

Autumn 2013



A WORLD FIRST
FOUNDED IN 1982

Helen & Douglas House

news

hospice care for children and young adults

Learn about
the Helen House
refurbishment project –
you could help

Read about why stays at
Helen & Douglas House
make a difference

See how music and play
opens up a world of fun
and communication
*for young people
with life-shortening
conditions*



www.helenanddouglas.org.uk

YOU told us!

Over 400 of you responded to our **Spring Newsletter Survey** in April.

We looked at each and every reply to make sure we're doing the best we can at keeping in touch about what matters to you.

The good news is that **92%** are happy with how often we're talking to you.

We've listened to what you want to hear about, and here are the top three:

- Family stories – see page 6
- Plans for the future – see page 4
- How your donations are used – see pages 8-11

It was also great for us to hear about the different ways you support the families who come to Helen & Douglas House; through donations, the lottery, Christmas cards, volunteering, visiting our shops, in your community, through your workplace, and in memory of loved ones – and many more ways.

A big **Thank You** to everyone for all that you do to help.

More than
400
of you responded
to our **Spring
Newsletter
Survey**



Helen House Refurbishment

Helen House opened as the world's first children's hospice in 1982. Now, over 30 years on, we really need to upgrade the house and improve the space we have, so that we can cope with the growing needs of children with life-shortening conditions. See page 4 for information about our aims, why we plan to do this and how you can help make it happen.

Douglas House fun!

Douglas House guests had an African themed day at the end of June with delicious cakes and biscuits, face painting and drumming workshops, thanks to volunteers Sandie and Freya and PR Officer Bobbie. There was a themed dinner in the evening and volunteer Gill created a floral masterpiece for the dining room. The day probably made quite an impact on our visitors from First Hospice Moscow, who were here to learn about Helen & Douglas House!



Connect with us on social media...

- Follow us on twitter twitter.com/HelenAndDouglas
- Find us on facebook www.facebook.com/HelenAndDouglasHouse

Oxfordshire Business Awards



At an awards ceremony in June, attended by 500 representatives of the county's business elite, **Helen & Douglas House** was named as **Oxfordshire's Charity and Community Organisation of 2013**. We are thrilled to have received this marvellous accolade for the charity. The award is now proudly displayed, next to the Thames Valley Charity of the Year 2012 award, in the glass cabinet in Douglas House reception.

PHOTOS



01 ◀ ANITA WHO VISITS HELEN HOUSE



ANDREW IN THE DOUGLAS HOUSE GARDEN

Helen House Refurbishment...

Our Appeal to You

Helen House has been a place of **respite, care** and **support** for thousands of families, since it opened in **1982** as the **world's first children's hospice**.

Now, over 30 years on, we have the opportunity to upgrade Helen House and improve the space we have, so that we can look forward to the future, responding to the growing needs of children with life-shortening conditions.

We have received some money from the Department of Health that will allow us to carry out some of the work that is needed, but with your help we could do even more for the families who rely on us for specialist care.

We would like to make the following improvements:

- A more welcoming and spacious reception area for children, their families and equipment.
- Better use of play and holistic therapy areas, so that children and their families can make the most of their time together here.
- Refurbish the kitchen so it can better deal with the demands of providing all day food and drinks for families.
- Improve the 'flow' between bedrooms, bathrooms and family areas, for easier accessibility with large beds and wheelchairs.
- 'Plumbed in' oxygen available in all children's rooms.

NEW RECEPTION

IMPROVED THERAPY AREAS

HELEN HOUSE
REFURBISHMENT

HELEN HOUSE
REFURBISHMENT

UPGRADED KITCHEN

SPACE FOR EQUIPMENT



Here **Kathy Patching**, House Manager, Helen House, explains why we need the refurbishment.

'When Helen House opened over thirty years ago I don't suppose anyone would have guessed how advancements in medicine and technology would impact on the lives of children and young people with life-shortening conditions and their families. Many young people who wouldn't have survived past their mid-teens, even as recently as 10 years ago, are now living until their mid to late twenties and quite feasibly within the next ten years they will be living even longer. This is an incredible advancement, but it does mean that young people living longer have increasingly complex conditions and needs and are physically bigger. They need larger specialist equipment and more of it. They need space and we need space to be able to offer them the best care possible.'

