

A tale of two Henrys

Old Etonian barrister Henry de Lotbinière and Nigerian psychiatric nurse Henry Ekpe are an unlikely pair. Six years ago they met in a London clinic where they were both treated for a rare form of facial cancer by the same surgeon. Since then they have become firm friends as they have endured marathon surgery and learned to face the outside world. **Ann McFerran** tells their remarkable story. Photographs by Jason Bell

Surgeon Iain Hutchison with his patients Henry Ekpe (left) and Henry de Lotbinière



TO THE CASUAL EYE, the two men sitting in the hospital waiting room could not look more different. One is a middle-class Englishman, of John Cleese-like height and demeanour, wearing the discreet uniform of the barrister. The other is a 32-year-old Nigerian psychiatric nurse, his jeans and sweatshirt emphasising his muscular, shorter build. Look more closely, however, and you notice that both appear somewhat peculiar. One side of each man's face is perfectly formed, in profile rather handsome. The other side, however, appears as though it has been pushed and pulled out of shape. The barrister has lost an eye; the socket droops alarmingly half way down his cheek, which also protrudes, as if he were sucking a huge gob-stopper. The Nigerian wears dark glasses; he appears to have a cleft palate and the right side of his face appears oddly flattened. The men might be wearing one half of those plastic masks children wear at Halloween.

These two very different men share a rare form of facial cancer. They also both happen to be called Henry. Since they met in surgeon Iain Hutchison's clinic six years ago, the two Henrys have become good friends. Old Etonian Henry de Lotbinière, and Henry Ekpe, who had never left Nigeria before he realised the lump in his nose was a malignant tumour, have confided in and encouraged each other in their fight against cancer. Their marathon operations have been notably perilous. Any faulty cut and the men could have bled to death or suffered a stroke. Henry Ekpe's main operation lasted 23 hours. Last year, Henry de Lotbinière was kept unconscious for nearly a week. For Iain Hutchison, their facial reconstruction is almost as important as the removal of the malignant tumours. Today, neither man looks grotesque or monstrous. Barrister Henry is back in court. Henry Ekpe looks after Alzheimer's patients in Hillingdon Hospital. Last year, he married 23-year-old Gloria.

Their future is uncharted terrain. For the time being, the two Henrys work and enjoy life with vigour and relish, tempered only by times when they feel 'a bit sorry' (Henry de Lotbinière) or 'very low' (Henry Ekpe). For the moment, they live as 'normally' as possible. Only the word 'normal' seems grossly inappropriate. Fifteen years ago, such facial cancers were virtually untreatable. Even 10 years ago, the men would be confined to a hospital ward, able to leave only wearing prosthetic faces, made of acrylic. At night, they would take off the false faces to reveal a hole. Their life expectancy would have been slim.

This gift of extended life, and the potential to live in normally, is why the two Henrys have 'faced' up to telling their stories. 'I never thought I'd want to talk about my cancer,' says Henry de Lotbinière. 'Now, I don't go around with a placard, but I prefer to talk about it than bottle it up. I feel quite happy to explain I had a lump in my face which was removed. I feel that if more people who look odd, like me, get out and are seen, then it would be easier for everybody.'

Paradoxically, facial cancer is also often virtually painless. Both Henrys describe how their illness has been almost pain-free. Yet the removal of their tumours has demolished that part of the human physiology which we prize most: the face itself, often described as the mirror of the soul. Small wonder that the two very regular visitors to Iain Hutchison's clinic have become firm friends. Amid the Smiths and Joneses, the nurses abandoned their surnames, so they became known as the two Henrys. For each Henry the other acted as an invaluable inspiration and support. 'It always cheered me up seeing Henry sitting there,' says de Lotbinière. 'Meeting him and talking to him about what he was going through, knowing he was in the same boat, made me feel better.'

'We clicked immediately,' confirms Ekpe. 'Henry is the kind of man you can confide in. Knowing Henry has helped me cope with my disability.' Not long after they first met, before an operation in which barrister Henry would lose his eye and half his forehead, Henry Ekpe happily demonstrated how he could still wiggle his eyebrows, grimace and screw up his face for his new friend. Meanwhile, Henry's wife, Anita de Lotbinière, helped Henry Ekpe choose dark glasses. 'The face is such a challenging area,' says oral and maxillofacial (maxillo means jaw) surgeon Iain Hutchison. 'It's not like the removal of bowel cancer, which you will replace with an unseen colostomy bag. My job is to remove the tumour and to reconstruct the face, using sophisticated state-of-the-art surgery, so that people can live comfortably in society.'



Henry de Lotbinière with his wife Anita, and twins, Kate and Andrew, at their home in north London

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Another slide shows what Hutchison likens to 'a slab of meat in a butcher's shop'. It is a muscle he has removed from Henry's lower back. With half a rib, the surgeon used the latter, rather like a curtain rail, on which to hang the muscle, to reconstruct the face. Using a microscope, he painstakingly joined the flesh from the back to the blood vessel in the neck to ensure the blood supply. The result is a true miracle of surgery.

