

# Welcome to Helen & Douglas House



Nathan and his mum rely on  
supportive care from the hospice



Helen & Douglas House

your local children's hospice

## Welcome to Helen & Douglas House

I am writing to welcome you, your child and your family to Helen & Douglas House. Your referral to our service means that you will have access to any of our services that you may find helpful.

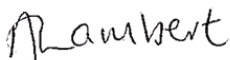
At your child's assessment, the team will discuss with you the possible options and the services that you may wish to use now or in the future. The assessment will usually take place at Helen House but may be at home or in hospital.

At this first meeting we can discuss your and your child's needs and wishes and start to plan the care that you will receive. Not every child who is referred to Helen & Douglas House may wish to use our in-patient service, but our aim is to provide care in the place that you choose.

Due to the Covid-19 pandemic, and the restrictions that this imposes, we are delivering a modified service and there is no indication as to when, if ever, we return to the old "normal". In the meantime, we will adapt our care to the families on our caseload to ensure that everyone has access to the care that is needed.

I hope that this information will help you to get the best from our services and we look forward to getting to know you and your child. Please do not hesitate to contact me and I look forward to meeting you.

Yours sincerely



**Andrea Lambert**  
Director of Clinical Services



# Our services



## Family Support

Provides emotional support, advice, and information for families during your child's life and afterwards, helping families to cope during the more difficult times.



## Sibling Support

Provides the opportunity for siblings during their brother's or sister's life, and afterwards, to help their understanding of what is happening.



## Social Worker

Provides emotional, social and practical support to families.



## Outreach Nursing

Provides specialist advice and support to parents in the community and the multi-disciplinary teams supporting them.



## Bereavement Support

Provides support for individuals / couples whilst you proceed through the grieving process.



## Youth and Transition Worker

Provides additional emotional and/or practical support to our young people with capacity who may be struggling with things, who may be socially isolated, or who just need an extra person to talk to. Once a child has reached their teenage years, help and support are given to the family in preparation for transition into adult services.



## Specialist Paediatric Palliative Medical Team

Provides medical review during supportive stays, specialist symptom management in-house and via outreach, as well as end-of-life care. The medical team is consultant-led and provides 24/7 back up for the service and to our partner organisations.

## In-patient stays

Our aim is to provide excellent care in a homely and comfortable environment whilst ensuring that we meet all necessary clinical safety requirements. Children are admitted to Helen & Douglas House for a number of reasons:



### Assessment stays

This is an opportunity for us to get to know you and you to get to know us.

We ask that a parent is resident for all of this stay as we will be focusing on assessing your child's needs and developing a care plan.

You will spend time with the doctors and nurses, sharing information about how to look after your child. We always ensure that, though hard work, you all enjoy this stay.



### Supportive Stays

There are times when caring for a child with complex needs can be exhausting, or times when parents need that extra bit of support to manage certain aspects of their child's care.

These are stays that are usually booked within the upcoming fortnight but can be booked up to a month in advance. Prior to the admission, the care team will discuss with you the reason for the stay and the outcomes that we would hope to achieve. These stays are generally 2-3 nights.

**NB** These stays are not guaranteed and may be cancelled at short notice if other children require a critical stay.



### Unplanned critical stays

Our aim is to offer nursing and medical support when your child needs it.

We give priority to children who require symptom management, or support during illness. And of course, we are always here for children if they are approaching the end of their lives.

'Hospice' used to be a scary word for us but now it represents safety, friendship, fun and an opportunity to be ourselves while Toby gets the best care and playmates any little boy could ask for'.  
Tim, Helen House parent

# Coming to Helen & Douglas House

If you are coming for a planned stay you will receive a call from one of the members of the care team. During the call we can capture any changes in your child's health or care and we will then send you a copy of the most recent care plan as discussed, so that you can make sure it is correct.

## Visiting the hospice

During the pandemic it is essential that the number of people coming into the hospice is limited. We are regularly reviewing our visiting guidance to ensure that it is the least restrictive that it can be.

Currently, children being admitted for end of life care can be accompanied by close family members, including siblings. Children being admitted for symptom management, or stepped discharge, from hospital may be accompanied by one adult only. In this instance, we will offer alternative options for ways that other family members can visit which may involve meeting in the garden, or by utilising our new teen space.

For those children having supportive stays, we may not always be able to accommodate a resident parent, but this will be decided on an individual basis nearer the time of admission.



## Family Flats

To accommodate members of the family who are staying with us we have two family flats available. These spaces are there to offer a place to relax and recharge, but still only be a few steps away from your child.

Currently the priority for the use of flats is for families whose children are staying in-house for critical stays.



