

# information for families

Richard House is London's first children's hospice. Situated in East London, it includes a purpose-built building, containing an eight-bed residential area and separate day centre along with family accommodation.



Richard House was established to address a very large need for specialised respite, palliative and end-of-life care, for children and young people aged 0-19 years, living with a life-limiting / life-threatening or complex health care condition within the Greater London boroughs.

Living for today, creating positive memories for tomorrow

# introduction

## **Core Purpose**

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



## **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-limiting, life-threatening conditions or complex healthcare 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.

## **Philosophy of care**

At Richard House, we are committed to providing the best care and services to:

- children and their families, and;
- young people as they gain their independence.

The underpinning values for Richard House provide the foundation for our philosophy of care, and inform how we aim to work with and support children, young people and their families. Our 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;
- will work in partnership to ensure the best for families and children;
- will all contribute towards creating a positive environment;
- will be responsive, pro-active and caring in all that we do.

In line with our values, our philosophy is based on the premise that:

- the child/young person is at the centre of the care and support we offer;
- the parent(s)/guardian are the child's/young person's primary caregiver and source of safety and support – a role that shouldn't change as a result of a life-limiting/life-threatening/complex health care condition;
- young people over the age of 16 years require support to gain their independence.

# care at Richard House

We are very pleased to welcome your family to Richard House and hope you will enjoy your time here.



We specialise in supporting children and young people with life-limiting, life-threatening and complex health care conditions. This support extends to your families and those closely involved with you.

We are guided by your expertise, hopes and wishes in providing the care your child needs. For this reason, it is necessary to ask a range of different questions and collect some quite detailed information about your child and your family.

During your first visit, we will need to learn a lot about you and your family. This is so our care team can provide the best possible care for you and your child.

Care plans will have already been completed. These then need to be checked at every visit to ensure we keep them updated with any changes. This can take up to two hours so please allow for this when arriving with your child.

We provide a range of activities and encourage each child or young person to participate and enjoy the fun. Every child and young person is encouraged to express themselves through art and music or simply rest and relax.

The care team is committed to making your stay with us as enjoyable as possible. If you have any particular wishes let us know and we will do our best to accommodate you.

The care team work 12-hour shifts. At the beginning of each shift there is a “handover” when information is shared about the children and young people we are caring for. This time is important to ensure everyone is aware of the needs of the family and the care required.

### **Arrivals and discharges**

We respectfully request you adhere to the times allocated to you when your booking was confirmed. These times have been allocated to allow for updates and handovers to and from you in order to ensure we have the right information to care for your child safely. If you are going to be late or early please call the care team to let them know, but please be aware that this may result in you having to wait longer than usual as the team may be busy admitting or discharging another child.



### **Personal belongings**

When your child comes to stay they will need to bring enough suitable clothing for their stay. The building can be very warm so your child may require some light clothing such as t-shirts and short pyjamas. They may also require outdoor clothing such as a coat, gloves and a hat. We will endeavour to wash your child's used clothes when they stay overnight.

If you would prefer us not to, please let the team know. Please ensure clothes are named – this will help to avoid items being lost. You do not need to provide bedding, towels or bath toiletries such as bubble bath or shampoo, unless your child prefers to use their own. However, your child will require their toothbrush, toothpaste and deodorant.



If your child requires nappies or pads, you will need to supply enough for their whole stay. If they have a favourite toy or comforter they are welcome to bring it with them. However, we do have a range of toys and activities suitable for all ages and abilities. Please do not send items of value in with your child.

### **Emergency Care**

By law, Richard House is required to have a plan that describes what we do if your child becomes unwell or requires resuscitation while in our care. The plan has to be agreed with you and your child (if appropriate).

If your child/young person is aged 16 years or over, we have a duty to consult with them about their wishes. In some circumstances we may need to involve an independent health advocate.

