

## STORY OF Mrs. SAH DEI, BRAHMAPURI LEPROSY REHABILITATION CENTRE.

Mrs. SAH DEI was born and brought up in a remote village of Garhwal Himalayas in Uttaranchal. In those days, 60 years ago, there was no school in her village and her parents never bothered to send her to the primary school in the next village, a four km walk through narrow mountain paths. It was different with boys, but girls were always engaged in household chores: collecting firewood from the jungle, bringing fodder to feed the cattle, fetching water from the far away sources, milking the cows, helping their mothers in cooking etc. Her younger brother had the privilege of going to school and completed primary education.

At an early age of 13 Sah Dei was married off, her husband was from the same village. Her husband's land and her father's land was on the same mountain slope, both the families met everyday and helped each other in the field work. 15 years had passed by, Sah Dei had no children. Many elderly women had described their own experiences and advised her to go to the temple of Lord Shiva on a hill top in the midst of five villages and say prayers to God to bless her with children. Sah Dei strictly followed their advice. She kept going up to the temple every Friday to worship, pray and make offerings. Another five years had gone by. No sign of a baby but visible signs of Leprosy had appeared. Everybody started to point at the abnormal shape the fingers of both her hands were taking, along with shortening of toes of both feet. Small wounds in the toes, pressure sores on finger tips and palms and burns during cooking had followed. Very soon the villagers had declared her a "Korhi" (Leper). Pressure had built up from all sides and her husband had to erect a small thatched hut away from his house. Sah Dei moved to her new dwelling. There was no objection for her to work in the fields, firewood and fodder collection and tending to the cattle but she was not to be allowed to fetch water or to enter into the house or the kitchen. Her husband provided cooked food for her. Lot of money was spent on her treatment by well known village doctors with indigenous medicines. Nobody knew whether Leprosy was curable or not. "Leprosy is absolutely incurable. It is the curse of Gods. A punishment for the sins committed in one's previous birth", head of the Village Council had pronounced his expert opinion on the subject.

After months of pondering over the condition of their lives, husband living all alone with no children, wife in half segregation, most painful of all was the sad fact that the husband had to cook for the wife and above all, the future of the household, the couple, after a lot of consideration, at last arrived at a conclusion that the only way out was to adopt a child. The husband requested his sister and brother-in-law to give one of their sons for adoption but they refused, on the pretext that they would never prefer to have their son in a family where one member is a 'Leper'. Sah Dei approached her brother and requested. He instantly sent his eldest son, 15 years old by then, without questions, conditions nor formalities of adoption. Sah Dei and her husband preferred to call the boy, "Nephew".

Sah Dei's brother had arranged for a hired horse and took her to the Government Primary Health Centre 18 km away by a bridle path, a five hour journey. She was provided with a bottle of antiseptic lotion, cotton and bandages for the treatment of ulcerations on hands and feet. She was advised to go to the District Hospital at Tehri, 60 km from the Health Centre, by bus. They returned home. Her condition steadily deteriorated. Loss of sensation in both hands and feet due to permanent nerve damage caused by Leprosy had resulted in frequent ulcerations and damage to bones and joints of fingers and toes. Her husband's health was no better either. Fruitless marriage, wife's discriminating disease and partial separation had all taken a toll on his health. The day had come. Much sooner than anyone of the family had ever expected. Sah Dei had become a widow. She collected her meagre belongings from her hut, climbed up the hill to the temple and made the

temple premises her abode where she did washing, cleaning and making preparations for the temple priest to make the daily routine worship and rituals. The laudable fact even in those days was that a person though suffering from Leprosy was not prevented from entering into the Sanctum Sanctorum, the only strict condition was that the person should belong to a high caste, Brahmin or Kshatriya. Sah Dei's decision was that she would spend the rest of her life in the service of the temple. The priest had anointed and blessed her to start a life of renunciation, meditation and spiritual enlightenment. She started a new life, clad in saffron clothes, string of beads around the neck, shaven head, she spent most of her time meditating and chanting the names of God and ate whatever came her way. She hoped to find peace throughout the rest of her life and to attain at the end a complete deliverance from her scourge.

