

# *Dignity Regained II*

Editors  
M S Rajagopalan & S S Rajput



Publishers

**Sarthak Manav Kushtashram, Jaipur, INDIA**

Supported by

**SASAKAWA MEMORIAL HEALTH FOUNDATION**  
Tokyo, Japan



## A PADMASHREE'S VIEWS ON DIGNITY

In those days in early 1970 even the people in the Medical side did not believe that the disease is curable and the Leprosy affected people could lead normal useful life like anybody else. That was the time when I started my work on socio economic rehabilitation for the affected people. Socio-economic rehabilitation in leprosy field started to grow from my days. I am thankful to all those organizations that all helped me in my service to widen my scope so that people could go back to the society and lead a normal life.

Now there is a momentum in the leprosy field to create an archive to document the truths and facts about leprosy, the treatment and the sufferings that the affected have gone through. It should be made available for the future generation to know as to what sufferings this disease caused and how they fought against leprosy. We were able to bring out the first book Dignity Regained and now the second book of Dignity Regained is coming out I really appreciate all those who have worked to bring out the successful life stories of leprosy affected people and their marvelous success I wish that this book should be made available in different languages to the young people. It should be kept in all college libraries and should be sent to all the social work department in colleges and universities so that people can do some study on it.

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A Collection of Biographies of Leprosy affected persons

Published by:

Sarthak Manav Kushtashram Jaipur.

With support from **Sasakawa Memorial Health Foundation**,  
Tokyo, Japan.

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*Getting affected by leprosy is something, but instead of living with it, fighting against it is else again. Some of the leprosy affected persons have chosen to fight with confidence, courage, character and commitment. And they have conquered as well. In the process, they have flooded the lives of other affected persons with new beams of light-light of hope-and self confidence, like the water which flows to irrigate the agricultural fields, also give water to the flowering plants they pass by. They are living not only for themselves, but for others as well.*

*To such committed persons, we dedicate this book wholeheartedly.*



## FOREWORD

In 2005, a collection of real-life stories of people affected by leprosy in India was published called *Dignity Regained*. In the history of leprosy in India, 2005 was an extremely important year, and one I shall never forget.

First, India achieved the target set by the WHO of eliminating leprosy as a public health problem. This is a prevalence rate of the disease of less than 1 case per 10,000 people at the national level. Everyone believed this would be too difficult for India to achieve, but it did so at the end of 2005.

In the latter half of the 1990s, India saw over 600,000 new cases of leprosy per year. Through the efforts of all concerned, however, this figure was reduced to less than a quarter of that number. Today, with annual new cases totaling some 120,000, the disease has not yet disappeared from India. Nevertheless, the elimination of leprosy as a public health problem represents a historic step forward. I visited India seven times in 2005, and I remember clearly traveling around the country, lobbying political leaders, encouraging people working in the field and listening to the voices of people affected by leprosy.

Another reason why 2005 was so important is due to the unforgettable day we began fact-finding research in the colonies around the country. This was important to understand the situation at hand, in order to better promote the rights of people affected by leprosy. This led to the creation of the National Forum, which is a network of residents of self-settled leprosy colonies all over India. The National Forum brings them together and gives them a platform from which they can make themselves heard in society. Seven years later, their voices now reach many people, including political leaders; for me, this is the greatest encouragement of all.

The changes taking place in India are influencing other parts of the world. After 2005, seven more countries in Asia and Africa have eliminated leprosy as a public health problem. At time of writing, only Brazil has still to achieve this target. The original volume of *Dignity Regained* was very well received when it first appeared, and similar

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collections of stories have been published in China, the Philippines, Ghana, Cambodia, Myanmar and Indonesia. These accounts by people affected by leprosy of their life stories and of the difficulties they have had to overcome have proved truly inspirational, and are helping to change attitudes and remove the prejudice that those with leprosy endure. Furthermore, organizations similar to the National Forum are becoming active in other countries.

In 2003 I approached the United Nations to take up the issue leprosy-related discrimination. Seven years later, in 2010, the UN Human Rights Council and the UN General Assembly unanimously adopted a resolution on “Elimination of discrimination against persons affected by leprosy and their family members.” As part of that process, the voices of people affected by leprosy were heard for the first time at the then UN Commission on Human Rights. I believe this played an important part in the eventual adoption of the resolution.

However, this resolution is only a step on the road to creating the conditions that will allow people affected by leprosy to live with dignity. Stigma and discrimination remain deep-rooted and we must do all we can to work for a just society.

As you read these testimonials, imagine that each person in this book is your parent, your sibling, your child or perhaps even you. Then please consider what you can do to create a society where we can all live as one. I hope that with the publication of this second volume of *Dignity Regained*, the courage of people affected by leprosy to talk about their lives and to share their emotions will elicit a response that will hasten the creation of a society in which all people can live with dignity.

***Yohei Sasakawa***

WHO Goodwill Ambassador for the Elimination of Leprosy  
Japanese Government Goodwill Ambassador for  
The Human Rights of People Affected by Leprosy  
Chairman, The Nippon Foundation, Tokyo





## **Note from the editors' desk**

Much has been said and written about leprosy work. Innumerable scientific papers and research articles have found way in various journals pertaining to leprosy. Of late the focus has shifted to the affected persons. Successful stories of various affected persons are sought and printed to bring to public notice the life of these people. Open minded, these people have talked about their sufferings, humiliation and eventual success. It is a sort of '*from the horse's own mouth*'. This book is a humble attempt towards bringing to limelight a few of such successful persons.

'Dignity regained' says the book title. But, first of all, how was it lost? Or is it more appropriate to say 'snatched' instead of 'lost'? If it was actually snatched, then it should be only logical to 'restore' it instead of regaining. But the society would not so easily restore dignity on these affected persons, in spite of the fact that they have succeeded in life. For, society is still drowned with irrational ideas. Hence they would never 'restore' dignity. The only way left for the affected persons is to go to society and proclaim their success. From thirteen states all over the country, people have come forward and narrated their success thro' this book.

The editors are thankful to all these individuals for not only their narration but also for their consent to share their experiences with us. But identifying them, arranging for the interviews, making travel plans and managing funds for this purpose is something of a Herculean task. Mr. Suresh Kaul, President Sarthak Manav Kushtashram has come out with flying colours in this work. Kudos to him! In their relentless tirade against leprosy oriented problems, Sasakawa Memorial Health foundation has always held out a helping hand and but for their financial and moral support the book would not have seen the light of the day.

This book is all the more decorated by the valuable foreword by Mr. Yohei Sasakawa the Chairman of The Nippon Foundation, Tokyo, Japan. Our heartfelt thanks go to him for his valuable write-up.

