

## Caring for children with life shorting illnesses at Helen & Douglas House



*'Mention Helen House and Charlie responds with knock, knock, knock. He remembers the red door. That's his special sign for Helen House...you can go through and you know you are among people who understand.'* - **Charlie's parents.**

### Helen & Douglas House

Helen & Douglas House has led the way in young people's palliative care since Helen House opened as the world's first hospice for children in 1982. Douglas House was opened in 2004 to provide care tailored to the specific needs of teenagers and young adults. We provide respite, emergency, end of life and outreach care for those with life shorting conditions, together with support and friendship for their families. We continue to learn, adapt and lead the field as advances in medical technology and treatments lead to children, teenagers and young adults surviving longer, with incredibly complex, acute and unstable conditions.

Our mission at Helen & Douglas House is to make a difference by:

- Valuing and responding to the joys, hopes and fears of each individual.
- Offering a safe, healing environment.
- Offering practical and professional support, respite and palliative care to the individual and their families.

**Our aim is to help every young person who visits us live life to the full, even when that life is short.**

*'It is just a wonderful place. It gives peace of mind, I don't know how we would cope without it'-  
**Grandparents summing up what Helen & Douglas House means to them and their family.***

### Nursing Care Provided by Helen & Douglas House

A range of nursing care is provided at Helen & Douglas House. We have always offered respite, emergency and end of life care but developments over recent years have led us to also now provide nursing care within the community for those who wished to be cared for in their own home, as well as more acute care in house for the increasing number of those suddenly diagnosed with conditions such as cancer.



Imogen receiving oxygen in her bed at Helen House.

### Respite Care

Providing respite care enables parents and families the chance to take a break for a few days. While the child or young person is staying at either of the houses during a respite stay, we provide personal care, symptom management, as well as being able to take the child or young adult out to do something they wouldn't normally be able to do, such as going to the cinema or bowling. Our patients often have highly complex conditions, with needs that cannot typically be accommodated by other respite centres.

### Emergency Care

The team is equipped to provide specialist care when a child or young adult has a medical emergency. This can prevent a hospital admission or enable a controlled transition from hospital to home in an environment that can accommodate personal and family needs as well as expert medical care. In these acute cases, the young people are too ill to be at home and there is nowhere else they can go to receive this level and breadth of care.

### End-of-life Care

Care at end-of-life is not just for the patient, but for their whole family. It gives the family some control at a time when everything else is spiralling out of control. The team can provide this level of care at the hospice houses or can support someone to die at home if that is what they wish. Each house also has a chilled bedroom and family suite where our nurses can continue to care for patients after they have died, up until the time of the funeral, whilst working closely with our bereavement counselors to support their families.

#### **Community Outreach Case Study**

*A young girl with a complex health condition was supported to stay at home as she became increasingly ill. She had daily visits and phone calls from a member of the Helen House nursing team to offer support to her, her parents and the community nursing team undertaking the bulk of her care. When staffing in Helen House allowed it additional staff went to the home to provide extra respite care and support for the parents.*

#### **Respite Care Case Study: Jack**



*Jack is eight and lives in West Oxfordshire. He has epilepsy and cerebral palsy and has been visiting Helen House since he was two.*

*His Mum, Jane says: "Helen House is a lifeline. When you get there, you are kind of cocooned in a place where everything is just all right. If Jack is in the lounge area having suction or a seizure, it is just all right. Everything is OK. That's for us as parents. For Jack it is somewhere he can go and do something a bit different: he can get away with a few more things than at home and have a bit of naughty time. The biggest difference is, knowing that at the end of the day, there is somewhere we can go, someone who can take over, and that is quite big actually, because there is no-one else at home."*

### Community Outreach Care

We are committed to responding to the needs of patients, whenever and wherever they need us. Over the past year we have identified a need to provide a level of care for some children, teenagers and young adults who would prefer to be in their own homes. As well as providing care within people's homes we are also supporting other community nurses by sharing our knowledge and expertise in the field of young peoples' palliative care. This area of development not only promotes a multi-disciplinary approach to palliative care but has also provided us a defined link to the community.

### **Acute Care Services in Helen House**

Over the past few years there has been a change in the care which we need to provide in Helen House. We are now providing medical care for more children with childhood cancer and cardiac conditions. To meet this need we have worked with the care team to develop their skills and confidence in this area so the best possible support can be provided. The provision of this type of care at Helen House has also led to increased links with other healthcare organisations to raise awareness of the specialist services provided and creation of care plans involving multiple agencies. We hope to be able to develop this area of care further, enabling us to offer the most appropriate support to those who require it.

### **How We Would Use Your Donation**

A donation to Helen & Douglas House would enable us to provide vital care and support. This kind of donation would be very significant to our fundraising programme as it would allow us the flexibility to direct the funds to the areas of nursing care which currently has the greatest need. Without funding like this, we would not be able to provide the services we do and would not be able to support those with life shortening illnesses when they need us most.

With your support we will be able to continue supporting children, young people and their families when they need us most.

**'Imagine children playing in the garden. Children, who can no longer walk, can't talk, eat or breathe on their own. This is their special place.'**

*A parent describing Helen & Douglas House.*