



Shaping future services at Helen & Douglas House

Service users, families and staff provided
the insight for improvement



Summary

Helen & Douglas House commissioned Picker to consult key stakeholders to help understand and develop services going forward. The overall aim of the project was to explore the needs of service users, families and staff to inform the design of care provided by Helen & Douglas House. The key questions explored were:

- What do users think about the environment in which care is delivered?
- How accessible and available are the services offered by Helen & Douglas House, and how well are user needs being met?
- How would users, staff and stakeholders like to see services developed, and what are their suggested changes to support future needs?

Interviews were carried out with patients and their families, and an online survey was used to consult with staff and wider stakeholders.

When parents were asked what mattered most to them about their overall experience of Helen & Douglas House, four key themes emerged throughout the data; Children's experiences, staffing and resources, attitude and demeanour of the staff, clinical confidence and reliability in the service.

Desired improvements included:

- Environment - stakeholders would like more specialised equipment such as beds, designated areas for staff, zoning of age-appropriate areas for the children, more or better designed outdoor space and more clinical space, eg a larger drug room.
- Accessibility and availability of services - Many respondents mentioned the tighter restrictions for dropping-off and picking-up children - including smaller blocks of days and loss of Sunday night stays. They wanted more sensory activities to be available, they highlighted the importance of support for the wider family and raised concerns at the lack of services once children reach 18 years.

When asked what they believe to be the priority area for investment, the majority of staff and stakeholders suggested:

- increased staffing, to help facilitate key aspects of care: more beds to increase respite flexibility and to cope with emergencies,
- therapeutic support for families; and
- more physio and occupational therapy input.

Challenges

Staff and stakeholders acknowledged difficulties in recruiting staff and would like to see more recruitment to enable their services to be extended. They'd also like additional resources such as a liaison nurse shared with Oxford University Hospitals and increased planning to support children with tracheostomies or who need ventilation.

When asked whether Helen & Douglas House would be able to meet their future needs, respondents mentioned three key areas of concern: transition care for teenagers entering adult services, emergency care in the case of progressive symptoms, and specialist equipment.

Helen & Douglas House sits within the city of Oxford and as such has challenges with space. Much of the charm and peacefulness of the hospice is due to its location, within the grounds of a convent. Their external and internal space is limited, so any improvements have to be done without any increase in ground/floor space.

Helen & Douglas House already needs to raise £3.6 million each year to care for children at the hospice. The additional support and services suggested would place a higher financial burden on the charity.

Parents touched upon the fact that children with a life-limiting condition are living for longer due to advances in medical care, therefore highlighting the importance of forward thinking when designing services.

Children's experiences

Staffing and resources

What matters most

Attitude and demeanour of staff

Clinical confidence and reliability in the service



Actions

In response to the suggestions and challenges faced, Helen & Douglas House has:

- Developed a new teen space - This is a modular building, specially designed to give teenagers a place to meet and hang out. It will also be used for young people who need a rest from the activity in the main building.
- Reintroduced part of the admission procedure - They now ask the child and their family what they would like to do during their stay. The chosen activities can be anything from having a spa, going to the ice-cream parlour, playing pool, doing artwork or going to the cinema. This new process enables the children to get the most out of the facilities.
- They have increased their music provision - One of the care team sings and plays her guitar with the children most days.
- They have reintroduced limited Sunday night stays - They now extend booked stays by adding another night to the weekend or have visits starting on a Monday, for one child at a time.
- The booking process and guidance for respite stays has been updated - This should reduce the frequency and impact of cancellations.
- They are recruiting more nurses and care team member at all levels.

Planned Changes

As more budget becomes available, Helen & Douglas House intends to:

- Refurbish the spa room to make it feel more like an oasis.
- Fit folding doors to close off one of the conservatories - This will provide some contained and quiet space for families.
- Refurbish Tree Tops flat - This very large flat is in a more tranquil area of the building. By splitting it into two separate units, they can provide a private and peaceful area for two families.
- They have a full garden redesign planned for 2021 - This will include removing the treehouse to give more space and light and replacing the decking. To decide on the full scope of the redevelopment, they will be consulting with the children and families.
- Purchase an additional "safe space" bed - This will allow them to be more flexible in offering respite to children that need the security of this type of bed.

Planned Impact

One of the key features of Helen & Douglas House is their ability to care for children with complex clinical needs; providing respite for the parents/carers and allowing families to have breaks.

The planned changes that will be carried out as a result of the survey will enable more families to benefit from the support of Helen & Douglas House. The increased flexibility of drop off will allow families to take breaks with their other children, make more use of the facilities when at the House and most importantly, achieve the respite and family time they need.

Testimonial

"Working with Picker on this research has ensured that we develop our services and facilities in the most appropriate way for our visiting families. We've been able to prioritise some quick wins and put longer-term plans in place to ensure the more expensive suggestions can be funded. We're excited to see the difference the changes make to the lives of our families."

Andrea Lambert, Director of Clinical Services



"You know they've dealt with so many poorly children, but they do know tricks that ordinary doctors don't know, so that's been brilliant..."

Parent

"So, going there literally it's all taken away from me and I am just mum and for the other kids as well."

Parent

About Picker

We are a leading international health and social care charity. We carry out research to understand individuals' needs and their experiences of care.

We work with NHS trusts, government bodies, charities, academic institutions, and commercial organisations, and are an approved contractor for the CQC.

Our eight Principles of Person Centred Care provide an internationally renowned quality improvement framework.

The Picker Principles



Fast access to reliable health advice



Effective treatment delivered by trusted professionals



Continuity of care and smooth transitions



Involvement and support for family and carers



Clear information, communication and support for self-care



Involvement in decisions and respect for preferences



Emotional support, empathy and respect



Attention to physical and environmental needs

About Helen & Douglas House

Helen & Douglas House was the world's first children's hospice. They provide hospice and palliative care services to babies and children up to the age of 18. They care for children with life limiting conditions at the hospice and through their outreach services in Oxfordshire and surrounding counties.

Their support services extend to parents, partners, and other family members, from the patient's first stay at Helen & Douglas House through to bereavement. Helen & Douglas House provide short-term respite stays, as well as support with discharge from hospital, symptom and pain management and end of life care.

The charity currently support approximately 150 children and their families, and provides bereavement support to around 75 families.

www.helenanddouglas.org.uk

Picker Institute Europe
Suite 6, Fountain House
1200 Parkway Court
John Smith Drive
Oxford OX4 2JY

+44 (0)1865 208100
picker.org

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