Our thanks also go to Mr.K.N.Madhavachari proprietor Annai Designs, who took great interest in the cover design, layout, photographs, production and printing. Eventually he has brought out a good work.

The editors feel honored to be entrusted with a task of such magnitude and hope that they have lived up to the expectation.

*M S Rajagopalan*  
*S S Rajput*

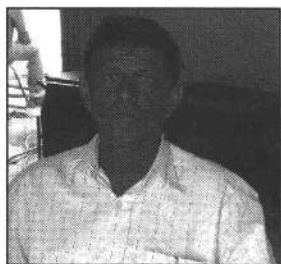


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## THE DISEASE WAS NEVER A HINDRANCE FOR LEARNING

- Arjun Mahato

*Interview by M S Rajagopalan*

**P**urulia is one of the most backward and poor districts of India, and is certainly the poorest and underdeveloped district of West Bengal. People are mostly of tribal community, with their own customs and traditions. In the backdrop of such scenario, if a leprosy affected person establishes himself as a successful entrepreneur, it is something to be talked about.

'Mahato welding unit', says the board in front of his workshop. Underneath is the proud word 'prop: Arjun Mahato'.

Arjun's father late Sonu Mahato and his wife was the proud parents of Arjun Mahato and his younger brother Vrinchi Mahato. Uneducated lot, all were working in fields as agricultural laborers or doing manual work for the daily livelihood. Life was an affair of day to day existence.

"Papa, I want to go to school" said Arjun one day.

His father Sonu looked at his son in consternation, as if he heard something unparliamentary.

"What?"

"Yes papa, I want to study."

"But don't you know that education is a costly affair, and no one in

our community has ever done it. I have no money for your education. Further, I have no strength to work extra hours”

“But education is free up to high school level”, said Arjun hesitantly as he looked at his father's mildly deformed hands affected by leprosy.

“What about other expenses? Books and notes are to be purchased. You will need pen, pencil and some decent clothing. No, I don't have money for all those. Forget it.”

“That you don't have to worry, Papa. I shall do some menial jobs and earn some money with which I shall look after those expenses. I need only your permission and blessing.”

Sonu Mahato was moved by his son's enthusiasm and gave his consent for his son's study.

As told to his father, Arjun undertook small errands between 6 and 8 in the morning hours and with that money he met his needs, not disturbing his father financially. This two-hour work earned him 2 rupees per day. He walked to the school which was three kilometers away. After attending school between 10 am to 5 pm he assisted in the household work as well.

Working hard, Arjun studied up to 12th standard. But he failed in the government examination. And with that he stopped his education. It was at that time Arjun was having problems with his health. He had developed pain in his knee joints and weakness and anesthesia in both legs. Also a patch had appeared on his forehead.

“What is wrong with you? I am noticing that you are tired now a day and restrict yourself to the corner of the room.” His father asked him one day. Arjun explained to his father the problems he was facing with his health.

Sonu Mahato immediately understood that his son has developed leprosy. He was himself a sufferer and hence did not fail to understand his son's ailment.

“Come; let's go to the doctor who has been treating me. He will also treat you.”

“But, why to your doctor? We can go to some general physician.”

It was a painful moment for Sonu, but he had to live up to the moment.

“Son, I do not know how to tell you this, but the truth is that your symptoms are that of leprosy, and my doctor knows how to treat you”. Arjun's heart broke at these words, but since he has been seeing a leprosy affected person for some time in the form of his father, he gathered composure quickly. Both father and son went to the doctor who confirmed the disease and started treatment for Arjun. He does not know the names of the drugs, but says that one was yellow and the other black. It was not prescribed, but was given from doctor's own bottle. The treatment went on for 9 months and Arjun got cured of the disease. Luckily for Arjun, he was diagnosed and treated at the very early stage and hence escaped from getting deformed.

He was nearing the age of 24 and wanted to contribute to the family's income. But he was afraid of working for others for fear of stigma. He decided that he would have his own business. Earlier Arjun had undergone a training in cycle repairing under a panchayath rural welfare scheme in which he was to be given training on cycle repairing and on completion of training, a sum of rupees 1000 to start his own business. Though he completed the training he was never given the amount promised. Angered by this he decided to start his own cycle repair shop.

A fat fowl that the family was rearing was sold for 26 rupees and with that he purchased a pump for filling air in cycle tyre and a wrench. With these two equipments, he started his cycle repair shop. Gokul nagar, the remotely located village of Arjun was quiet a distance away from Balarampur, the nearest town. It was connected by rough macadamized road and the main mode of transport was either a bullock cart or cycle. Hence Arjun's shop suddenly gained importance. On the very first day he earned 5 rupees with which he purchased puncture pasting solution, a can of grease and other equipments. His business thrived and he further expanded his business.

Arjun was not a person to be satisfied with small successes. He was ambitious and was dreaming of expanding his activities. One day when a cart owner was talking about the lack of welding facility in the village for repairing of cart wheels, Arjun snatched the idea. He decided that he would enter welding line, though he had absolutely no idea and knew nothing about welding. He did not want to start another cycle repair shop and be a rival to his own brother. He handed over the ownership of the cycle repair shop to his younger brother Virinchi. Virinchi was also a grown up man and needed to do something to sustain the family. Then Arjun started his look out for getting trained in welding. Someone suggested him the name of one Niranjana Karmakar in Balarampur.

"I want to learn welding" said Arjun to Niranjana as he stood in front of the welding workshop of Niranjana Karmakar at Balarampur.

"Who are you?"

Arjun told all about him and his family, excepting that he is a leprosy cured person.

"But you have the knowledge of cycle repairing. Why don't you start a trade that you know very well?"

"Because, Gokulnagar is too small a place for two cycle repair shops. And I don't want to be a rival to my own brother. Also the inhabitants are peasants who depend heavily on bullock carts. If the cart wheel breaks, then they have to come all the way to Balarampur for repair. Once I learn this welding work and start my own shop there, it will be of use to one and all."

"I can teach you the trade free. But I shall not be able to pay you any wages. All I shall give you is a cup of tea in the evening, and of course I shall impart you with all knowledge about welding that I possess. Will it be alright for you?"

Arjun readily agreed to the proposal and started attending Niranjana Karmakar's workshop. He was helped by his younger brother with 2 rupees each day. In precisely one week Arjun learnt the trade completely and was ready with knowledge to open his own business. He had two obstacles, though.



There was no electric connection for his house. And through Niranjan Karmakar he had learned that an initial capital of Rs. 10,000 would be needed to start the workshop. First priority was electricity. He approached cousin, a maternal uncle's son for help.

"You want five hundred rupees for what?"

