Services available



- An in-patient unit that provides excellent care in a homely and comfortable environment where children may stay for assessment, symptom management, early transfer from hospital or supportive stays. And, of course, we are always here for children if they are approaching the end of their lives.
- Provision of 24-hour telephone nursing advice and support with access to the medical team when a specialist opinion is required.
- Provision of specialist advice and support to parents and other health teams in the community by our Outreach Nursing Team.
- Provision of family support during your child's life and afterwards, helping families to cope during difficult times.
- Sibling support for brothers and sisters to help them understand what is happening.
- Emotional, social and practical support for families from our Social Worker.
- Emotional and/or practical support for young people in their teenage years and in preparation for adult services.
- Bereavement support for individuals and families whilst they proceed through the grieving process.

Helen House opened in 1982 and provides specialist care and support for children and their families in a comfortable and homely environment.

Tel: 01865 794749 (24-hour care team) Email: <u>reception@helenanddouglas.org.uk</u> <u>www.helenanddouglas.org.uk</u>

How to find us: the entrance to Helen House for families and children is Helen House, 37 Leopold Street, Oxford OX4 1QT.



Helen & Douglas House is a registered charity and no payment is requested from families or those who come for treatment, accommodation and care.

Registered Charity No: 1085951

Helen & Douglas House, 14a Magdalen Road, Oxford, OX4 1RW (Registered address)



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How can we help?

Supporting you and your child with their diagnosis of a life-limiting or life-threatening illness

Introduction

This leaflet is designed to help you plan the next phase of care for your child, and support for you and your family.

Living with the implications of a life-limiting, or life-threatening diagnosis can be very daunting and can impact on many aspects of life. At Helen & Douglas House we are here to support you for however long you need.

Who we are and what we do

Helen & Douglas House is a hospice providing care for babies, children and young people aged from birth to 18 years who have life-limiting or life-threatening illnesses.

We can help to manage your child's symptoms and, if needed, offer a range of palliative care services. We provide short supportive breaks for babies and children and, where current restrictions allow, their parents, siblings and other carers.

Members of the team can visit you at home or in hospital to discuss ways we can support you wherever your child is being cared for, in hospital, at Helen House, or at home.

Privacy notice

Your information is held securely and in the strictest confidence. Our privacy notice can be found on our website at www.helenanddouglas.org.uk/privacy

Aliza-May's story



Aliza-May was born in June 2017 with a rare syndrome called Edwards. She spent the first week of her life in hospital and, after multiple tests, was given just 3-6 weeks to live. She was then referred to Helen & Douglas House.

'Our first visit to the hospice was filled with angst and concern. But, once we settled in, it became like our home-from-home. It was a safe place for Aliza-May who went on to live for 10 months, despite her original prognosis. During that time the support and regular respite visits meant we never felt alone with her care and condition and they gave us the chance to do things we hadn't thought possible.

They granted one of our wishes; to be able to swim with Aliza-May in their small therapy pool. This may not seem a lot to many, but we never would have been able to swim with her anywhere else due to her syndrome. During her visits, we had no worries, stresses or concerns because the nurses were there to deal with everything else, whilst our family could just enjoy spending time with our little girl and enjoy the moment.'

Emma-May, Aliza-May's Mum

Amana's story

Amana was born in 2005 and lives in Abingdon with her mum, Tania and younger brother Dilly. Amana has spina-bifida and has been supported by Helen & Douglas House since she was 22 months old. Coming to the hospice means that she can be looked after medically and benefits from their specialist facilities. Amana is also regularly visited by our community nursing team who also help to care for her at home.

'Coming to the hospice means that someone else takes over all of the medical and day-to-day care for Amana for a few days, and I get to be mum. During her visits, she enjoys plenty of



activities and is often found getting creative in the art room or enjoying the therapy pool. During her visits, I can have a break from being her carer and just enjoy time with my daughter. Sometimes, I may also get the rare chance to have some time-out and just relax with my knitting, or even take a holiday.'

Tania's family are very familiar with the hospice as her other daughter, Imogen, who was severely disabled and had complex lifeshortening conditions, was a regular visitor. As Imogen approached the end of her life she came to the hospice for care and was able to spend precious time with her family. When she sadly died in December 2015 the hospice was there to support Tania's family through a difficult time.