But all her hopes were shattered very soon. A small ulcer that had developed a year ago in her insensitive sole had grown wider and deeper. Bacterial infection ensued. In the absence of medications, the bacteria rapidly invaded the whole foot causing a lot of pain, swelling and fever and the ulcer oozing with pus. The priest provided some crushed medicinal leaves to apply on the wound, some old clothes to cover the foot to protect from flies and a few pills for fever and pain. Hearing the news, her brother and nephew arrived. They felt helpless, all they could do was a regular supply of milk and blankets to keep her warm. Word spread that Sah Dei was seriously ill and the villagers started coming to the temple to pay her a last visit, but from a safe distance.

A man who came to meet his relatives in the village had heard people talking about a "Dying Leper at the temple". Many years ago he had taken a Leprosy patient of his own village to Brahmapuri, got him admitted there and when he went to meet him later, he found the patient altogether a different person. He went to see Sah Dei and reacted on the spot insisting that her brother should take her to Brahmapuri without wasting a single day. He hastened things up, got a horse ready, along with the brother he brought her to the Primary Health Centre and tried to put her in a bus, but the bus conductor refused to take a seriously ill patient lying on the roadside. Two more last buses to Rishikesh went by, no luck. It was the end of November, winter in India. It was almost dark, an empty truck returning to Rishikesh had stopped as if God sent. The two men loaded her into the truck, laid her comfortably and sat on either side. Reaching Rishikesh just before day break they hired a taxi to Brahmapuri, 8 km beyond Rishikesh, on the Badrinath road.

Thanks to the 'Good Samaritan', Sah Dei in early December 1989, found herself surrounded by men and women of Brahmapuri, talking to her in Garhwali dialect while she was given a tablet to reduce fever and pain, followed by a refreshing mug of tea. The medical team was swift, they gave her a good hot water bath and a change of clothes, soaked her foot in a bucketful of warm water mixed with antiseptic, washed with soap and water, bandaged the wound, dabbed it with strong deodorant and laid her in a bed, the foot was kept in elevation to help reduce the swelling. Two weeks of hard work of the medical team, twice daily cleaning and bandaging, potent antibiotics did not bring much result except some reduction in swelling pain and fever. Nutritious food, vitamin protein supplements combined with the homely atmosphere and psychological support have helped in her general health.

That was not normal. There must be something seriously wrong. A careful, close look at the ulcerated surface showed a fine, white hairy growth resembling a cauliflower like growth, a probable explanation for the offensive odour. A pathologist in Rishikesh was consulted, he advised to see a pathologist in Dehra Dun, who after listening to our medical worker's description of the clinical picture of the case, he provided a container with preservative and asked to bring a few pieces of the affected tissue. The biopsy was done at Brahmapuri. The specimen was sent by courier to Lucknow, capital of Uttar Pradesh 350 km from Dehra Dun for examination. After two weeks the report came, saying that the condition of the foot was a cancerous growth. The Pathologist suggested an amputation at the earliest. Sah Dei was taken to Government Hospital,

Rishikesh. The orthopedic surgeon looked at the biopsy report and advised to go to Doon Hospital. The next day Sah Dei was taken to Dehra Dun. The surgeon, after half a day's wait, did not bother to look at her foot, just the biopsy report, scribbled on the Patient's Registration Form, "Referred to Meerut Medical College", he did not care to order for a fresh bandaging even after repeated requests. Returning to our Leprosy Rehabilitation Centre in Nala Pani, Dehra Dun, cleaning and bandaging was done in the Centre's dispensary. After a late lunch and rest, our medical worker took Sah Dei to Delhi by night train.