"I intend to draw electric line for my house, so that I can start a welding workshop."

"How would you repay it? What is the guarantee that you would ever repay?"

Arjun had no answer for this sort of questions and he kept silent.

"Don't worry. I shall give you the money. Return it if you can. Otherwise it shall be my gift to you."

Arjun got the sum of 500 rupees with which he got the electricity supply. Money for initial investment started coming in. His aunt's cousin gave 4000 rupees; Niranjan Karmakar gave 1500 and his own brother 1500. He approached Gandhi Memorial Leprosy Foundation, Balarampur and got a help of rupees 500. Arjun acquired the necessary equipments with this money and was ready with his workshop. But unfortunately he was left with no money for purchasing raw materials. Once again he approached GMLF and this time he got a sum of rupees 4000. Arjun's unit started to function. Regular orders were coming in for manufacture of cart wheels and Arjun started making regular income. Business grew so successfully that he appointed local boys in his workshop, trained and employed them for wages. Boys were willing to come and learn the trade as well as earn.

One day a villager was talking to Arjun about power shut downs and the need for batteries to sustain the power supply. He urged Arjun to start a battery servicing unit. Arjun decided to learn that trade too.

"Go to the person opposite the J K College. He is famous in battery line and would certainly teach you about it." the villager told Arjun. Arjun thought that it was a good idea and set out to know about batteries.

Standing in front of the man who was running the battery shop Arjun repeated what he had once said to Niranjan Karmakar. After due

conversations, Arjun was baptized in to Battery business and started learning about batteries. As is usual with Arjun, he started picking up the intricacies of the work very fast. Soon Arjun found one thing. In batteries which became faulty, while the negative plates were often intact it was the positive plates which went wrong. The thin wires which went along horizontally and vertically snapped and gave away and thus caused trouble. He went about setting them alright and to everyone's surprise the batteries started functioning. Thus Arjun struck a gold mine in battery business.

Returning home Arjun took up servicing of batteries as well.

Jamshedpur, one of the big towns of Jharkhand was only seventeen kilometers away from Gokulnagar. And power cut was so severe, that people were frustrated. Because they could not watch TV programs! And it was not long time before Jamshedpur residents heard about Arjun's skill in batteries. And clients started pouring in. Someone suggested that Arjun, apart from servicing, should also assemble new unbranded batteries. Taking up their suggestion, Arjun procured various components for making of new batteries and started assembling them in to workable batteries. It not only turned out to be a success, but also profitable. People who did not as much bother for brand names but were looking for low cost, started coming up to Arjun. An assembled battery fetched Arjun a profit of 400 rupees and he was able to deliver fifteen batteries in a month. Thus his hands turned out to be profitable in this new trade as well. His workshop now has about 10 persons working in both welding and battery fields.

Mahato Community marriages are usually within relatives and rarely do they go outside for boys or girls for marriage. The only criterion for marriage was that if boy likes to marry a girl, the approval of boy's father is a must.

Arjun saw Sundara Mahato and took liking for her. He duly got the approval of his father. With a bicycle as dowry he married Sundara. It is a poetic justice that Arjun, who started his carrier as cycle repair man, should get a cycle as dowry! Two years after marriage their eldest female child Janani was born. Four years hence boy Pinku was also



born. The boy is in his college days, while the girl has been given away in marriage. But they are all living together.

For such a big joint family a big house is a must. Arjun has purchased not only a new site alongside his ancestral house for his workshop, but also a house where the entire Mahato family lives happily together. The unit consists of Arjun's mother, Arjun's family as well as the family of Virinchi the younger brother who also got married and is having his own children.

The house has seen not only an increase in the number of trade activities. From cycle repairing it has witnessed the addition of welding unit and then battery unit all under one roof. Similarly this house may witness new generations getting added to the family.

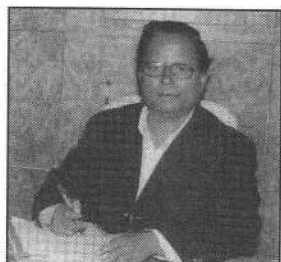
When I walked out of the house, I had the feeling that Arjun may add some more trades under the roof and some more new entrants in the family as well. And all would be prospering under the leadership and guidance of Arjun Mahato.

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*Interviewer's note: Arjun was indeed lucky not to get deformity and the consequential stigma. But he as shrugged off his earlier fears of stigmatization and has now turned out to be a successful and resourceful person. A typical example of how a committed person can come forward in life.*







## PERCEVERANCE PAYS DIVIDENDS

- Goswami Tribhuwan Giri

*Interview by O.P. Bisht*

**I**f Tribhuwan Giri had got the proper treatment at the right time, no doubt today he would be on the top of his career.

Genius Tribhuwan perhaps regrets that, but in spite of those situations he has reached such a place, which only a few leprosy affected persons can reach.

Turning the pages of his past life, Tribhuwan Giri told that he was born in a small village named Saleemapur distt. (Chhapra) in Bihar in 1949. Recalling his past memories he told that he was born in a Brahmin family. His father Sabha Shankar and his mother, who was a simple lady, both loved him very much because he was the eldest son of the family. He has two brothers and two sisters. He was brought up under the loving care of his parents.

Giri got his primary education at the local school.

The main occupation of Giri's family was agriculture. Whole family was depended on agriculture. There was no leprosy patient in his family. But in their village a man was suffering from some severe type of leprosy.. Giri's family used to take milk from that person. At that time they didn't know about his disease.

Being the eldest son Goswami Tribhuwan Giri had to go to that person to take milk. At the age of 12 Tribhuwan noticed some patches on his body, but he didn't take it seriously. When they spread on the whole body, he became worried. The persons around him told that it was 'Sunbahri disease'." His father took him to many sages and saints. But they were all in vain. His hands and feet lost sensation and he had developed an ulcer in the big toe of right foot. He was suffering from the pain in the nerves of his hands and legs. His fingers of both hands became deformed.

Seeing the pitiable condition of his beloved son, his father became very anxious. He was told to take his son to Mairwa. Hospital. He took him there.

There, after check-up, it was diagnosed as leprosy. This news spread in the village and all of a sudden the behavior of villagers and relatives changed. Goswami Giri had to face stigma, discrimination, hatred and isolation. At that time this disease was considered an incurable disease. Goswami Giri could not bear the hateful attitude of the society. He left the village and began to live in a rented house in Chhapra. There he continued his study. He completed his graduation (B.A.) and post Graduation (M.A). His parents gave him money to meet all his expenses.