A likeable, enthusiastic man, Iain Hutchison relives the thrill of the chase to defeat malignant tumours. He is no Oliver Sachs, patiently exploring the way in which disease can be a philosophical metaphor for the human condition. Rather, he is like a Green Beret, mustering all his medical forces to conquer cancer and 'reconstruct the men's faces as perfectly as surgically possible. In the brief breaks during his marathon operations, he eats fig rolls; anything more substantial would make him sleepy. During Henry Ekpe's 23-hour operation, he sat in a chair and closed his eyes for 15 minutes. A devoted father of three children – he is married to Helena Kennedy QC – he missed his daughter Clio's recent birthday party because an operation developed time-consuming complications. He has never lost a patient. 'But it is very stressful,' he says. Ask him if cancer has changed his patients' philosophical outlook and he replies: 'Of course, but I don't know to what extent. I do know that they encourage me enormously; they are terrific people.'



Henry Ekpe and his wife, Gloria, at their home in north London

'Sometimes, I'd feel sorer for him. He's an upper-class lawyer in a country where disability, for all the hype, has a negative face. I'm more used to being treated badly'

Alongside colour, culture, age and class, the reactions of the two Henrys to their cancers are also very different. Where Henry de Lotbinière parades his facial disfigurement to the world, Henry Ekpe hides behind dark glasses. While barrister Henry exemplifies British stoicism, Henry Ekpe rages at his fate. Describing the moment he realised he had cancer, Henry Ekpe weeps. It is a heartrending sight as he removes his dark glasses to wipe tears from an eyesless cheek. 'I'm never sure what that means,' says Henry. 'If Iain said to me, "You've only got a year to live, Henry," I wouldn't think: "I'd better go around the man who would make me feel under a sentence and hurry along death. I simply work on the principle that I carry on like I do because I enjoy my life."'

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able to describe his reaction. 'While I wished it hadn't happened, I knew there was nothing to be gained by feeling sorry for myself. Why ask, "Why me?" An old legal maxim says: "If you don't know the answer to a question, you don't ask it."'

The de Lotbinière twins were 12 at that time, an age when children assume their parents are invincible. Henry felt reassured when, some weeks after the operation to remove the tumour, his daughter Kate became irritated with her father. She remarked that, if his behaviour was any yardstick, much of his brain must have fallen out of that gaping hole in the roof of his mouth!

After his operation, Henry initiated a fast-track recovery course, starting a speech therapy programme on his way home from hospital, muttering the difficult 'y's and 'm's to himself, attending radiotherapy before work. 'I was in no doubt that people who sit around getting depressed take longer to recover.'

'I didn't want to cook you lunch every day,' chivvies Anita. More than three years later, with Henry 'up and running', the de Lotbinières must have been devastated when Henry learnt he had a more serious recurrence of the cancer. They treated it with courageous stoicism: 'You just think, "Sod

it," and get on with life,' says Anita. By then the surgeon who had operated in 1987 had retired, so Henry saw his successor, Iain Hutchison. Surgeon and barrister hit it off immediately. 'I was absolutely convinced that Hutch would go out of his way to give me the best treatment possible. Maybe because he's married to a barrister, he made me feel entirely comfortable.'

As a cricket fanatic, Henry was pleased to recuperate in the W.G. Grace ward, and much preferred 'the mateyness of a four-man ward, where a nurse was four times as likely to come in as she would to a solo private ward.'

After the operation, Henry looked 'horrendous'. Characteristically, he refused anti-depressants, and felt a lot sorer for his wife and children. 'Much harder for them than me. How I look isn't high on my list of priorities. If I was 20, and wasn't married or didn't have a job, of course it would be different.'

Having had most of his forehead removed, Henry reluctantly abandoned his 'rough village cricket. I'd be slightly nervous that a ball could go straight through my brain.'

'You still play beach cricket,' prompts Anita, cheerfully. In Iain Hutchison's waiting room, Henry noticed Henry Ekpe. 'We both looked like wounded soldiers. I'm the kind of person who talks to other people, and it was marvellous to meet someone who looked as though he was going through the same thing as me.'

After losing his eye, Henry's 'effort to look on the bright side' extended to wearing eye-patches, matching his ties, made by his wife. Sober patches for court, brighter patches for more casual wear. Henry explains: 'Instead of people saying: "Oh Henry, I'm so sorry to see you've lost your eye," they said: "What a fabulous eye patch." For goodness sake, let's make it as fun as possible.'

At a Test match at Lord's, when Henry wore his bright red and yellow MCC tie and patch, he was delighted to overhear two older members wondering why they hadn't spotted 'that damn smart patch in the catalogue.'

The cancer, however, did not stop, nor did the operations. Henry abandoned eye-patches after an American friend advised: 'For God's sake, Henry, let it all hang out.' Which is exactly what he did, and still does. When people stare at him, he often explains why he looks different. When a small child pointed at Henry on a bus, he relates how 'I explained to her how I'd had this lump cut from my face. I gave the mother full marks for letting her five-year-old chat to me. Now I'm happy to talk to anyone; I think it makes people like me, who look odd, marginally less surprising.'

In a major operation a year ago, Henry lost so much blood that the transfused blood wasn't clotting properly and he was kept sedated in intensive care for six days. Anita and the twins visited daily. Henry recalls having vivid dreams for the first time ever. He dreamt he was watching thousands of soldiers chasing two tiny bandits on Salisbury Plain. Were the soldiers cancerous cells chasing the hapless Henrys? Henry is amused at such an interpretation. From his flamboyant eye patches to his repeated insistence that life must go on, you might surmise, in psychotherapeutic parlance, that Henry is 'in denial.'

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