poor prognosis.

■ Complex Health Care Conditions

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

■ Palliative Care

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/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 which 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

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 as and pain free as possible. It is important to the child's relatives that the death happens with as much dignity and respect as possible. Those experienced in terminal care can help relatives to prepare for death and to 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)

■ Young Adult Group Referrals

We will accept referrals for young adults aged 16-25yrs with a life limiting/threatening condition solely for the purpose of attending the young adults group. Referrals can be made by anyone including self referral so long as the young adult has given their consent.

7. Services Provided

Any child and young person aged up to 19yrs, accepted to use our services will have access to:

- **Short Breaks** - all families will be eligible to an assessed allocation of pre bookable overnight stays.
- **Day care** - day care is currently offered on an ad hoc basis as and when residential beds have not been allocated, there is no stipulated allocation for day care.
- **Non clinical home based support** - through our service level agreement with The Rainbow Trust.
- **Emergency /crisis stays** - these will take priority over booked residential short breaks and will usually be given to families as additional nights.
- **Bonus nights** - these are available during quieter periods and will be offered to families on a rotational basis as extra nights.
- **Step down care** - from hospital prior to discharge home (additional to 14 nights).
- **Family support** - all families will have access to a full calendar of social events where they can meet other families in similar situations. They will have access to individual counselling sessions as required either from our family support services manager or through therapy students on placement. Siblings will be eligible to access the sibling support group or be allocated a befriender for more individualised one on one support.
- **Post Bereavement Support** - access to a trained bereavement counsellor
- **Health Advocacy service** - where English is not a families' first language Health Advocates will be available through our service level agreement.
- **Bereavement Suite** - access to the use of a bereavement suite for children and families who have used Richard House and also for those who have died at home.
- **Spiritual care** - access to a faith leader of choice is through the Newham Hospital Chaplaincy team, and we hold a service level agreement with Newham Healthcare Trust for this service.

- **Multi-Sensory Room** - this provides stimulation and entertainment in a relaxed atmosphere
- **Messy play area**
- **Computer room**
- **Parents' Accommodation** - we have two self contained family flats where families can come and stay.

Referrals received for the young adults group only will have access to

A monthly social session where they can meet and make friends with other like minded young adults and gain additional support from experienced care staff. All nursing needs can be met during this session by appropriately trained carers and volunteers.

8. Privacy and Dignity

Each child /young person will have an individualised care plan and care staff will recognise the unique wishes of each child/young person and their family and accommodate these into the plan of care.

All details concerning the child/young person and family will always be dealt with in a confidential manner.

The children's/young peoples' notes will be locked away with access only by care staff.

Each child/young person will have its own room and washing facilities.

Care will be carried out in the child's/young person's room or in the treatment room away from other families.

Care and comfort will be given to children/young people who are dying and their death handled with dignity and propriety. Their spiritual needs, rites and functions will always be observed.

The privacy and dignity of the dying child/young person will be maintained at all times and

the body of the child/young person who has died will be handled with dignity and time allowed for family and friends.

The Bereavement Suite at Richard House will offer a quiet place where families can spend time with their child/ young person after death.

When a child / young person dies a rainbow will be placed on the door so that staffs are aware of the death and do not intrude. This allows the family further privacy without interruption.

9. Contact and Visiting arrangements

Parents and other family members are able to contact Richard House at any time during their child / young persons stay. Visiting hours will not be restricted and parents can come and go as they please. The services at Richard House are provided over a 24-hour period and parents of children / young people already known to Richard House are able to ring for advice and support at any time.

10. User involvement

We are committed to providing the best level of care and support to all our users, we are therefore very interested and keen to receive feedback about our services, we endeavour to do this via an annual user feedback survey and by informal feedback through our comments and suggestions boxes which are located in the reception area, communal dining area and residential area. In the event that our standards do not meet users expectations we are very keen that we are made aware of the problem. We take all complaints very seriously and aim to deal with them in a timely and sympathetic manner.

We have a user forum which meets on a monthly basis.

1. Complaints.

■ Verbal complaints

All complaints, wherever possible will be dealt with as soon as possible. In most cases this will be face to face with the individual who has cause for making a complaint.

■ Written Complaints

If the matter cannot be resolved in discussion with the complainant, then the complainant must put their concerns in writing. If the complainant is talking directly with a member of staff (in person or over the telephone), the member of staff must refer the individual to a more senior member of staff if appropriate, who then must take notes of the concerns raised, including the date, time, any other person(s) involved, as well as summary of the complaint itself.

Depending on the seriousness of the complaint and the outcome of the telephone conversation, the senior member of staff, having taken notes from the discussion, must then put this into a letter to the complainant. This will allow the complainant to modify or change the written record of the complaint.

Once the Hospice has received confirmation of a written complaint, the Head of the Department under which the complaint falls, will refer the complaint to the Chief Executive who will decide who should be appointed to lead an investigation. The designated officer chosen to investigate the complaint will then be briefed, and will be allowed access to all staff and volunteers, and any documentation relevant to the matter.

The lead person holding the investigation will provide a written acknowledgment letter to the complainant, within five working days, acknowledging receipt of the complaint and attaching a copy of the complaints procedure.

Where the investigation is still in process after 20 days, a letter explaining the reason for the delay is sent to the complainant.

A full response will be made within 5 days of a conclusion being reached.

The complainant has the right to respond to the complaint once a full explanation has been

offered, and when appropriate, an apology extended. If the complainant is not satisfied with the outcome of the complaint, then he/she has the right to request a further investigation which will be carried out by the next most senior level within Richard House (this may include a member of the Board of Trustee Directors).

If the complainant is not happy with the response and their complaint is regarding the care received at Richard House, you can contact the Care Quality Commission on the number below once the above process is completed:

Care Quality Commission
CQC National Correspondence
PO Box 1258
Newcastle upon Tyne
NE99 5AU

Richard House is a member of the Fundraising Standards Board and if the complaint is about fundraising and the complainant is not happy at the end of the process outlined above, they can register a complaint with the Fundraising Standards Board at www.frsb.org.uk or by phone on 0845 402 5442

Should the complainant feel they have been discriminated against and are not happy at the end of the process outlined above, they can gain advice and support from:

Equality and Human Rights Commission Disability Helpline
FREEPOST MID02164
Stratford upon Avon
CV37 9BR
Telephone: 08457 622 633

Should the complaint be about how Richard House is run and they are not happy at the end of the process outlined above, they can gain advice and support from:

Charity Commission Direct
PO Box 1227
Liverpool
L69 3UG
Telephone: 0845 3000 218

contact us

**Richard House Children's Hospice
Richard House Drive
London**

E16 3RG

Tel: 020 7511 0222

email: info@richardhouse.org.uk

www.richardhouse.org.uk

Registered charity number: 1059029