After completing study, Tribhuwan Goswami Giri's sickness became more serious. He got high fever and suffered from pain in both his wrists. Someone advised him to go to Ranchi and take treatment at Brombey Hospital. Goswami Giri immediately went to Brombey Hospital, Ranchi. He was all alone. The doctors saw his serious condition and admitted him. There he remained for six months. He got some relief but there was not any improvement in his physical condition. Meanwhile some of his fellow patients told him about a hospital Jalma. This hospital was run by Japanese. Goswami wanted to recover as soon as possible, so he went to Jalma hospital. There he took treatment for three months. After three months, he was cured completely and got the negativity certificate.

Goswami Giri knew that his village and his society will not accept

him. He could not tolerate their hatred. So he decided not to return to his village.

In the hospital he came to know that some leprosy affected persons were living near Red fort in Agra. They had made their huts and led their lives. Goswami had no place to live so he went to Agra and began to live with them.

Goswami Giri was not happy and satisfied with that. He noticed that there was some land in the middle of Jalma hospital. He, along with his fellow patients, cleared up that land and made huts there. Then he and his friends went to donors and requested them to help them with clothes, food etc.

One day a foreigner lady came to visit their ashram'. Goswami showed her his deformed hands and legs and requested her to send him in some hospital for surgery. That kind lady sent him in Bandarwala Leprosy Hospital, Kondawa in Pune, Maharashtra. She gave money for all the expenses of his surgery. After surgery Goswami came back to his ashram and began to spend his life with the help of donors.

In 1975 Goswami married a girl who was also leprosy affected and lived in Puruliya in west Bengal. God blessed them with a son.

Goswami Giri was working hard to improve the living conditions of his ashram in Agra. Hearing of his noble work, the leprosy affected of Shikohabad also came to him for help. Giri found out a government land and made a Kachhi Basti (Colony) and thus solved their problem. He also helped the leprosy affected people in Gwalior.

After that he went to Jhansi. There he gathered some leprosy affected persons and made huts for them near 'Kali Temple.' Later on, this land was purchased in the name of Kushtha Ashram Laxmi Gate Jhansi. There he made about 30 rooms with the help of government and others donors. This ashram is running very well.

Goswami Giri liked the peaceful environment and positive thinking of the people of Jhansi. He decided to settle in Jhansi. He started a tutorial Centre. The people liked his way of teaching. They began to send their children to Giri. Gradually Giri saved some money. He

purchased a piece of land there. Later on he constructed ten rooms on that land and started a school. At present this school has been upgraded to a High school. It is a government recognized school. Goswami Giri is the head of this school.

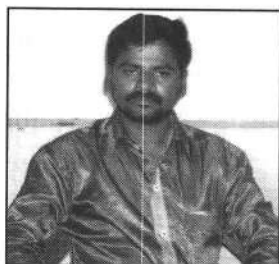
Once again Tribhuwan Giri lost in his memories and said, "I have no complaints against my villagers or my society, but I am deeply hurt because my family members could not understand my feelings. When I returned home, after getting six months treatment, I was shocked to see that I was put in a room and no one was allowed to come to me. I was isolated in my own home. I was dejected, and was all alone among my own parents, brothers and sisters. They never cared my feelings."

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*Interviewer's note:- Tribhuwan Giri wants to forget everything which gives him pain and sadness. He worked hard, never gave up hope. He brought up his only son in a good manner. His son is a well educated person with M.Sc. (Chemistry) and B-ed. He got his son married in the same society which earlier rejected him because of his disease. But now he has received the honour, the acceptance and the love which he deserved. This respect and acceptability he regained, because he worked hard and never looked behind. He walked all alone but people joined him and at last he got his place, as a leader.*

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## PERCEVERANCE BROUGHT NEW HOPE IN MY LIFE

- K. Rajanna

*Interview by M S Rajagopalan*

**“I** am telling you for the last time. Your son should get out of this house.”

Rajanna was about to enter the house when he overheard his sister's voice. There was no need for overhearing, for she was shouting at the top of her voice that it was audible four houses away. He paused at the door steps to listen further.

“Why are you so much adamant about chasing him away from the house?” his mother was asking her daughter.

“Because he is having leprosy and I don't want my children also to have the disease from him. It is dangerous to have one leprosy affected person in the house. We have two. Both of your sons are affected persons. What is the use of keeping them in the house? And they don't make any contribution to the family income. They are burden on my husband. And my husband is not rich to feed your two sons. I have my own children whose future we have to think of. No, it is not possible to keep them in the house. Tell your younger son to leave the house.”

“But where will he go?” Revamma tried feebly to defend her affected son.

"It is not my concern. And I don't care as to where he goes. All I want is that he goes away from this house."

Without making any sound Rajanna moved away from the house with a heavy heart.

Discrimination against leprosy affected persons is not something new. It usually comes from the society, particularly in a village set up. But in Rajanna's case it was his own sister who sowed the seeds of discrimination and stigma in the minds of her mother as well as other members of her community.

Chakrappa and Revamma were a poor couple of Kamalapura, a small hamlet near Bellary town of Karnataka. Belonging to the washermen community, The family had no education to speak of, which was traditional. Each generation did the dhobi work and inherited illiteracy. But Rajanna was an exception.

The couple had three children, a boy, a girl and then Rajanna. Collecting the village peoples' dirty clothes, washing, drying and ironing them, and delivering to the respected houses were shared by the family members. Though Rajanna was also helping in the traditional trade of the family, he showed a great interest in studies. His dream was to go to school and then college and get a degree. And he managed to get education as it was free up to 10th standard.

But Rajanna's elder brother had developed leprosy. And the trouble started. His sister and her husband did not like the idea of the elder brother staying in the house. The boy maintained that the house was theirs and none had any right to object his stay. So a cunning plot was conceived and the sister started telling the villagers that her brother had leprosy and hence they should refrain from giving clothes to him for washing.

Thus the elder son's economic and social positions were demolished.

He started a laundry in the nearby village, minding his business and coming home only for food and sleep. But his sister damaged that also by informing people of village where he was working about this disease.

People stopped patronizing him and building owner refused permission for running the laundry any more. Out of desperation he turned a vagabond. Never caring to get proper and sustained treatment, he was loafing around and none knows what he is doing for livelihood. Needless to say that he remained unmarried.

But Rajanna was blissfully unaware of anything that was going on in the house. Though he helped in the family trade, he was completely drowned with his studies. He was so much involved with his education that he failed to take notice of the pale yellow lesion that was developing on his face and ignored it completely. He successfully completed the 10th and wanted to join college. But the family income was too meager to spend any money on his studies. The mother, sister, her husband and their three children and Rajanna together made a big family to feed. So they discouraged him and refused any help for his education. But some neighbor came forward to help him and he joined college.