As a hospice, Richard House does not offer advanced resuscitation measures. However, there is equipment to initiate basic life support, including suctioning, oxygen and the use of an ambubag.

For children who need full resuscitation, the nurses and carers are trained and equipped, to perform basic life support until the ambulance paramedics arrive, and the child is transferred to hospital. If you aren't present with your child, we will contact you as soon as possible.

In the hospice, all staff know where the emergency equipment is located and how to get help from the emergency services.

Where the young person is aged over 18 years and has made an advanced directive, this will be acted upon where the circumstances indicate this to be valid and applicable.

On each visit, the wishes of you (and your child, where appropriate) will be discussed regarding emergency treatment.

### **Consent**

As part of the care plan we will ask you to sign to indicate that you consent to the care team providing the care described in the plan. We will also ask you to consent to your child participating in activities and outings. We do have students on placement at Richard House and we will ask your permission to allow them to participate in your child's care. You have the right to decline to consent to any of these.



## Medications

The medicines children receive during care are usually the continuation of a long-standing medicine regime with which their families are very familiar. When care is provided by Richard House you must provide sufficient amounts of your child's medicines.

Medicines must be in the original containers with the original dispensing labels. By law, staff are unable to give medicines that have been re-labelled or have been decanted into another container. In these circumstances, you will be asked to go home and collect the correctly stored and labelled medication. If replacement medicines cannot be obtained, it is unlikely we will be able to care for your child.

Prior to each care session, a nurse will:

- check your child's medicine history for any updates;
- complete the Medicines Administration Record (MAR), recording all medicines your child is currently receiving;
- clarify who is to take responsibility for the administration of medicines (applicable if you are staying in the family flats);
- confirm which medicines require administration and which have already been administered;
- compare the current medicine regime with the previous one, clarifying any alterations;
- clarify any discrepancy or concerns about the dose or type of medicine.



If your child wishes to self-administer their own medicines and is assessed as competent by Richard House staff, they will be supported to do so. Alternatively, if you choose to stay at the hospice, you will have the choice to continue with the ongoing administration of medicines to your child, if preferred. The medicines will be kept secure in a lockable cabinet in the clinical room. Medicines that

require refrigeration will need to be stored in the hospice drugs refrigerator.

Staff must be advised prior to the care session if your child is receiving homeopathic medicines to assess if they have the appropriate knowledge to administer the medicines safely. Resident families at the hospice must keep their own personal medications in the family flat. If applicable, resident brothers or sisters must have their medication administered by a family member.

### **Equipment**

We only keep a small amount of stock and equipment, it is therefore essential that you bring enough supplies of all equipment to last for the duration of your child's stay. This includes feeds and feeding equipment and syringes for administering medications plus any larger pieces of equipment such as sleep systems, standing frames and suction machines.

## Family accommodation

We have two self-contained family flats for use. Each flat has a double bedroom, a sofa bed in the lounge, and a fully-fitted kitchen. A cot and pay phone are also available in each flat.

Mobile phones may be used within the hospice. Please consider carefully your choice of ring tones and volumes, as they may upset sensitive children.



Your flat will be prepared by a member of our housekeeping team. A welcome pack containing basic essentials will be provided. You are very welcome to supply and cook your own foods in the flat kitchen or if you prefer you can order from the main menu in the dining room. Orders need to be placed by 10.30am. You are welcome to have all your meals in the dining room. You may also bring in a takeaway or go out for a meal, if you prefer. There is a folder in the flats with details of local takeaways. Takeaways will need to be paid for by you.



You may enjoy a glass of wine etc in the privacy of your flat. Please, however, respect the other families staying and the different cultures

and beliefs they may have. Many of the windows have been fitted with child safety locks. These will prevent them from opening more than a few inches. It is important that the windows remain on the safety catch.

If you wish to stay downstairs in your child's room, this can normally be arranged.

