

Pariahs' comfort

Even when diagnosed with leprosy herself, Leah Pattison refused to turn her back on some of the world's most abused and isolated women. **Sue Summers** meets the Angel of Nagpur. Photographs by **Ziyah Gafic**

Leah Pattison would hate to be described as a saint but many people undoubtedly see her in those terms. At the age of 34, she has chosen to immerse herself in caring for some of the most wretched and forgotten people on earth. For the past eight years, she has dedicated herself to providing help and support for the people India considers among its lowest of the low – women with leprosy.

Every year more than half a million people are infected with the disease, even though medical science has found an easy cure. To be effective, the cure must be administered as soon as the first symptoms appear. And to people – above all, women – in India, where the largest number of sufferers are to be found, the stigma of leprosy is still so great that many are afraid to confess to having the disease until it is too late. 'In India the stigma of leprosy is still terrible for women,' Pattison says. 'It's a problem because a family will not consider allowing their son to marry any woman who has had leprosy, even if she is cured. In India now there's such pressure on women to be perfect – to be fantastic looking, educated, have jobs and be good housewives and mothers – and having leprosy means they are not perfect. So they hide it to the point where nerve damage sets in and deforms them. Then it's too late.'

If an Indian woman is discovered to have leprosy, she can expect to be left by her husband, thrown out of her home, ostracised by her family and community, cut off from all contact with her children and, in the most extreme cases, shut up alone and left to die. Until Pattison took up the cause of women in this predicament, they had nobody to champion them. 'We found one woman who had been a property consultant – she was publicly shamed, her business failed, she lost everything and went mad as a result,' she says. 'Women who are on the streets tend to take it more in their stride. But they are all real women with real personalities and we try to get them to believe in themselves again – to believe that they are somebody.'

Even when, while working there, Pattison was diagnosed with leprosy herself – she is completely cured – she refused to leave India. And yet, she insists, she is as surprised as anyone else to find herself doing this kind of work. 'I'm the wrong person,' she says. 'I'm a hypochondriac, I'm neurotic – I didn't have any aspirations to do what I'm doing at all. "Doing good" just wasn't me.'

'What happened to me happened gradually. It wasn't like a bolt of lightning. In fact, I was quite reluctant because I felt strongly that,

Leah Pattison at the leprosy colony near Nagpur in central India where she first worked as a 23-year-old graduate





although India was a very exciting place, I couldn't live there. I only went there for a working holiday and at first I was very homesick. Yet every time I came back to England, the people I'd met in India pulled me back. These people are forgotten about and they just resign themselves to it, and that seems so awful and wrong. I don't believe in religion and it sounds corny but there's just something inside me which makes me believe this is what I'm made to do.'

Pattison is an elfin figure whose deep-set blue eyes under her auburn hair seem almost too large for her small, pale face. The daughter of an architect and a former teacher, she grew up a world away from the incessant noise and bustle of India, in a remote house on the edge of the Pennines where her nearest neighbours were cows and sheep and the botanist David Bellamy. Educated at a private convent school – she was the class rebel – she had a severe brush with anorexia in her teens and at one point came close to death. 'It lasted for two years and it was very hard overcoming it, but

'If you go into a leper colony as a child you can be there for 40 or 50 years and never go out again. It's a terrible life. The colony is your world'

maybe that experience has made me appreciate how valuable life is,' she says. 'I feel I should grab every moment.'

Her chosen career was painting, but after getting her degree in fine art at the University of Central Lancashire in Preston in 1995, she decided to go on a working holiday to India. Her father, Derek, had been to India in the 1960s when Le Corbusier was building the new capital of the Punjab at Chandigarh, and his best friends were Indian. Leah decided to set off in her father's footsteps.

Like Mrs Moore in EM Forster's *A Passage to India*, Pattison wanted to see 'the real India'. Through a friend of her father, the 23-year-old was invited to stay in a leper colony in the countryside outside the small city of Nagpur in central India and to teach English at a nearby school.