Liz Leigh, Deputy Director of Clinical Services, Helen & Douglas House adds; *'Over the years Helen House has adapted and made the best use of the hospice that was built over thirty years ago, but we can't expand the existing walls and we cannot find space we haven't got! By refurbishing Helen House we can create an environment that makes the stays of children and their families that much more comfortable and we can make sure that we are providing an environment suited to modern needs and the young people and their families.'*

How will it happen?

It is planned that Helen House will be closed for the refurbishment, which should take 6 months. During this time children needing respite, emergency and end-of-life care will be looked after in a designated part of Douglas House, just across the garden from Helen House.

will you join in...

...and help improve the facilities for children with life-shortening conditions and their families?

We are hoping to raise further funding to complete the full refurbishment.

Your support of the refurbishment will make a huge difference to the care we can offer the children and families who need it now and the thousands of those who will need it in the future.

Would you like to help?

Received this newsletter by post?
Please use enclosed donation form.

You can also make a donation (and follow our appeal and the refurbishment) on www.helenanddouglas.org.uk. Or contact the Fundraising Team T: 01865 799150 E: fundraising@helenanddouglas.org.uk

PLUMBED IN OXYGEN

...THANK YOU!



FAMILY MATTERS

'You have to acknowledge that you are different from other people, but you just want to continue with your daily life as everyone else does really.'

'You're very much living with other people's structures. So that's what's great about university and coming to Douglas House. I have choice over what time I get up and go to bed.'

Josh is 19 years old and has just finished his first year of a politics degree at the University of Surrey in Guildford. His home

is in Buckinghamshire, where he lives with his mum Jane, sister Ella and brother Thomas. Sadly his dad Robert died 10 years ago.

He has Duchenne muscular dystrophy and is dependent on a wheelchair. He knows he has a progressive condition and how it affects other lads, but at the moment he is healthy and he feels his family are key to him feeling 'normal'.

'It's a good place to get respite care and let the family have a rest. You know you're going to be looked after well here, so everyone can be reassured.'

'I'm very fortunate actually, as I have a very supportive family who get me involved with as many things as possible. They don't really treat me any differently than anyone else in the family. That's the way I like it. I have a stair lift so I can sleep upstairs with the family and that's what I really value. You have to acknowledge that you are different from other people, but you just want to continue with your daily life as everyone else does really.'

Josh began visiting Helen House in 2004 when he was 10 years old. *'I stayed with my family the first time because things were quite new. I hadn't really stayed away from home much and never really been cared after in that sort of, how can I put it, in an institutionalized way.'*

Two years ago he made the transition to Douglas House. *'It was nice to get away from the childlike environment of Helen House. I'm not really nervous about meeting new people, so it wasn't so bad.'*

'It's a good place to get respite care and let the family have a rest. You know you're going to be looked after well here, so everyone can be reassured. My mum can have a break from looking after me, as it can be quite stressful looking after a disabled person.'

'It's somewhere to come for a bit of respite care and then go back home; everyone is a bit more refreshed and then can get on with each other better.'

At University and Douglas House Josh has a room designed for a person with disability. Because he has a carer he is free to choose what time he gets up, but at home this is not so easy.

'When I am at home Mum will get me up, but she has to get up a little bit earlier to get things ready for me. You're not like other people. You're very much living with other people's structures. So that's what's great about university and Douglas House. I have choice over what time I get up and go to bed.'

Josh loves debating and has joined the politics and debating society at university, but says it is difficult to be part of group activities, especially at home.

'At Douglas House I will often go with a carer into Oxford, to the cinema, museums, or Christchurch Meadows. They also have group activities that you can't do at home; things like the African day, The American gangster evening and the Murder Mystery. Although my disability doesn't play an awfully big part in my life, when I come here it's nice to dip into that other scene; where there are people like you and if you need to you can reach out to them.'

'The best thing about Douglas House is the friendly environment and getting involved with the activities. I had a brilliant time on my last two visits.'

Why you make a difference...