Leprosy was usually diagnosed by someone attached to a hospital or PHC. But in his case, Rajanna's disease was diagnosed by his friends in the college. They were noticing that Rajanna was frequently dropping things from his hands. Dropping things was not something unusual, but the friends knew that his family has already an instance of leprosy in his elder brother's form and there was the lesion on the face of Rajanna which was a telltale symptom. They were diplomatic not to use the word leprosy, but suggested that he should consult some doctor, because some weakness is making him drop things from his hands.

To cut the long story short, Rajanna's education terminated after 3 months of college going and he was confined to the house. History repeated itself and whatever discrimination his brother was subjected to, Rajanna also suffered.

He was not to move around in the house any more. He was shown a corner in the house, where he was supposed to confine to. Separate plates, tumblers, bed spreads and pillows were allotted to him and he had to wash his own plates and tumblers and keep them in the place allotted to him. One day, absentmindedly, he put his washed plate along with other family utensils and the punishment meted out to him was



severe. No more washing of plates after eating ! It was left to dry, and he had to take next meals in the unwashed plates, earlier infested with plenty of flies. In short a hell was created for him in his own house.

The battle between mother and daughter was repeated many times and eventually the mother agreed to banish her son once for all from the house. If the boy is treated in the local PHC he will have to stay in the house. Hence a diabolic plot was conceived. It was decided to take him to the Central Leprosarium, located at Magadi Road, Bangalore, admit him there and forget him once for all. It was also decided that none of the family members will go, but send some outsider with the boy to do the job !

Having overheard the quarrel between his mother and sister Rajanna dejectedly left the house without entering it, and wandered aimlessly in the streets of Kamalapura. Someone called his name and he stopped.

“Rajanna, come with me. “

“But where to ?”

“We are going to Bangalore. I have been asked to take you to leprosy hospital there and get you treatment.”

The words between his mother and sister were ringing in Rajanna's ears and he silently followed the stranger. Reaching Central Leprosarium, Bangalore, Rajanna was duly admitted and started on anti leprosy treatment with dapsone and lamprene. In the meanwhile the anesthesia in Rajanna's hands had led to deformity. After some months of treatment he was referred to CLT & RI, Chengalpattu for reconstructive surgery on his right hand. He was admitted in to the Karnataka block of the sanatorium and was started on pre-operative physiotherapy. But Rajanna had developed his first planter ulcer in the meanwhile. While traveling from Bangalore to Chengalpattu, he was sitting close to the driver, near the bus engine. The heat generated by the engine had caused a blister which ended up into an ulcer.

One day Dr. Durai called him.

“You are an educated person, aren't you?”

“Yes”

“You see, you have developed an ulcer and it is going to take some time to heal. Also your hand muscles should be soft and the finger joints flexible for any surgery. That is going to take time. Instead of wasting the time why don't you accept some work till the hand is ready? If you agree I shall fix you with some job in the ward. You would be getting some money by way of wages. What do you say?”

Thus Rajanna became the unofficial ward boy of CLT & RI for a wage of Rupees 150.

The physiotherapy and ulcer dressing went on well and after a few months, as Rajanna has saved some money, he decided to go to Kamalapura and see his mother. But he found the hard way that the attitude of the people towards him had not changed. Again he suffered the humiliation of isolation and unwashed plates for the next two months. Unable to bear the torture, he left once again for Chengalpattu, to resume his activities as ward boy.

Once surgery was performed and post-operative physiotherapy was successfully completed, the hospital management discharged him. He returned to his own Karnataka state and got admitted in Central leprosarium once again.

“You are young and educated. Don't waste your life here in this hospital. Go to Sumanahalli leprosy treatment and rehabilitation centre. They would somehow find a way for your future.”

The hospital administration gave a referral letter to Sumanahalli hospital, with which Rajanna met the Father James, who was then in charge of the center.

“Stay here for some time. Let us see what we can do for you”, Father James told him as he was given a place in the hospital. Rajanna did not have to wait long. He was sponsored for a course of training on tailoring, not of clothes but of Rexene and soft leather. Rajanna soon found the training to be difficult and not suitable for him. The stitching involved fine and minute work and handling the scissors was a problem. Also, inserting thread in the needle was difficult for him. The ring on

the thumb side of the scissors pressed hard on the anesthetic thumb and soon he found that he was developing ulcer in his thumb. He had to discontinue the work, though he was able to make about ten small vallets each day.

One Gokuldas & co, exporters of readymade garments, was in need of labor. They were philanthropic and wanted to employ handicapped and leprosy affected people in their organization. Twenty two persons were sent from Sumanahalli hospital and our Rajanna got the job of office boy in Gokuldas & co.

Sr. Mary and Dr. Nagendra Prasad are two selfless and service minded characters. Dr. Prasad is a medical practitioner of the Karnataka state government. Sr. Mary of sumanahalli is working in the rehabilitation section of the hospital. Both have great zeal and commitment towards the welfare of leprosy affected persons and their rehabilitation. Sr. Mary was not happy with the office boy job of Rajanna. She was constantly contemplating and finally with the help of Dr. Prasad, got a good job for Rajanna in Victoria Hospital, which is a government run institution. Contrary to expectations, Rajanna was given the job in endo-gastrities department and not leprosy section as grade 4 assistant.

With a secure government job Rajanna proved worth his salt. As ward boy, his daily chore included taking dirty hospital linen to the centralized laundry, bringing new set of linen, changing of bed covers, applying swab to the floor of the ward and running small errands to get things that the patients may require. When he was asked to first carry a patient in a stretcher, Rajanna was doubtful if the patient's relatives would like his handling the stretcher. But no stigma was shown to him and people in the ward accepted him. Also he transported patients in wheel chair. Food items that he bought were consumed by the patients without any hesitation or inhibition. He became the darling of the hospital inmates that marriage proposal started coming.

In the leprosy ward, a woman was taking treatment. Noticing Rajanna she developed good respect for him. Her husband's sister was of marriageable age and they were looking for a suitable boy to marry

her off. This lady suggested Rajanna as the prospective candidate for her sister-in-law. Negotiations went on and a decision was made to give the girl to Rajanna. But Rajanna insisted that he speak to the girl in private. He bluntly told the girl about his health and disease, for which he got the reply that her father has told everything and she whole heartily consents for the marriage. Rajanna still insisted that there should be no stigma in any form whatsoever, because of the disease. The girl categorically replied that actually she has been looking forward to marrying a handicapped, and Rajanna is the perfect choice for her.