## What to bring for each visit

To ensure that your child's visit goes smoothly, and we can look after them safely, there are a number of essential items that you must bring with them:

- Copies of any recent medical correspondence
- Medication: It is essential that your child has their current medication. We do not have a supply of medication in house. Medicine must be:
  - in date and not expiring during the stay
  - in its original packaging
- Prescribed feeds or any very specialist foods
- Please also provide syringes for medicines and feeds

Please note, if you do not provide any of the above, we may ask you to go home to get these things as we may not have stock/alternatives available.

- Specialist equipment such as feed pumps, saturation monitors, CPAP machine. Always remember the charger. Please note that we will use our own suction machines, as we will not accept one from home due to infection control measures.
- Slings and any other specific moving and handling equipment (even if you don't use them at home)
- Clothes
- Nappies/pads and wipes
- Toiletries and skin creams

And finally, these are the things you can leave at home:

- Towels and flannels
- Bedding
- Food



Please arrive at the agreed time when your child's room will be ready and the correct staff will be available to admit you.

# Things to note about your child's stay

## Food

We'll provide three meals a day for any resident child and family staying with us.

We have two wonderful chefs who will endeavour to meet any dietary needs, but they must be made aware of anything prior to the admission so that they can prepare for this.

If you are just picking up or dropping off your child at a mealtime, then you may also choose to book a meal with us. We want to make each trip as easy as possible for you, however, any requests need to be made the day before, so our care team can inform the kitchen.

**NB: We are unable to provide a blended diet to take home as it is not advised by food safety regulations. We may, however, be able to provide a packet meal.**



## Discharge home

The time and day of discharge is often decided prior to the start of the stay. This enables you and us to make plans. We ask that you adhere to this agreed time unless circumstances have changed. As with admission, it ensures that we have the right staff in place and have time to prepare the rooms for the next child.

If your child's needs or condition changes during admission, we will work with your local team to make sure that everything is in place at home. We will organise for you to go home with any new medicines. We will always write a discharge summary to go to the other healthcare professionals involved in your child's care.

# Things to note about your child's stay. continued.



## Infection control

We are a healthcare facility, regulated by the Care Quality Commission. We adhere to the infection control standards set by the CQC and other regulatory bodies. During this pandemic we will react to all changes in government guidance.

## Safeguarding

We will proactively protect and safeguard the welfare of all those who use the services of Helen & Douglas House. This commitment is underpinned by our safeguarding training statement. We have a safeguarding team who can be contacted at any time. This information is visible across the organisation.

Our safeguarding framework can be found at [www.helenanddouglas.org.uk/about-us/governance](http://www.helenanddouglas.org.uk/about-us/governance).

## Feedback and raising a concern

We welcome any feedback, positive or negative, and we will use this to improve our services to you. If you wish to make a complaint, then our policy can be found on our website.



## Contact us

Should you need to contact us, our phone lines are available day and night.

- Please call our care team on 01865 794 749.
- Or, for less urgent enquiries, email us on [HHKeyholders@helenanddouglas.org.uk](mailto:HHKeyholders@helenanddouglas.org.uk)



## How to find us - please use postcode OX4 1QT

Driving Helen House entrance is via 37 Leopold Street, OX4 1QT. Douglas House entrance (for parking/office only) is via 14a Magdalen Road, OX4 1RW (NB. the entrance on Magdalen Rd is part of a one way system which is entered from Iffley Rd – it becomes two way just past our entrance).

From M40 London: Leave M40 at Junction 8 onto the A40 towards Oxford. Take 2nd exit at roundabout onto London Road signed Headington and City Centre. Carry on straight for about 2 miles until the next roundabout. Take 2nd left onto the Iffley Road; Magdalen Road is approx. ¼ mile on

**Public transport** The nearest railway station is Oxford where taxi and bus facilities are available. For bus, take a No. 5 from outside the station to Blackbird Leys. Get off at the Christian Life Centre (corner of Cowley Rd and Magdalen Rd). Cross the road at the traffic lights and Magdalen Road is in front of you.

Buses from the centre of Oxford leave St Aldates at regular intervals and are No's 1, 5, 10 and 12.



## Your notes

Use this space to write any notes or questions you need to ask about Helen & Douglas House:

'Both physically and emotionally the team have lifted us as parents off the floor, helping us to recover from what life has thrown at us'.



'It is the only place I switch off and just relax. I usually have constant guilt that I am not playing with our daughter enough, but when I am here I don't have that guilt as I am not trying to clean or work out how to get to the shops'.



'We're incredibly proud of the care they give us and the other families that visit'.



Find out more about Helen & Douglas House us at  
[www.helenanddouglas.org.uk](http://www.helenanddouglas.org.uk)  
01865 794 749

  
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