The money **our supporters** donate to the charity helps us to run both hospice houses and provide the **specialist care** and support for the families who rely on our services. Everything from paying for **specialist doctors** and **nurses**, to providing

a **family support** and **bereavement service**, to keeping the place clean and safe and buying specialist equipment. Here we tell you about a **very important** part of the **holistic care** we can offer, only because of **people like you**.



'Play can be a really lovely way of bringing a family together. Doing something really positive around a really horrible situation and seeing the effect the memories have on the families is so heart-warming and you can't put a price on that at all, it means so much to them.'

Our Play Specialist Sarah's role involves using play to create experiences and opportunities suited to each individual child.

Sarah said; *'This lad with Duchene muscular dystrophy really liked painting, but had lost so much of his finer motor skills. So, we used syringes to paint and squirted it over big pieces of wallpaper to make amazing patterns. 'Messy play' was a good way for him to experience new sights, smells and textures.'*

'Another example is; the other day we did some cooking and hooked up the blender to a switch button. The children were able to operate the blender instead of us stirring and them holding the bowl. They loved it.'

Sarah also organises activities for the whole family. *'I remember one week there were 3 siblings whose brother or sister had died. They were all similar ages and going through the same thing, so doing the activities and being engaged in other things gave them the opportunity to open up and start talking. They were just the best support and therapy for each other, because they knew exactly what the other was going through.'*



A play session costs £16

'Memory making is another thing we do with the families; they do a lot of hand and footprints and fingerprint jewellery. It's a really lovely way of bringing the family together and doing something really positive around a really horrible situation.'



'Music has the capacity to draw out responses when all other means of communication have gone. It provides the most powerful means of communication and interaction possible, bridging the language barrier.'

Music therapy plays a very important part of the holistic care for families. The Music Therapist works with children and their families. Music Therapist Ceridwen explains here what a difference it makes to the children and families she works with.

'Music therapy offers children and their families a chance to communicate and express themselves through music. The role of the therapist is to support them in this process using a combination of singing, playing and listening. There is no set agenda, and so every session is unique to each child, and different children draw different things from our time together. Music also allows them to focus on something other than their condition.'



A music session costs £30

'Music has the potential to reach out to any child. It can touch them at a very deep level.'

'Sometimes the whole family is involved. The point of music therapy is to see what the child can still do, rather than what they can no longer do. I remember a little boy who came in for end-of-life care. His mum really wanted him to have some music therapy. They came in and at the point I was strumming on the guitar, he opened his eyes and smiled. His mum said it was then she knew he was still with her.'

'The best bit of music is singing, because it fills my lungs up with joy and I really enjoy it.'



Ellie, who visits Helen House



Charlie, who used to visit Helen & Douglas House



Sian, who visits Helen House

Ellie

Ellie visits Helen House. Her mum, Denise, explained what music therapy means to her daughter;

'Ellie loves her music therapy sessions. She uses her hands independently, which she finds difficult, as she wants to play the chimes. She smiles, giggles and vocalises to join in with the songs.'

Charlotte

Charlotte (Charlie) came to Helen House as a child and later Douglas House. Sadly she died aged 18 in March of this year. Here her mum Sue tells us about the impact music therapy had on Charlie and the family.

'Charlotte enjoyed all types of music; she came alive and it seemed to give her extra breath. Although she had difficulty with her breathing she could always sing.'

'Music was a way for Charlie to express her feelings without fear and take a more active role at school. It was music therapy and Helen House that gave her an outlet for this. She was able to express anger and the fact that she often felt invisible. She used the words 'help me' in her music. She was allowed to 'play around' with music and was encouraged to explore and experiment. She didn't really get the chance to do that in any other way.'

Whenever we were in Helen House and there were 'music for all' sessions we all took part. We would be in the garden banging on tambourines! It was the best thing for Adam

(Charlie's brother). He had 1-1 sessions with the music therapist and sometimes group sessions, right from the start.'

Charlie's favourite musical was 'Les Miserables'. The Music Therapist at Helen House brought the music to the hospital when Charlie was in a coma.'