We knew about a Leprosy Hospital run by the Missionaries of Charity (Mother Teresa's Sisters). Five to six hundred Leprosy patients are under treatment in the Hospital. Once a week 20 to 30 patients are discharged and about the same number are admitted on every Friday. Everything is free of cost, food, medicines, surgeries and other treatments and every care. Not knowing clearly about the day of admissions, our medical worker with Sah Dei sat at the main gate of the Hospital on that Wednesday morning. Bad luck, no chance of admission, not even a change of bandage, must wait till Friday. Thanks to the gatekeeper who told about a Leprosy Settlement run by the Municipal Corporation of Delhi and its Dispensary, a ten minute walk. Sah Dei was taken there. They were kind enough to make a fresh bandage. The Dispensary in Charge said, "You can stay on that building verandah and eat at one of those tea and meal shops". A dilapidated building, locked all over, waiting for renovation, the big long verandah was empty. Soon after the nightfall the verandah was crowded with Leprosy beggars returning for the night, after begging on the street of Delhi all day. The lonely, silent and dull place woke up with the noise of their talking, shouting and laughing. They ate their dinner, spread out their blankets and gone to deep sleep. Very early next morning they were all gone, carrying their belongings, for another day of begging.

Friday morning, Sah Dei was sitting at the gate along with a big number of patients, mostly with ulcerated hands and feet. The Sister Doctor studied the Biopsy Report, examined the foot and ordered her admission. One or the other of the medical workers kept going to Delhi to meet her. A below knee amputation was done within two weeks and it took two months of post-operative care for complete healing. After discharge she was brought back to Brahmapuri. As per advice she had to wait for two months before going for an artificial leg. She learned to walk with the help of crutches and was introduced with a spinning wheel, she started to learn thick yarn spinning.

The only place in those days (1990) for artificial limbs in North India was Jaipur. A charitable Organisation aided and run by the Jain Community of Jaipur city, well-known to make and provide good quality artificial hands and feet for amputees due to medical reasons and accidents, entirely free for the poor. Accompanied by two of our medical workers, Sah Dei arrived at Jaipur. Her name was registered in the office of the Institute. A Physiotherapist examined her leg and prescribed her, what is called, "Jaipur Foot". Free food was provided to the patients and their attendants, in the big dining hall and a long tin shed for the people to take shelter and sleep on the floor. Sah Dei's Card was shown to the technician to whom her job was assigned. He told her to sit. Nothing was done the whole day. The workshop was closed in the evening and she was brought back to the shelter. Three days went by, the technician did not start her job even after many requests. There were more than a hundred people wandering all over with their broken prostheses, waiting for replacement. The Organisation provides utensils and materials to patients to start a tea shop or a meal shop to earn a livelihood. They provide sewing machines to those who know tailoring and cycle rickshaws for those who can ply with an artificial leg. This has explained for the crowd. There were a number of rich people who stay in hotels, come there, get their job done within a day and return home. Two more days passed, nothing was done. In the evening a man came to Sah Dei's attendants and gave a piece of advice, "How long do you want to wait and waste your time? Just pay him Rs. 500/- your job will be done in a single day and you can go home." First thing in the morning they paid the amount to the technician. He said, "Go, get a pair of shoes for her" and got to work. A Plaster of Paris mould was made as per the size and shape of the knee joint, a P. V.C. plastic pipe softened in an oven was worn over it, shapened and polished. The leg was

ready, a pre made leather strap was glued at the knee joint, a pre- fabricated rubber foot was inserted and fixed with screws. The leg was strapped above the knee joint, new shoe was worn over the rubber foot, and an hour's walking practice with the help of iron bars and that was it. Sah Dei was on her own feet. The appreciable fact was that all through her long travels and stays at unknown places in harsh conditions, she never complained of any inconvenience.

Back in Brahmapuri, Sah Dei continued with her daily worship at the Shiva Temple of Brahmapuri. She has learnt to walk with ease, managed with her cooking, washing, cleaning and doing spinning. During the past 15 years. She has been contributing to our rehabilitation work with her regular supply of cotton yarns for weaving. Her nephew got married and has children, he comes to Brahmapuri to meet his aunt/mother.

Our grateful thanks to SOIR-IM for their kind sponsorship support for elderly workers like Sah Dei.

K. Bangaraiah.

Medico-Social Worker,

K.K.M. HANDWEAVING.



Mrs. SAH DEI

BRAHMAPURI