

Shova - aged 15

Hello dear friends,

I'm Shova, and I'm 15, and I live in Khirhar village... that's in Bihar, India.....



This is my first ever letter - I only went to school till class 3 - that was about 7 years ago - so I can't really read or write ... except for my name. So the doctor is helping me, and he says I should first tell you my story....

Well.. I got married 3 months ago, when I was still 14. Yes!

This is still quite an exciting big thing for me, but the Doctor said you'd probably find it rather startling,

Of course it's not unusual in my village and some of my friends got married younger than me. So I'll tell you just a teeny bit about this first, and then tell you about my leprosy which I caught when I was just 7 years old... which you'll understand makes my wedding even more surprising

Of course, my marriage was arranged between my parents and my husband's family... it's always done like that in my village. I'd never seen my husband before we got married - and neither had he seen me.... which is probably fortunate because although I got treated for leprosy several years ago, the leprosy is somehow still slowly eating away at my fingers, hands and feet. So I know I was very very lucky that our families arranged for me to find a husband

My family gave a large dowry to my husband's family for the wedding... there was furniture including a bed and a table and a wardrobe, and also 30,000 rupees (about \$300). And my husband gave me some nose jewellery and 2 gold bangles for our wedding.

My husband, Kishan Dev, is 25 years old and tall ... I think he is handsome, but I'm too shy to tell him. As soon as we were married, sadly he had to go back to work. He works far away in New Delhi in a soap factory. I've never been anything like that far away from my village. But one day if I can get my hands and feet better, I hope my husband can take me to Delhi.

Since my wedding I went to live my husband's family ... it's a big family of 10 people. It's about 3 hours away from my own home village. I cook the family food and help mother-in-law with the housework. She is nice and kind to me. Her own husband died some years ago. And we have 1 buffalo and one goat, so I help feed and look after them too.

But now let me tell you a little about my leprosy.... the doctor says I'm in a real mess with it.

I somehow first caught leprosy when I was only 7 years old. I've no idea how. No-one else in my family - my Mum and Dad and my two brothers - had anything like this.

It started with one or two pale numb patches on my skin, first on my arm then on my front and back, and after a few months there were several of them. And I started to get pins and needles and tingling in both my hands and then soles of my feet ... and gradually I couldn't feel anything much with my hands or feet.

My Mum and Dad didn't know what to do...

Actually there are 2 other people in my village who had leprosy with similar skin patches to mine, and they told my Dad he should bring me to Lalgadh Hospital. But at that time we couldn't imagine I might have leprosy, we were all so frightened, so we really just hoped things would clear up by themselves. But they didn't. They just got worse and worse. I got very sad and depressed.



So eventually when I was 10 - that's 5 years ago - my Dad brought me for the first time to Lalgadh Hospital. It seemed such a long trip then, but now that I've done it several times and am grown up, I'm used to it and now I like coming. We have to catch three different buses. If we start at 7am, we can arrive at Lalgadh Hospital at 2pm that afternoon, still just in time to see the doctor.

The doctor got upset when he first saw me. He says that even now he still feels weepy when he remembers.

I had soooo many skin patches all over.... on arms and all over my legs and up and down my back and front. Both my hands and feet had lost all their feeling. I couldn't walk properly because I couldn't make my ankles work and lift my feet. My fingers were starting to curl over like a claw on my left hand. And I had large infected ulcers on my feet - my right 3rd toe, and my left 2nd toe.

So here I was, still very small and at age of 10, ... in my file that they keep in the nurses office, it says I have severe Multibacillary Leprosy all over my body, a Type 1 leprosy reaction, bilateral foot drop, bilateral ulnar and median nerve palsy, muscle atrophy, anaesthetic hands and feet, claw fingers, and nasty infected foot ulcers on both feet. ... and as the Doc says, I was truly in such a sad and horrible mess... it made him, and some of the nurses, and my parents, and me too... we all of us cried.



Of course I cried the most, because my parents had to leave me in Lalgadh Hospital and for a little 10-year old, very sick, and away from home for the first time that's very scary . I stayed in Lalgadh Hospital for about a month on some special medicine that helps stop the loss of feeling getting worse. And I soon found I was having a great time with other girls who had a problem just like mine in their hands and feet

And... I started getting better and the skin patches and Type 1 reaction all started to subside and fade. And I went home feeling better and carefully taking my anti-leprosy tablets every day for a whole year.

But I have to say that although I keep trying to be so very careful looking after my hands and feet. I've had to come back to Lalgadh Hospital a couple of times over the last 5 years because of ulcers on my hands and feet. The nurses taught me about hand and foot care when I was in hospital. I learnt how to look at my feet everyday, and how to stretch my fingers and feet, and how to pick up hot things even when I can't feel them.



But slowly, bit-by-bit, no matter how hard I try, my hands and feet are still getting worse. I'm slowly losing my fingers... My left hand is worst.... all my fingers are swollen and lumpy and getting shorter. And my right thumb is plain awful. And now I can't lift my feet properly, and I've now got nasty ulcers on the soles of both feet. Pretty ugly aren't they?

That's why I'm back in Lalgadh Hospital now.... and I've been in hospital here for 11 days now. The ulcers on my feet got bad and infected and so awful-smelling so I had to come back for foot surgery and to get them healed. They are almost better now, although you'll probably think they still look pretty awful. You should have seen them a week ago.

Once these are better I can go home.... and I think my Dad may come for me in two or three days.

If my mother-in-law says its OK, I'm going to be coming back to Lalgadh Hospital again in November. There's a famous hand surgeon coming from England ... Dr Donald, who comes here for a week of hand-surgery every year. He is going to operate on my hands to see if he can make them look nicer and work better. Of course Dr Krishna here at Lalgadh Hospital is a marvellous reconstructive surgeon... but he says it's a wonderful chance for me to have the famous Dr Donald rescue my hands in a way that he can't.... and Dr Krishna will focus on my feet. I know there will also be many many people like me from all round this end of Nepal, and from nearby India too, that will come to Lalgadh hoping Dr Donald can fix their hands.

That's my story up to now. If you'd like to hear about how this works out, I can write to you again after Dr Donald has mended my awful hands.... and hopefully I will be able to show you a little miracle in hand surgery..... it will be in December and the nurses say it will be "Christmas present" for me.... though I've never heard of Christmas before.

Meantime Bye for now. Thanks for reading my first-ever letter, and listening to my sad but hopeful little story ... and love to you all.

Shova