Richard House is pleased to welcome siblings to stay and join in activities. We do ask, however, that they give their brother or sister some quiet time at bedtime. During their stay, all siblings remain the responsibility of their parents. For children who are visiting, not resident, we ask that they visit only until 8pm. You may also have visitors but please be respectful of other families staying and we do request that all visitors have left the building by 11pm.

### **Confidentiality**

Richard House regards all information shared with them as confidential. We do work in partnership with other organisations and there may be occasions where it is necessary for us to share information, we will seek your permission to do so. However, Richard House has a duty of care to share information with statutory agencies if there are concerns around the safety or wellbeing of your child.

We also ensure that your child or young person and family are protected from unwanted publicity and media. We will inform you of any media visits to the hospice.

You will also be asked to sign a media consent form. This will provide a record of what publicity, information and media accessibility for which you have given permission.

### **Professional boundaries**

Richard House care staff are required to maintain professional relationships with the children and their families at all times and, therefore, are unable to discuss other children and families with you, accept personal invitations to family events, give families their personal telephone numbers, accept you as a friend on facebook, or accept gifts.

### **Bookings**

All families are offered an assessed amount of pre-bookable respite. We encourage you to book in advance if you have a particular request. To meet each families needs, more beds are available at weekends and during school holidays. Emergency care, however, will always take priority. This may occasionally mean postponing booked short breaks.

### **Security**

To protect the privacy and safety of the children, families, staff and visitors, we feel it is important to have security guidelines. On entering the building you will be asked to sign the register and will be given a visitor's badge to wear. On leaving you will be asked to sign out and return your badge. If you are expecting visitors during your stay please inform a member of the care team.

### **Fire safety**

There are fire notices on the back of the doors in the family flats. Please read and familiarise yourselves with the fire procedures and the fire exits around Richard House. Should the fire alarm sound at any time, please leave the building by the nearest fire exit. Please do not go through the house to find your child or go to your child's bedroom, the team on duty will care for your child.

### **Incidents**

Richard House promotes an open and honest culture for reporting incidents. In the event of an incident such as drug error or an injury involving your child, immediate action will be taken by staff to ensure their safety and medical advice will be sought and acted on. Once your child's safety is assured, we will contact you and fully inform you of the situation.

### **Transfer to hospital**

If your child needs admission to hospital while in our care, they will be transferred to the local hospital by emergency services or taxi. Once the staff have handed over to the paramedic team/hospital team, they assume responsibility for the ongoing delivery of care. It may not be possible for the staff to escort your child to hospital. We will advise you of the situation as soon as possible.

### **Inviting your comments and feedback**

We hope you enjoy your stay at Richard House. We learn how to improve our care by listening to you. We are interested in any feedback you can give us. Your comments and suggestions are welcome either verbally or in writing. We will carry out an annual satisfaction survey; the results of this will be published in our family newsletter.

We also have a family forum which meets every two months; all families are invited to participate.



## **Endings**

A family may end their involvement with Richard House for various reasons, including:

- Your child's illness or condition improves and they no longer meet criteria for our services. This will be discussed with you and services withdrawn over an agreed period.
- Your child requires transitional care to adult services. We will start discussing transition to adult services when your child is approximately 14 years old.
- Your family moves from the area. We will, wherever possible refer you on to another service within the area that you are moving to.
- At any time up to, two years, after the death of your child. Following the death of a child, the family support manager will facilitate the ending of regular support as part of an agreed bereavement plan

## **Complaints**

If you have a complaint, please see the shift lead personally or, if you prefer, you can request to speak to a Team Leader, or write to them. We follow up every complaint and will respond to you with a written answer within 20 working days or sooner.

The Care Quality Commission inspects Richard House regularly to ensure good standards of social and health care are being provided. Our inspection report is an open document and you can ask to see it at any time.

**Contact details Care Quality Commission, Finsbury Tower, 103 – 105 Bunhill Row, London EC1Y8TG.**



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## contact us

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