Sian

When Sian stays at Helen House she has music therapy and she loves playing the piano and singing. She says; *'I sometimes play on the piano. I did a performance for everyone of 'Twinkle Twinkle'. I'd only just learned to play.'*

The music making she enjoys best is singing and for very important reasons. Sian has congenital heart disease, high pressure in her

lungs and a ventricular septal defect (VSD) with pulmonary atresia. This means she is on oxygen for at least 12 hours-a-day and needs lots of medication. Breathing can be difficult for her, but singing helps with this.

She said; *'The best bit of music is singing, because it fills my lungs up with joy and I really enjoy it.'*

The Helen & Douglas House carol service is on **Sunday, 15th December** at 4pm at the Wesley Memorial Chapel, New Inn Hall Street in the centre of Oxford (OX1 2DH).

CHRISTMAS CAROL SERVICE

For more information please contact our Chaplain, **Stephen Harrison**
E: sharrison@helenanddouglas.org.uk



Help bring some festive cheer to the heart of Oxford!

This will be the **seventh** Helen & Douglas House **Santa Run** – and we hope to make this year's the **biggest** and **best** yet!

Since 2007, **7,000** people have donned a red Santa suit to take part in our fun run and for many it has become part of their Christmas calendar and marks the start of the festive period. So far the event has raised an amazing **£309,000**. This has really helped us towards providing specialist care and support for children, young adults and their families.

'This festive themed run is suitable for all the family, is just amazing so close to Christmas and is for such a good cause!'

Kate, who has taken part every year

The sight of **1,500** people dressed as Santa taking over Oxford city centre is one to behold – from teams of friends, families and colleagues, to groups of students and Helen & Douglas House families. The Santa Run appeals to the young and the young at heart alike!

Hannah, who took part in 2012, had this to say about her experience; *'The Santa Run was really good fun. It was amazing to see hundreds of people dressed up as Santa and it was such a great atmosphere! It's so lovely to see everyone out to support such a great cause; from 2 year old Santas to 70 year old Santas! It's a really brilliant community event!'*

Registration will open in early October via our website www.helenanddouglas.org.uk. Be sure to sign-up early to secure your red suit!

For more information contact the Fundraising Team
T: 01865 799150
E: fundraising@helenanddouglas.org.uk

Cooking up a storm of support!

CORPORATE MATTERS

Economics consultancy and long-term supporters, Oxera, have been busy raising money for us through a cookbook called 'We Love Food', which features recipes submitted by guests and staff at Helen & Douglas House.

The decision to create the book came from a Dragons' Den-style Team Day, run by Helen & Douglas House. On the day, Oxera staff pitched their fundraising ideas to the 'dragons' to win the investment needed to bring their concept to life. The team behind the winning recipe book idea were then given a target of **6 months** to raise a minimum of **£5,000**.

A bake-off at Douglas House back in February saw guests like Fleur (pictured) baking her 'fancy plum and almond smiling cupcakes', to be taste tested by local cake baker and decorator Tracey Mann and acting compère, Oxera's Alison Gomm. Oxera helped make the event happen by sponsoring the cost of the ovens needed for the bake off and the guests' recipes then went on to feature in the recipe book.



Since the book was launched in April, Oxera have managed to raise a whopping **£8,700** through book sales and other fundraising activities, including a coffee morning and an auction at the North Oxford Golf Club.

'The icing on the cake'

Not only did the team smash their target to raise vital funds for the hospice, they also raised awareness of **Helen & Douglas House** in the local business community. Future book sales will continue to boost invaluable donations for the hospice too!

Thank you to our friends at Oxera for your hard work and dedication to this exciting project, as well as many other local businesses who contributed through sponsorship, or donating their time and expertise. We have loved working with you all!



For a copy of the cookbook, priced at **£5 each**, please contact the Fundraising Team **T: 01865 799150**

ACTIVITIES & EVENTS

TAKE UP ONE OF OUR CHARITY PLACES IN THIS ICONIC EVENT

When: Sunday 13th April 2014 **Where:** Central London



VIRGIN LONDON MARATHON

***** Take part in the Virgin London Marathon – one of the world's most iconic runs – in aid of Helen & Douglas House. It takes place in central London and you will run by all the major landmarks, whilst being cheered on by crowds of spectators. The atmosphere is spectacular and you'll feel a part of something very special.