In spite of the insults and humiliations that his mother and sister meted out to him Rajanna wanted to give due respects to the two ladies and get their approval and consent for marriage. When Rajanna's sister had to deliver a child, she came to Victoria Hospital. During the post-natal time she needed help and Rajanna's would-be wife was asked to help. At that time when the subject of marriage came, Rajanna's sister insisted that the girl's side should give a heavy dowry. Rajanna was furious.

"Look here, sister. I want to make it clear that I have not forgotten the ill treatment that you handed over to me when I was at our village. In spite of it, if I have invited you for my marriage settlement, it is purely because I want to give you the due respect. Remember, you are here as an elderly person to approve our marriage, and nothing more. So kindly act in what capacity you are expected to act. If you are particular about talking of dowry then you have no place here. Please remember."

"You are going to perform your marriage without receiving a dowry?"

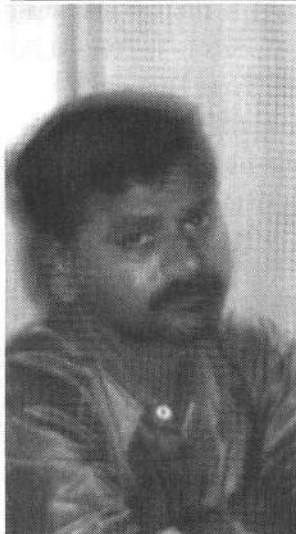
"Yes, of course I am going to marry without any dowry. Is that clear to you?"

"Then let me see as to how you marry this girl."

"Are you throwing a challenge?"

"yes."

"Then please know that my marriage would take place without you."



The marriage took place. And it was a marriage of great magnitude. Both the sister and mother of Rajanna did not attend the function. But Dr. Prasad saw to it that it was a grand occasion. A famous marriage hall was fixed, invitations printed and distributed and a good marriage lunch was provided. No need to say that the couple received a lot of gifts and presents. Overall it was a great event for the level of a grade 4 worker and found its place in the annals of the history of Victoria hospital.

Rajanna and Lalithakumari got married in 2004. He is 35 years old now and is blessed with a daughter of about 5 years. Even before his marriage, out of his earnings, he has purchased a small house in Dhoddabalapura, a place about 40 kilometers from Bangalore. Why did he not buy one at Bangalore ? For one, it was beyond his means to buy one at Bangalore. Next he wants this house as a property or asset. He is not interested in giving it or rent either. The girl is going to school and Rajanna plans to give her the best education within his means. He is currently living in a rented house in a colony, in harmony and dignity with his neighbors.

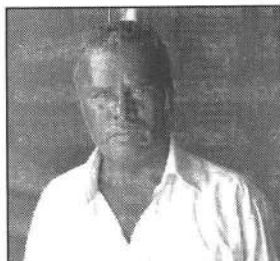
His house has everything that a lower middle class person can aspire for. There is refrigerator, washing machine, color TV, mixie, wet grinder and what not.

Also present in side this house is peace, joy and happiness.

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*Interviewer's note:- All persons working in the field of leprosy strive for eradication of stigma. In Rajanna's case, his own sister has instigated stigma against him in the minds of his mother and other members of his community, because of ulterior motives. This should work as a wake-up call for all of us to guard against such evil designed motives.)*





## SACRIFICE FOR DEAR WIFE

- M. Sathyaiah

*Interview by M S Rajagopalan*

**T**his not the story of one but two leprosy affected individuals who fought hard and got respectability in the society.

At the age of 56 Sathyaiah has happily accepted the role of a 'house wife' while his wife Maniyamma is the breadwinner of the family. Sathyaiah does the cooking, getting provisions and vegetables and collecting water, while Maniyamma leaves house for her duty as the Hyderabad Municipality sweeper at Old Nagar part of Hyderabad. Her total salary per month is about rupees 26,000 and her take home salary is around 20,000.

One side of the coin is smooth and glittering. But what about the other side?

When sathyaiah was about 12 years old and was studying in class five he became the object of ridicule by the fellow students. Half of his body was covered with skin of different colour. This made the other students laugh and sooner than later he was identified to have leprosy, the cause of the second color in his body. The boys started avoiding him. His teacher, though considerate, could do nothing about it. This resulted in discontinuation of his education, and the boy was confined to his house without any treatment, which naturally led to deformity of his right hand. Now Sathyaiah's health became a public knowledge.

As he was walking along the riverside one day, Sathyaiah felt thirsty. There was a spring on the bank of the river the water of which was believed to be purer and tastier. The villagers used the spring water exclusively for drinking and not for other purposes. Sathyaiah went to the spring, knelt down and was about to take a handful when a voice from behind beamed.

“What are you doing there, you leprosy affected! How dare you try to contaminate the pure water of the village with your diseased hands? Get up and get lost before I do something more damaging.”

A village senior was standing with an admonishing posture and gesticulation, ready to hit the boy if not obeyed. Silently the boy got up, without drinking, wiped the hands on his trousers and silently started walking away.

“Be careful not to come near the spring anymore.” shouted the villager from behind.

By evening the news spread and Sathyaiah's teacher was sorry for the boy.

“Sathyaiah, will you listen to me?”

“Of course sir. You have always been my well wisher. Tell me as what I should do?”

“Go to Moulali.”

“Moulali?”

“Yes, Moulali. You see, there in that place there are many persons who have the same disease like yours. They would help you for treatment. It is not good for you to remain untreated.”

“But I don't know the place.”

“I shall take you there.”

The teacher was perhaps not aware of the difference between a leprosy colony and a leprosy hospital. Moulali was a colony of leprosy affected persons. Thus, Sathyaiah left Mehboob nagar and landed in to a leprosy colony.



Inmates of the colony took pity upon Sathyaiah, when they came to know about his not having taken any anti-leprosy treatment thus far. Immediately they enrolled him in the treatment registers of the mobile unit. Sathyaiah was baptized into dapsone treatment. After some months of treatment at Moulali, Sathyaiah was referred to Victoria rehabilitation home, popularly known as Dichpalli hospital for further management of disease and the reconstructive surgery that was to follow. And he stayed at Dichpalli Hospital for about four or five years.

On completion of the purpose for which he had come, the hospital management wanted to discharge Satyaiah from the hospital. One day he was summoned and informed that he was being discharged. The management suggested that he should go back to his native place. Sathyaiah did not like the idea a wee bit. As a flash back he recollected the incident on the river bank spring and the boys' teasing him for his two colored skin. 'Alright, I shall go if management so desires. But not to my native place. I shall leave for some other destination.' Sathyaiah decided and he left for Mumbai.

Satyaiah's arrival at Dichpalli hospital, his stay there for physiotherapy, his doing small jobs for the hospital, his surgery and his eventual departure were being noticed by an adolescent girl named Maniyammal with some sort of admiration. A calf love, perhaps, for she was at best 10 years old then. She felt sad when Satyaiah left.

