

PERSPECTIVES

New face for leprosy “A positive image for leprosy”

Leprosy has been a stigmatizing disease for centuries. Imagine yourself newly diagnosed with leprosy and while looking for information you find many negative images on the internet which reinforce your fears. The good messages, that leprosy is an infection curable with a 6 or 12 month course of antibiotics and is only mildly infectious, are hidden.

We aim to alter this negative balance through the New Face for leprosy project showing leprosy patients having a normal life, working and having a family. In 2018 we photographed and interviewed patients in Ethiopia. They openly discussed their experiences, fears and hopes. When we showed these pictures in Ethiopia in February 2019, one patient said “we are beautiful”, a new way of looking at herself.

We presented these positive pictures of people affected by leprosy at meetings and at the 20th International Leprosy Congress in Manila, in September 2019, and people affected by leprosy wanted this project to expand. We have photographed and recorded patient stories in India, to catch their voices. We asked them what had been tough and what had given them hope. Many patients had been delayed in diagnosis because their symptoms were not recognized by health workers. Many patients had tried natural or spiritual remedies. When told of their diagnosis most felt despondent and even suicidal and could not share their diagnosis. Participants had taken the 6 or 12 months’ course of anti-leprosy antibiotics that cures the disease. They had positive messages about taking antibiotics and knew that these were curative. They were often supported by staff from the referral centres and other patients. Women suffer a double jeopardy: they fear for their own position and worry about their daughters, fearful of the challenges in having a marriage arranged for them. These pictures show strong people who have overcome their diagnosis and even work in tough building and agricultural jobs.

We shall be showing these pictures at exhibitions in London and India and around the UK. We are publishing these pictures in *Leprosy Review* and hope that it will stimulate recognition that people affected by leprosy are strong in overcoming challenges.

These images will be available on the Lepra website. The project will be expanding to other countries. Globally about 220,000 new patients are diagnosed each year. A majority of these are in India.

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Diana N. J. Lockwood, Tom Bradley

DNJL is the author. TB is the photographer (www.tom-bradley.com).



Krishna, photograph Tom Bradley

I am Krishna, 55 and I live in a leprosy colony. I was 12 years old when I was diagnosed with leprosy. During my treatment, I suffered reactions to the medication and painful skin lesions across my body. For 15 years, I took medication and tried to work in my local village. As a teenager, I was sent away from my family and lived in a leprosy colony. Despite taking medication, my hands and feet were numb and I couldn't work. For years, I suffered from serious mental health problems. I often feel depressed and suicidal. "Many people won't sit beside me. I am grateful you have." I refer people to Leprosy referral centres in the area.



Chilaamma, photograph by Tom Bradley

I am Chilaamma, 70 years old. I was diagnosed with leprosy when I was 40. My feet were deformed and I had patches of numb skin on my body. A doctor prescribed me multi drug therapy for two years. After my diagnosis, my husband abandoned me with our four children. My sons have all moved away from me and do not want to see me anymore. After my diagnosis, I felt depressed. I still feel like that sometimes, although my friends are supportive. I practice self-care, bathing my feet and wearing protective footwear.



Papakanti, photograph Tom Bradley

I am Papakanti and I am 30. 5 years ago I noticed numb patches and discoloration on my face. I spent much money travelling from doctor to doctor without answers. My skin condition deteriorated. A doctor recognised the symptoms of leprosy and sent me to one of Lepira's referral centres. With a mixture of multi drug therapy and steroids, I improved. As the medication began to take effect, my confidence grew and I ventured out into my village again. I encourage others to visit the Lepira referral centre and seek treatment. "Be regular with your medication, be patient, it will work."

**Patlavat, Tom Bradley photograph**

I am 38 and I work in construction. I developed painful blisters on my feet. I visited a private doctor, who misdiagnosed me and prescribed me injections for a disease I did not have. The private doctor was very expensive. I went to a local hospital and was diagnosed with leprosy and sent to a Lepra referral centre. I was prescribed Multi Drug Therapy (MDT) for twelve months. The sensation in my feet and hands slowly improved. Every second day, I practice the self-care Lepra taught me and bathe my feet.



Mandula, photograph by Tom Bradley

I am 45 and I work as a labourer. I developed deformities in my hands and feet. I was misdiagnosed and my deformities worsened. I visited Lepra's Blue Peter Health and Research Centre and was diagnosed with leprosy, and prescribed multi drug therapy for 12 months. I work as an agricultural labourer but I cannot always protect my hands in the fields. I now refer people to Lepra with suspected leprosy.



Muneer, photograph by Tom Bradley

I am 59 and I have been a professional tabla player for 30 years. I developed pain and weakness in my hands. I visited a doctor who recognised the symptoms of leprosy and started me on medication. I did not see improvement and stopped taking the multi drug therapy. I later resumed treatment, and took multi drug therapy again. 'That newly affected people should take constant medication and adhere to doctor's consultation, as it helps the disease to be controlled.'



Manikyamma, photograph by Tom Bradley

I am Manikyamma, 52 yrs old. I grew up in a leprosy colony in India. Both my parents had leprosy and I grew up understanding it was curable. In 2000 I was diagnosed with leprosy. I started on multi drug therapy and followed Lepra's advice on self-care and prevention of disabilities. After being cured I became a lab attendant at the Blue Peter Public Health Centre and trained to become a lab assistant. "There is no need to be worried about the disease. It can be cured through regular medication and treatment."



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Ramadevi, photograph by Tom Bradley

I am 36 and work as domestic help in several homes and support my two children. I developed numb, discoloured patches of skin on my body. The doctor did not diagnose my condition and prescribed medicines that did not help. My husband, an abusive alcoholic left me to raise our children and support the household financially. At a Leprosy referral centre I was diagnosed with leprosy and provided treatment. “Leprosy provided me with counselling at their referral centre and it has helped me. Leprosy are providing my son with educational support.”



Anasuya, Tom Bradley photograph

I am 33 and married with one son. At 11 years of age I began to notice numb, discoloured patches of skin on my right thigh. I became suicidal. One day, I purchased some pesticide to drink, but I could not go through with it because of my older brother and grandmother. Local doctors misdiagnosed me and gave me herbal medicines, until one doctor finally recognised my symptoms and diagnosed me with leprosy. I took Multi Drug Therapy for one year and was eventually referred for reconstructive surgery. I began working as a 'lokodooth' – someone who educates ASHA workers about leprosy. "There is no need to get depressed about leprosy. It is like any other disease and it is curable with medicine."



Zaibun, photograph Tom Bradley

I am 34 years old and I am a house wife. One day I noticed a small blister on my right hand and by the next morning my body was covered in painful nodules. I was diagnosed with leprosy and was afraid I was going to die. For 12 months, I took Multi Drug Therapy. The staff at the hospital were unhelpful. I was very unwell, and was referred to a Leprosy Referral Centre. Leprosy staff reassured me and prescribed steroids. Gradually, my symptoms reduced and I felt better. “Leprosy were sweet and affectionate, took very good care of me and explained things clearly. If I was to say to someone newly affected by leprosy, I’d tell them not to be afraid.”