After a nightmarish 36-hour train journey on which she had all her money stolen, she arrived at the colony in the middle of the night. 'I was picked up from the station in an old camper van and it was only then that I started to think about what the colony would be like,' she says. 'We drove down a very dark road with no street lights and went through an archway. As a foreigner coming to stay, I thought I would be treated as an honoured guest.' Instead, Pattison found herself shown to a room with a broken basin and a bare mattress on the stone floor. The next day she managed to get hold of a bicycle and find her way to the school where she was meant to be teaching, only to discover that the teacher knew nothing about her. 'The colony was like a small village with huts for residents dotted around a central hospital, and for the first week I felt alone there and totally alien,' she says.

Then the wife of the colony's director invited her to see a hostel that was home to about 20 girls between the ages of six and 20 and showed her a poem the girls had written out. Called *What is Life?*, it started, 'Life is a gift: accept it/Life is a challenge: meet it.' 'I was feeling so low that these words seemed to have huge significance for me,' Pattison says. 'I suddenly felt a sense of purpose to my being there. The next morning I had been called to Hindu prayer and had my pyjamas on and the girls in the hostel were laughing at my outfit.

One of Pattison's 'clients' (left), an old woman crippled by leprosy, holding a neighbour's baby. She makes money by begging and pays the woman on the right to take care of her



I joked with them and started developing a really good relationship. I connected with people through humour – and I still do in my work today.'

She agreed to teach the girls English, and over the next few months found herself being drawn more and more into their lives – into both their fun and games and the tragedy that surrounded them. 'I began to see them not as lepers but as real people with real personalities,' she says. Among them were two sisters, aged eight and 13. Pattison asked about their story and was told they were orphans. Their mother, who also had leprosy, was doused in kerosene and burnt alive by their father, who then killed himself.

One of her pupils particularly fascinated her – a girl of 19 whom Pattison discovered had been there since the age of 10 with a case of leprosy so severe that as a child she couldn't eat, sleep, lie down, stand or even bear the touch of clothes on her body. The disease had been brought under control but, although she had no permanent deformity, the skin on her face had lost its elasticity and she was so self-conscious about her appearance that she refused to go out in public.

This was Usha Patil, who was to have a profound effect on Pattison's life and with whom she would set up the charity Start in 2000. Now an attractive 31-year-old with waist-length dark hair and a wide smile, Patil hides a strong character under her quiet exterior. She was told to resign herself to spending her entire life in the leper colony but was determined to leave and nagged her doctor into helping her find a way to improve her appearance. He eventually put her forward for the first facelift ever to be carried out on a leprosy patient, which was given to her free of charge by a plastic surgeon in Bombay when she was 21.

But when Pattison met her, Patil was 19 and so miserable that she refused to talk to anybody. 'She spoke more English than the others but she was reluctant to talk to me,' Pattison says. 'She refused to go out because she was afraid of people staring at her but I eventually persuaded her to come out to see a film. We went and no one even looked at her, which gave her confidence. Gradually she started to open up and I discovered that underneath she was a very strong person whose dream

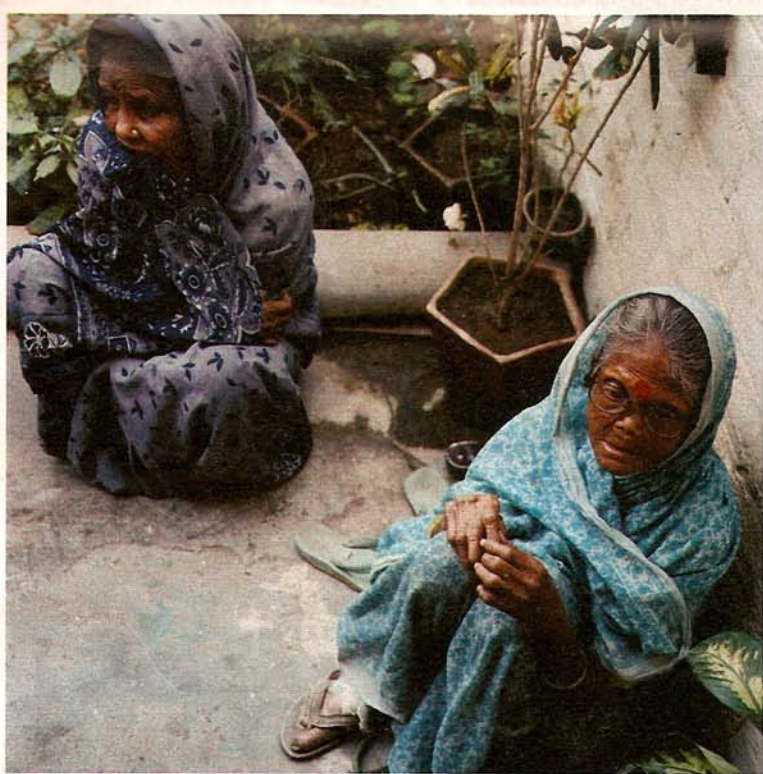
was to shake off the label leprosy had given her and help other women to do the same.'

