



Dean: "I'd come here more often if I could. Your link with the nurses is closer. We go shopping, to the cinema, that sort of thing. I don't really associate it with hospitals. It's more like a hotel."

A first from Oxford

There are high achievers aplenty in the city of dreaming spires and bright young things, but in the suburbs something very special is being accomplished. **Andrew Bence** visits Douglas House



“He came to us in January. Eight years earlier a car accident had left him with locked-in syndrome. Fully aware but completely immobile, he was only able to communicate by the flicking of his eyelids. It was the stuff of nightmares. And for the first time in eight years his mother was entrusting his care to others. She left the building in the arms of her daughter, sobbing.”

Liz Cornish, Head of Care at Douglas House finishes her story. It's my turn to speak but I don't know what to say. “What's great,” she adds, “is that the charity, SpecialEffect, is working with us to part-fund an IT post that will allow us to develop gaze control for some of our computers”. →

That optimism is telling. Against all the odds, Helen and Douglas House are bright and positive places, where the emphasis is on living life to the full, even when that life may be short. Helen House, which opened in 1982, was the world's first children's hospice. It stands in the grounds of All Saints Convent, just off the surprisingly funky Cowley Road to the east of the city. In 2003 it was joined by Douglas House, the focus of my visit today and the world's first hospice dedicated to providing respite and end of life care for young adults aged 18 to 35. The founder and inspiration for this Oxford double first, Sister Frances Dominica, is in the lounge with Director of Clinical Services Clare Edwards, waiting to talk with me just as soon as Liz has finished the tour.

There are facilities that I expect to see (sensory room, a games room) and some I don't (the bar, the music room, a beauty parlour). The building is spacious, the décor warm and stylish. At a discreet distance (upstairs) there is equally comfortable accommodation for families. At first glance, the only thing acute about this place is the care with which it has been designed, its clinical requirements subtly incorporated.

At the heart of the building, just along from the jacuzzi, is a simply furnished, air-conditioned bedroom and side room. The Starfish room is where the body of a young person who has died is placed, and where bereavement can begin. "Families need the privacy, time and permission to do the things they want to do, the way they want to do

them," says Liz. "Many bring a quilt covering, their own pictures and photographs to hang on the wall, whatever feels right."

In another quiet room Jo is giving Stephanie a hand massage with essential oils. Jo tells me she used to do her nursing at the Radcliffe Infirmary, but it gave her little chance to practise her clinical aromatherapy skills. Stephanie, who has profound and multiple learning and physical disability, appears to be enjoying the attention. "For a lot of our guests," says Jo, "care usually amounts to lots of manual handling for clinical reasons. Hand-holding therapeutic touch is an important experience that many of them lose in the transition to adulthood."

This observation weighs heavier the longer you ponder it. Especially when you hear that Stephanie was a normal, healthy little girl until, aged 10, a devastating disease of the nervous system began to kick in. "Even now we can't be sure how much she understands," says Jo, between her reassuring words to Stephanie.

Not all young people with life-shortening conditions (the criteria for Douglas House) are like Stephanie, or the young man Liz was telling me about. Everyone's condition is unique, every person's challenges different. Tom Hill, Chief Executive, tells me, "We've realised in these early years that there are many issues to be addressed here, not least those of special importance to young adults: what we jocularly refer to as 'sex and drugs and rock n roll'."



"There are many issues to address, not least those things of special importance to young people – 'sex and drugs and rock n roll'"

In conversation

With Sister Frances Dominica, founder of Helen and Douglas House, Clare Edwards, Director of Clinical Services, and Liz Cornish, Head of Care

Opening Douglas House in 2003 must have been a huge undertaking. What made you do it?

Frances: When we began Helen House, back in the early 1980s, boys with muscular dystrophy were dying in their early teens, cystic fibrosis had a much poorer prognosis, there were no gastrostomies for those with genetic conditions. The group we have here today would not have survived into adulthood. But over the years we heard stories that troubled us, such as the 13-year-old girl with Batten's disease who was offered unaccompanied respite care in a psycho-geriatric ward. Sadly, even today, some people believe that if a person is cognitively impaired then it doesn't matter where you put them. By opening Douglas House we hoped to address the needs of this older age group.

