

Bringing women back from the brink

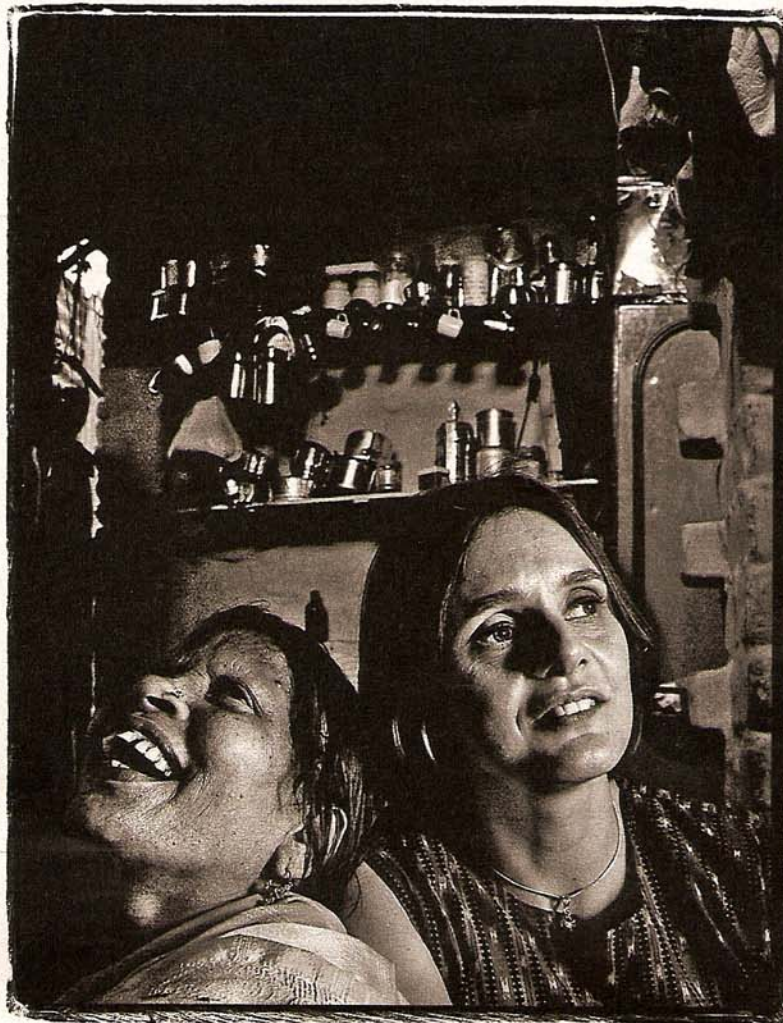
LEAH PATTISON, 36, has spent 12 years working with leprosy victims in India. She recalls her first trip to the country as a student — and how she only got serious about helping other leprosy sufferers when she caught the disease herself

I stumbled into what I'm doing today, really. After finishing my degree in fine art, I decided to take a break before settling down. It wasn't that I had any burning desire to go to India — but a family acquaintance was in touch with a leprosy colony there, so I arranged to go. I was fairly selfish — it just seemed like an exciting thing to do, and I wanted to gain experience before moving on to the next phase of my life.

I almost left during my first weeks at the colony. I was terribly homesick and I realised I wasn't the intrepid explorer that I'd thought I was. But I decided to try to make the most of it. Not many people spoke English, but I found I could use humour to make connections — just silly little things to get a laugh and bridge the language gap. There were a lot of badly disfigured individuals who'd suffered the nerve damage leprosy causes. It often renders the sufferer's hands and feet insensitive, so they injure themselves. And it impairs circulation, so healing is very slow. Many had terrible ulcers, and if they get infected, you're looking at amputation. I found myself face to face with real individuals — many girls my age — in dreadful situations I'd never have been exposed to at home, and I realised I was getting more involved, emotionally and practically. When my visa ran out and I had to go home, I was desperate to return. For the next three years, I only went back to England to renew my visa.

Then I got leprosy myself. Only then did it strike me that this was real, not just some kind of adventure, and that it was time to commit myself properly or go home. I was only diagnosed by coincidence — a visiting doctor noticed some light-coloured patches on my wrists. I'd put them down to eczema. I was gobsmacked — it hadn't occurred to me I might catch it. And I was more familiar with the severe deformities leprosy can cause, not the early stages. I hadn't noticed a loss of sensation in the patches until the doctor pricked them with a pin and it didn't hurt much.

Maybe I got it in the colony — but everyone there was being treated, so



Above: Leah visits a leprosy sufferer at her home in Nagpur. Top right: Leah at work. Bottom right: a patient's hands

they weren't infectious. It's just as likely that I caught it outside the colony, crushed with 10 other passengers in an autorickshaw that's meant to take three, for instance. But there was a great deal of embarrassment and alarm at the colony. And my family were worried.

I decided to stay in India for treatment. I felt people there knew how to deal with it better than in the UK, and I had friends who knew what it was like. It was nine months before I was cured, with a multi-drug therapy — though I never felt particularly unwell and I don't suffer any aftereffects.

I now know at first hand that if leprosy is caught in the early stages, it's no big deal. But there's still such superstition and stigma surrounding the disease that people don't come forward until they've developed severe deformities. Many families choose not to keep individuals who've had leprosy within the home,

even if they've been cured: it's thought to continue the curse. And that hits women the hardest. Even if a man's nearest and dearest won't support him, his wife will. Society demands it. But it doesn't work the other way around. So even though there's free treatment, women aren't coming forward, then they develop deformities that mark them out for the rest of their lives. It was as much the idea of doing what I could about that injustice as it was about compassion that made me decide to stay in India.

I founded a charity, Start, with one of the girls from the colony, Usha. She had suffered badly from leprosy herself. We trained as paramedics, and set out to work with women in their communities, rather than hiding them in a colony. We try to help with the problems leprosy can cause — often drugs and medical care are the least of it. These women have been through terrible experiences — abandoned by their families, left very ill in extreme poverty. We found one elderly mother-in-law, for instance, who was cured but disfigured. Her family had just



'WE FOUND A MOTHER-IN-LAW, CURED BUT DISFIGURED. HER FAMILY HAD PUT HER IN A BACK ROOM AND LEFT HER TO DIE'

put her in a back room and left her to die. She was half-dressed, and the ulcers on her legs had maggots in them. When we took her to hospital, we had to bribe the doctors to treat her.

We also have to convince the women they didn't deserve the disease — many believe they brought it on themselves. If they have deformities, it can be difficult for them to look after themselves or cook — they often injure themselves, so we treat their wounds and deliver meals. And we try to set them up in small businesses, so they don't have to beg, and encourage locals to buy from them.

I sometimes miss the stability I'd have in the UK. But while I'm capable of doing this, I'm going to carry on. When we see women who, with our help, have turned things around, I get a real sense of achievement. When I caught leprosy, I got off lightly. They haven't. It's a privilege to be involved with their lives ■
Start is at www.start-leprosy.org

**Interview: Katharine Hibbert.
Photographs by Atul Loke**