'I am doing this work to show people that you have to fight to get things,' Patil says. 'If you go into a leper colony as a child and keep quiet, you can be there for 40 or 50 years and never go out again. It's a terrible life and it was my life. You go to school, come home and are locked in. The colony is your world and you don't know what's happening outside. The way Leah and I work is different. We go into women's homes, try to re-establish links with their families – which can be difficult – and help them to help themselves.'

It was Patil who realised that Pattison herself may have contracted leprosy when in 1997 she noticed some light-coloured patches on her friend's wrist. (The disease is transmitted from person to person, probably via respiratory droplets, but transmission rates are relatively low and Leah had never considered the possibility of catching it herself.) By then Pattison had been back to England, but realising she missed India, had sold everything she owned, including her drum kit, in order to buy a bicycle and a scalpel and return to the leper colony to do a paramedical training course.

At first Pattison thought she had eczema and refused to see a doctor, but when she did she was immediately diagnosed with tuberculoid leprosy. The doctor also advised her not to tell anyone that she had the disease; he himself had had it as a medical student, he said, and his professors had disowned him. Pattison was distraught. 'I was scared because in the colony I was seeing a lot of badly deformed people,' she says. 'I'd never found it a problem mixing with them but you suddenly think, Is there a possibility I could become like that?' Unable to confide in anyone at the colony, she rang home in tears. 'Most kids ring up and say they've got chicken pox,' her mother, Sandy, says drily. 'Mine said, "I've got leprosy."'

Pattison's parents wanted her to come home immediately but she refused. 'I decided that the best place to be treated for leprosy was in a leper colony.' She was given a course of drugs and within three months the patches started to disappear. The experience made her realise, she says, that 'if the disease was this easy to cure, the



Left a leprosy sufferer (right) who Pattison visits and provides with food, medication and comfort, as she does for many similar women in Nagpur. **Below** Usha Patil (left), Chindabai (a leprosy sufferer) and Pattison in 2004

would not treat either her mental condition or an ulcerated foot that was crawling with maggots. Pattison got her drugs and medical care and, she says, 'suddenly this articulate, bright, fantastic personality started to emerge. Now she has a business selling dried fish and has moved in with some relations and is 99 per cent normal.'

Another woman, Anusaya, had been thrown out by her husband and brought up her children by working in the streets selling rice. 'At first she lived in a little hut she made out of bits of rubbish, but she did well and had a property built for her,' Pattison says. 'Then when her son grew up and married she was thrown out of her house. So she built a little hut outside and refused to leave. She worked as a beggar – she was quite good at it, actually – and her son, daughter-in-law and grandchildren would abuse her and steal her begging money. What used to really get to me was that despite that, she talked about her grandchildren with such love and affection.'

Another old lady, Mainabai, who had lost her

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ostracism of Indian women was an even greater injustice than I'd thought.'

Unlike many Indian families who disown their daughters if they are diagnosed with leprosy, Usha's parents had never abandoned her. After a day's work as a road labourer, her mother would regularly cook the evening meal for her four other children, then pack some up for Usha and make the 75km bus journey to stay with her overnight.

So when Pattison and Patil decided to set up Start, they moved in with Patil's family in Nagpur for the first 18 months and based their work in the city. The Patils are a family of 10 living in three small interconnecting rooms. Pattison didn't mind having to take her turn queuing for water at the pump but for someone used to the Pennine moors the lack of privacy in a family that lives, eats and even sleeps together was intensely difficult. 'Sometimes I'd hire a rickshaw to drive me round the city just so I could be alone. Otherwise the only place I could find any solitude was the toilet.'