Leaving Dichpalli, Sathyaiah went straight to Mumbai, with the intention of making a livelihood and some money, if possible. Immediately on reaching Mumbai, he met a group of leprosy affected persons.

"You have come here to get a job and earn some income! This is Mumbai, boy, Mumbai. It is not easy to get a job, particularly when you are an affected person. Forget those thoughts."

"Then what shall I do?" the boy asked as he was almost drowned in disappointment.

"Come with us. We shall show you."

Satyaiah was shown a cart. It was not a cart in the accepted sense of the term. It was a two by two wooden plank with four wheels, two in the front and two in the rear, attached to the bottom of the plank.

“What am I supposed to do with this?”

“Either a very severely disabled person or a kid would sit on this cart. And you should drag it through the streets, where we go for begging. You would get your share of collection for your work.”

“You mean I shall have to beg?”

“What did you think, you would get? Mumbai Mayor's post?”

With no choice left, Sathyaiah had to agree and engaged himself in begging, but with great reluctance.

Emergency period brought an end to Sathyaiah's agonies. All leprosy affected beggars were rounded up. They were sent, either to their respective native places or were sent to various leprosy colonies in Mumbai. Sathyaiah found a place in Worli leprosy colony. He was not favored there because, he was not a local lad, but a 'Telugu' boy. Discrimination within discriminated !.

Once emergency was lifted, a new life and activities awaited Sathyaiah. But they were by no means legal ones. One was selling of illicit liquor brewed by a local 'dada', and the other was smuggling of food grains from Gujarat to Maharashtra. There was restriction of food grain movement into Maharashtra.

Needless to say that Sathyaiah was readily inducted in to the business. And he was successful in both liquor selling and food grain smuggling. Life in a big city like Mumbai, plenty of cash flow left and right, teen age and absence any seniors to guide, all these drew Sathyaiah in to the vortex of irresponsible life. But it also ended one day.

While smuggling food grains from Ahamadabad to Mumbai, Sathyaiah was caught by the railway flying squad. This earned him a jail term for two months. Luckily for him his deformed hand prevented others from giving heavy manual labor.

In the meanwhile Maniyamma attained puberty and the leprosy affected society wanted to perform her marriage.

"Look, Mani, You have become an adult now and attained marriageable age. We have to look for a suitable boy for you. What do you say?"

Maniyamma, also from Mehboob nagar was almost an orphan. Her father was so ignorant that he did not even know how to board a train. When the girl developed leprosy, he could do little about it and Maniyamma was sent to Dichpalli hospital with an uncle as escort. As he admitted his niece and returned, he died in the train itself. So Maniyamma was left with none excepting the leprosy affected community to guide her.

"What do you say?" repeated someone.

"You don't have to look for any one."

"What do you mean?"

"I mean that I have already decided as who my husband shall be?"

"What? You mean you already have someone in mind. You are really secretive for your age. And who is the guy?"

"Sathyaiah."

After some time it dawned on them as to whom Maniyamma was mentioning. "But he has left long before and we even don't know about his whereabouts."

"I am firm in my resolve." insisted Maniyamma. The affected society decided to send feelers to locate and if possible bring back Sathyaiah. Hearing a gossip, a team was sent to Mumbai. And they located him there.

"Sathyaiah, come, let us go back to Dichpalli."

"What have I got in Dichpalli? Everything is over for me there. I have been treated, operated upon, and duly discharged. I am not coming. Mumbai shall be my future place. I have nothing there for me."

"You fool, you have everything there. In Mumbai, you would have

only illicit liquor and smuggling. There a beautiful girl is waiting for you, to become your wife. Understand? Come with us."

On reaching Dichpalli, Satyaiah understood the whole scenario. "But what shall I do for a livelihood?

"We have already thought about it. Many well to do people have cycle rickshaws, but no drivers to run them. You would get one for daily wages with which you can run the family"

Sathyaiah accompanied them back to Dichpalli. In fact he was undecided as to what to do when he completed the jail term, and was pondering about his future. So when the offer was made he accepted it.

The marriage was duly celebrated and Maniyamma finally got the man she loved. As suggested a cycle rickshaw was arranged for Sathyaiah to run to earn his livelihood. The wheels of fortune started moving and Days passed by happily. Two years hence, Sujatha was born as the first child and then they had Vara Prasad as their son. In between they had another baby which died. Meanwhile Sathyaiah fitted a diesel engine to his cycle rickshaw, which has reduced his physical strain and also generated more income.

Vara Prasad is now 23 years old. He is a commerce graduate, currently working in a hostel as manager, waiting for a good employment and would then think of his marriage.

Sujatha is 35 years old and is the nursing superintendent of Dichpalli hospital. She is married and is having two children; Shaini is the senior and is 7 years old while Chikku the boy is 5 years.

When Andhra Pradesh government brought out a scheme under which they gave employment to the physically handicapped including leprosy affected, the Dichpalli hospital management influenced the government and managed to send 60 affected persons for employment. But the government rule was categorical that if both husband and wife were affected persons, then only one would get employment. Satyaiah willing withdrew his candidature in favour of his wife, choosing to run cycle rickshaw while his wife would get the job. Thus Maniyamma became a government servant as a grade 4 worker. Her job of

Corporation sweeper, unlike other government jobs, her job was a permanent one from day one, with the benefits of provident fund, ESI and pension.

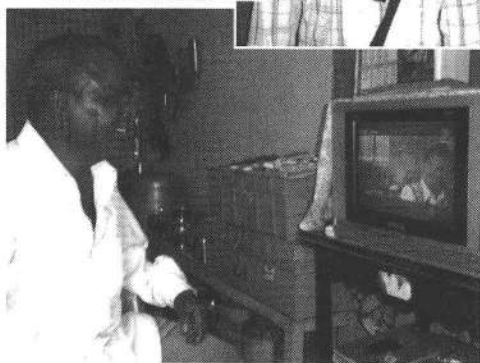
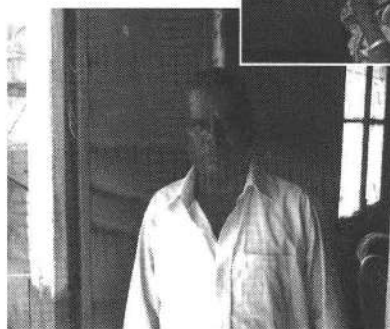
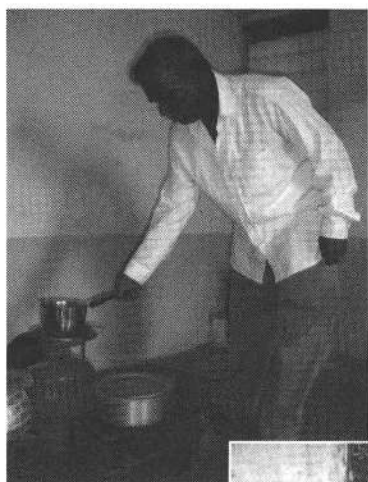
Unlike other leprosy affected, who depend on social welfare organizations for educating their children, Sathyaiah gave education out of his own resources. Also making plans in a shrewd way he saved and purchased a house and subsequently a plot.