THROUGHOUT THE YEAR

Tea at 3

Support Helen & Douglas House by hosting a tea party! Wherever you are - at home, in the office, at school, in church - put the kettle on, bake a cake, open the biscuits and ask your guests to make a donation. You can host your 'Tea at Three' any time or anyplace, it's up to you! Get in touch with us to request your 'Tea at Three' pack.



route will give runners a glimpse of the Mini Plant, as well as the stunning Christ Church Meadows.

Keen to get involved with this event but not on running?

You can volunteer! As the partner charity for the event we need people to help out on the day – things like manning water stations, giving out medals and goody bags. Get in touch if you're interested.

MARCH 2014

SUNDAY 2ND

Silverstone Half Marathon

A fantastic opportunity to follow the tracks of the world's greatest racing drivers. If this is your first marathon, the flat circuit of Silverstone is perfect!



OCTOBER 2013

SUNDAY 13TH

Oxford Half Marathon

Join the Helen & Douglas House team for this run through the historic heart of Oxford. The unique

ACTIVITIES & EVENTS

JOIN US ON A ONCE IN A LIFETIME EXCLUSIVE TRIP TO VIETNAM

When: Thursday 16th To Saturday 25th October 2014 **Where:** Vietnam



VIETNAM TREK & COMMUNITY PROJECT

***** This trip to Vietnam is exclusively for hospice charities, so join us to support Helen & Douglas House. You will experience traditional minority tribes, mountain passes, breathtaking views and being involved in a community project. For those of you seeking the challenge of a lifetime, Vietnam will leave you with memories that last forever.

APRIL 2014

* VIRGIN LONDON MARATHON

See top left page for details

We have a number of charity places in the 2014 London Marathon.

Our ballot will be drawn shortly after the results of the public ballot are released in October.

MAY 2014

FRIDAY 16TH TO SUNDAY 18TH

Ten Peaks Challenge

This challenging one day trek in the Lake District takes in England's tallest mountain Scafell Pike and the surrounding nine peaks. We begin at Buttermere and finish at the equally beautiful Langdale.

JULY 2014

WEDNESDAY 2ND TO SUNDAY 6TH

London to Paris Cycle Ride

Cycle 300 miles, over four days, between two of the world's most chic capital cities! The route passes through lovely English villages and the stunning countryside of rural France, ending at the spectacular Eiffel Tower.



OCTOBER 2014

* VIETNAM TREK & COMMUNITY PROJECT

See above for details





Thank
you...

Jack,
who visits
Helen House

- » We care for children, young people and their families from **Berkshire, Buckinghamshire, Gloucestershire, Northamptonshire, Oxfordshire, Warwickshire, Wiltshire** and parts of **London**.
- » The charity has to raise **£5 million** every year to run the two hospice houses. We rely on **people like you** across our region to raise **over 80%** of this amount.
- » **Thank you** to all individuals, schools, colleges, groups, businesses and Trusts for your amazing support. We sincerely appreciate your time, donations and fundraising activities that enable us to do the work we do.

Connect with us on **social media**...

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twitter.com/HelenAndDouglas

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About this newsletter

- Could you receive this newsletter by email and cut our costs? Please also let us know of any changes to your postal or email address. Contact Lin Beekar [E: lbeekar@helenanddouglas.org.uk](mailto:lbeekar@helenanddouglas.org.uk)
- The newsletter is also available as a downloadable PDF on our website www.helenanddouglas.org.uk
- **Photo credits:** Front and back cover – Kate Raworth.
- With many thanks to all the families, young people, staff, volunteers and supporters who appear in this newsletter.

Design: Chris Woodrow design@chris-woodrow.co.uk

A Lasting Legacy

Did you know that the equivalent of 1-in-5 of young people and their families we care for are funded by gifts in Wills?

Legacies are absolutely crucial to us. Without them we just wouldn't be able to help as many families as we do. We would therefore like to say a big thank you to the solicitors who participated in Free Will Writing Fortnight back in April, and also to those who included us in their wills, or made generous donations.

We are planning to repeat this offer in spring 2014. For further information about this, or any queries you have about leaving us a gift in your will, please contact Kim Hall **E:** khall@helenanddouglas.org.uk **T:** 01865 799150.

Contact us

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