Even more difficult was making contact with the women they wanted to reach. The pair faced hostility and suspicion from government officials and paramedics plus they had to go into notoriously dangerous slums. The fact that Pattison is white intensified the suspicion and meant they were often followed by groups of threatening men.

Gradually, however, they found the women they were looking for – women who desperately needed them, but who had cocooned themselves with an anger that made it difficult to help them. They had to break down these barriers before even trying to tackle the women's problems. One of the greatest of these was combating years of deep depression. Pattison's well-meaning attempts to give women hope for a better future were often met with weary sighs or disbelief and irritation. 'These women bear the emotional scars of years of physical and mental abuse and suffering,' she says. 'It takes time to befriend them. But one thing that seems to work is humour. Even if they are miserable we joke with them about being miserable.'

Pattison and Patil now have a clinic and more than 300 women on their books. They plan to extend their work all over India and, even more ambitiously, to deal with the other problems

women have to face – such as HIV/Aids, mental illness and abuse – through a new charity they are setting up, Women in Need International. Their aim is to try to establish women in their own businesses in order to give them a measure of independence. At the clinic they sort out medical and personal problems, provide counselling, legal advice – even false teeth. All this is accomplished on a total budget of £15,000 a year, which comes from private donations from people who have read of Pattison's work or been at one of the fundraising presentations she returns to Britain to do each summer. This November she will be one of the recipients of the prestigious Beacon prize – the Nobel of the charity world – whose previous recipients include Sir Bob Geldof, Jamie Oliver and Zac Goldsmith.

She will, of course, have to raise much larger sums of money if she and Patil are also to help the many HIV/Aids sufferers they are currently having to turn away. 'But if we don't do it, who will?' she says. 'We have to start thinking bigger now. We are exploring the possibility of getting some land from the Indian government so we can have a bigger place with X-ray facilities, a pathology lab and small wards. Our [leprosy] women have been banned from many of the local hospitals. Most of them are completely cured but the doctors think their deformity frightens other people away.'

One of these women, Basanti, was living in the grounds of a hospital where she had been dumped by her family when they discovered she had leprosy. Due to the strain of her situation, the once successful businesswoman, then in her early forties, had developed schizophrenia, but the hospital's doctors

fingers through leprosy, was blinded by cataracts and could only crawl to her lavatory or sit outside her house waiting for somebody to help her. Her son was hoping she would die so he could get her shack. Pattison and Patil paid for an operation to restore her sight. 'When she saw me, she was really shocked because I was white,' Pattison says. 'But she blossomed, it has really transformed her life.'

Even now that the charity is firmly established and Pattison has her own little flat in Nagpur ('With a washing machine!' she says excitedly), her life is far from easy. Her mother, Sandy, a trustee of Start, recently visited her daughter for the first time to see the work for herself. Years of involvement with the charity had still not prepared her for the shock of the reality.

'I'm a pretty tough cookie and I thought I knew it all but I didn't know a thing,' she says. 'Leah took me into a Muslim slum area and we went up some steps into this dark little room. In the corner was what looked like a bundle of rags. For me it was like going into Hell. I sat there for an hour and watched the girls tease the woman up out of the rags. She hadn't been eating and the girls sent out for some samosas and got her to eat them. She was so pleased to see them. Having seen it for myself, I am so proud of these two girls and what they are doing. It's just incredible.'

Although Pattison has had boyfriends in India, it is her work that comes first. 'Anyway, I'm not sure that cross-cultural relationships can ever really work out,' she says. 'I'm every Indian mother's worst nightmare.'

One day she wants to settle down and have children. One day, she believes, her 'inner voice' will tell her she has accomplished what she set out to do and it is time to leave. But for now her life is in India – however difficult it may sometimes be. 'Every day while I'm out in India I'm battling with myself and my insecurities. I see what I'm doing as a great challenge. One day, when I'm old, I'll be able to look back on what I'm doing now and think to myself, "I did it."'

Contact Start and Women in Need International clo Frosterley Cottage, Intake Lane, Frosterley, Bishop Auckland, Co Durham DL13 2TH, or see leahpattison.org or start-leprosy.org