After many years of being funded entirely by charitable donations, you now accept some state funding. What made you decide to do this?

Frances: It's a double-edged sword because the more you get from statutory sources the more they are going to call the tune. But after much debate we decided to accept a small contribution towards Douglas House because we were so incensed that at age 19 the county adjudged that there were just two young people requiring respite care – two in the whole county! By your twenties your paediatrician is unlikely still to be your doctor, yet they may have been a very important person in your life. Suddenly you are divided into your parts and whichever bit doesn't function, that's the specialist you go to. We were so angry that the state seemed not to recognise

“Hand-holding therapeutic touch is an important experience that many lose in the transition to adulthood”

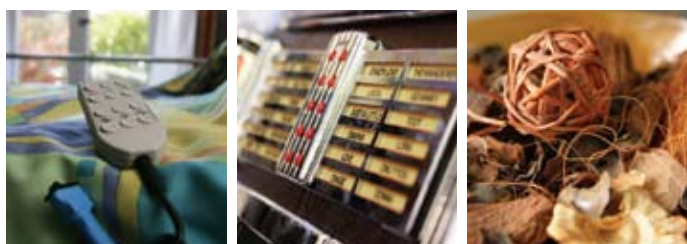
There was a striking illustration of this during the 2007 BBC documentary series, *The Children of Helen House*, where, in one episode, we followed the story of a young man with a very particular dilemma: he wanted to have sex at least once before he died, but his muscular dystrophy prevented him from independently procuring the services of a sex worker. After many discussions and careful consideration, his outreach support worker at Douglas House was given permission to help him procure such a service.

Around the place I also meet guests Dean, Spencer and Richard, all benefiting, in their different ways, from a get-away break at Douglas House. Like some 150 other young people, they can spend an allocation of 20 days each year (aside from emergencies) making the most of life in a setting uniquely equipped to meet their needs. They know better than most what a special place this is.

Liz tells me that the young man with locked-in syndrome stayed for the whole weekend. When his mother came to collect him she said she knew, knew instantly, that he had been ok. After visiting Douglas House, I'm able – against all the odds – to believe it. Another first from Oxford.



Richard: “Everything I need is here.”



that these people existed and that they have needs, so we decided we had to press for some funding.

Clare: I don't think people in the NHS are mindfully neglecting this group, but everyone is aware of this funding cliff edge, and the need to manage this transition, but because we are still talking about a relatively small number of people, their needs continue to be neglected. Advocacy is an important part of our work.

Is continuity of care between Helen and Douglas House important? When do young people transfer across?

Clare: Everyone's different, so they come when the time is right for them. But we're passionate about this being adult provision, and not simply an adolescents or under 25s service. This is about saying you're grown-up now: how can we help you with your independence and your advocacy?

Liz: It's recognising that issues that are massive at 14 are not necessarily so at 20. Frankly, we also find that our

young adults don't want teenagers kicking around! Those who have used Helen House previously comment on the differences positively – not because it's better here, it's just pleasingly different.

Clare: I remember a mum telling me that her 25-year-old son liked Teletubbies, Thomas the Tank Engine and blondes. And I thought, yes, that's the key – acknowledging that chronological age makes a difference.

Liz: We try always to go to the young adult first for their opinion. These young adults are often wrapped up in cotton wool, the parents, understandably, used to speaking for them. It can be a difficult pattern to break.

Clare: And sometimes there are tensions. We've got a profoundly disabled guy comes here who we know likes to go bowling, but his family don't want him to, because it would put his feeds out. We need to listen to him, and at the same time, be sensitive and respectful of his parents' feelings.

In conversation continued

Are you always able to resolve those tensions?

Clare: Not always. Another young man, aged 20, was removed from here by his parents. He was competent but would not say how he felt in front of them. It was sad, but we also had to recognise that we were but a small part of his life, and that he was going to be living with his parents the other 345 days of the year that he did not spend here with us. If he did not want to rock the boat then it would be wrong for us to force that situation. The key is developing a partnership with the family whenever possible.

How is nursing at Douglas House different?

Clare: People hear “hospice” and think acute setting, but the skill set we require is very wide. We value communication skills on a par with acute skills. The pace is very different. The work is one-to-one and certainly not acute the whole time. In fact, we have fewer deaths here than they have, say, at a normal community hospital. There’s an art to this kind of nursing, you need to truly engage.

Liz: We like to have nurses from all parts of the register, a wide range of experience. We even have a midwife.

Clare: And we’re quite autonomous, quite nurse-led, while working in close partnership with our doctors. We need people who are going to be alongside the young adult, not make decisions for them. They need to be risk takers. If a young person wants to go shopping, or out of an evening to the Carling Academy (local nightclub), then so be it. And we provide one-to-one training for our newly qualified learning disability nurses, to make sure they are able to deal with the more acutely clinical parts of the role.

That risk-taking element was highlighted, I seem to remember, in last year’s BBC documentary series.

Clare: Ah, yes! The procuring sex episode. We thought we might be in conflict with the Code. I certainly got the ear of the NMC adviser when I phoned to explain the situation and ask for advice! She said she would get back to us within 14 days, and she did, to say we would not be in contravention of the Code.

Is nurse recruitment a problem?

Clare: It can be. In and around Oxford there are a lot of opportunities for nurses. It’s a very competitive market place. And this kind of nursing is not for everyone. Working with this group is not as attractive a proposition as working with children. Helen House has no trouble recruiting the nursing staff it needs, but we do. We’re the equivalent of six full-time posts down at the moment.

Frances: Here is an opportunity to nurse in a way that many of us went into nursing to do. One-to-one care, adapting to the individual needs of people staying with us. Focusing on the family. The opportunity to take good risks. The main accountability is to the young adult and their family. They are the experts. Everyone’s different because everyone’s unique. Nursing here involves being infinitely adaptable, which is a challenge, but I can’t think of many places where there would be so much privilege as a nurse or a carer.

• Current vacancies can be viewed on the Helen and Douglas House website www.helenanddouglas.org.uk

Sister Frances Dominica



Sister Frances trained to be a paediatric nurse at Great Ormond Street Hospital in the early 1960s. Then, suddenly and unexpectedly, she decided to become a nun. By the late 1970s – while still in her early 30s – she had become Mother Superior at All Saints Convent in Oxford. Around this time her friendship with the parents of a profoundly disabled young girl led her to spend time caring for the child and supporting the family. Inspired by this experience, Sister Frances went on to found the first ever children’s hospice. Named after the little girl she had helped care for, Helen House was built in the grounds of All Saints and opened in 1982. Douglas House (also named by Frances in memory of a young person who died), was built within the same grounds and was opened by the Queen in 2004. For 26 years, Frances – as she is known to everyone here – has been figurehead and chief advocate for Helen and Douglas House, as well as a friend and inspiration to many hundreds of children, young people and their families.

Clare Edwards, Director of Clinical Services

Before landing her “dream job” in 2005, Clare trained in Oxford in the 1980s and completed a community nursing degree at King’s College, London. She worked as a dual health visitor and district nurse before becoming a manager at a community hospital in Wantage. Promoted to locality manager and children’s lead by the PCT, she went on a coaching course and began exploring new ways of working. She was frustrated



by the bureaucracy in the NHS and the consequent slow decision making. “I rushed to put my application in for Helen and Douglas House – I remember it well, it was also my wedding day. Working here I’m using all my skills and some I thought I’d never have, like talking to the Duchess of Cornwall!”

Liz Cornish, Head of Care

Liz worked in Bedford then abroad for some years before returning to work on the chest unit at the Churchill Hospital in Oxford. “I loved working there but got frustrated with the mentality that said if we’ve got the technology we must always use it to treat people. It was sometimes incredibly inappropriate, this refusal to recognise when someone was dying.” Liz took a degree in palliative care and worked for Marie Curie prior to arriving at Douglas House. “Early on, in a discussion about resuscitation scenarios, a senior colleague said to me, ‘We don’t talk about “Do not resuscitate” here at Helen and Douglas House; we talk about “Allow natural death.”’ And I thought this is it: we are talking the same language.”