Sujatha had a friend who was also working as a nurse in the same hospital. Starting as a simple friendship, it grew close and thick, that the other girl contemplated Sujatha as her future sister in law. She had a brother in law (husband's younger brother) with whom she wanted Sujatha to get married. Feelers were sent and proposals were made. So, Sujatha has seen the boy, his face came into her mind. Dr Ramesh was medium height, medium built and medium complexioned sporting a thin mustache. Sujatha simply suggested that a proper approach be made to her parents. Negotiations were made and the marriage settled. As dowry for marriage, Sathyaiah gave 4 tholas of gold, a motor cycle and twenty thousand rupees. Besides he agreed meet 75% of the marriage expenses. The marriage duly took place.

Sathyaiah is now leading a comfortable life. The daughter has been married away. The son is a graduate waiting for a good employment opportunity. As Maniyamma's assigned area of sweeping is far away, she has to leave the house early. Walking some distance, she has to catch a bus and travel five kilometers towards Charminar, and from there walk some distance to reach her assigned area. Obviously she could not do both house hold activities and attend her job. Sathyaiah Willingly agreed to look after the house while Maniyamma could leave the house in time for her duty. He gave up cycle rickshaw driving, to concentrate fully on the house.

“Maniyamma, you are leaving the house early. So you don't find time for cooking. And Sathyaiah does the cooking. How good is his culinary caliber? Is he a good cook? Is his cooking worth eating?”

“He is a better cook than me.” With a beaming laughter Maniyamma replied, as she threw a shyful side glance at her husband.



“Tell me one thing Maniyamma. You are not educated. And you are getting a good amount of salary. Can you count the money correctly?”

“No, I can't.”

“Then how do you know that you have received the correct sum?”

“On salary day my husband comes to the office and he receives the money and counts it for me.”

“In other words, you input hard work for 30 days and this man takes it away in one day?”

After a hearty laugh Maniyamma said, “Sir, does it make a difference as to who receives the money? It is neither my money nor his. It is our family money. So what difference does that make?”

With such type of woman any man can be happy. Also, on retirement Maniyamma would bring home a provident fund accumulation of about 16 lakh rupees, besides a monthly pension of 9 thousand rupees. Also he has a house allotted to him under lower income group housing scheme of the government. All that Sathyaiah is now worried is about a good job for his son and a good daughter in law.

“Hello Sathyaiah.” Someone tapped the shoulders of Sathyaiah and shook hands with the deformed right hand of Sathyaiah. The friends gossiped for a couple of minutes.

Sathyaiah and Maniyammal are the ideal idols of integration with dignity, social acceptance and economic advancement in its true sense.

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*Interviewer's note:-I have always maintained that social status and social discrimination are inversely associated. The higher a person is socially placed the lesser the stigma he suffers and vice versa. This story is a good proof of my theory.*





## THE WORST AND BEST IN LIFE

- Mangilal Chauhan

*Interview by Sarang Gyedhyane*

**M**angilal Chouhan is standing on the peak of success. He himself is affected with leprosy but surprisingly he is an inspiration for all the persons who have lost their self confidence and faith in God because of other disease. Mangilal Chouhan is a well known person in Indore. The only aim of his life is to bring hope in the dark lives of persons who are affected with leprosy. He wants to make their lives full of happiness and contentment.

Let's go some years back and it was not long ago when Mangilal Chouhan himself was sunk in the darkness of despair, dejection and sorrow. He did not want to live, so he tried to commit suicide many times, but failed. He was lucky enough since his friends and some well wishers supported him at every step. Their good wishes, support and financial help drew him out of the gloomy nights of despair and grief. Mangilal Chouhan did not want to let his friends down, so he gathered up his courage, stood up with full confidence and tried hard to turn his aimless life to a success. And indeed he had done what he wanted. Today he is successful.

His life is like a "Light House (Tower)" spreading light of hope and guides them to move on without taking rest, and without loosing heart or giving up hope.



This "Karmyogi", was born in a very small village named 'Upari'. Dariyav Singh Chouhan and mother Seeta Bai Chouhan named him 'Maharaj' meaning king. Telling about his childhood days Mangilal says, "I was born to my parents after a lot of prayers and "Mannat" so my parents changed my name from 'Maharaj' to 'Mangilal'. We were four brothers and two sisters. My aunt (father's sister) was childless. Seeing her sorrow my parents put me in her lap. At that time I was only six years old.

After adopting me as her son, my aunt was blessed with other kids. So I had been considering lucky and was brought up with love. I was very happy and so too were and my parents aunt. During my school days the symptoms of leprosy were being developed in me. I was taken to the local hospital where Dr. Govind Devra diagnosed and told me that I had leprosy.

My bad luck started from that very day. The attitude of my aunt and my parents changed all of a sudden. Their behavior was no more affectionate as before. My neighbors began to show stigma. I could understand their stigma, but how could I bear the ignorance, discrimination and dislike of my own parents and my aunt? They kept me in isolation. They separated my clothes, my bed and even my utensils. The children of the family were not allowed to come near me. I was only twelve years old at that time. I got frustrated so much with their behaviour that I left my home and came to Indore.

Indore city was a strange land for me. I could not understand as to where I would get my food and shelter. I wandered the city for a week. Meanwhile I used to sleep on footpath and ate whatever I got. A young boy of twelve, who needed the loving care and protection of his parents, was wondering here and there thirsty and hungry.

While wandering in search of work, I went to 'Chhawani Mandi'. There I happened to meet Mr. Gajan Chhogalal Bansal. He had a shop in 'Mandi'. He took pity on me. He gave me a job in his shop. Also he made arrangements for my lodging and food. He gave me a salary of 15 to 20 rupees. He loved me as his own child. After school, I worked at his shop. I worked there for four years. Meanwhile I met Mr. Narendra

Udhani, a restaurant owner. He proposed that I work for him. He offered me a salary much higher than Mr. Bansal. So I left Mr. Bansal's shop and began to work in Mr. Narendra's Restaurant. He was running a hotel with his partner Mr. Iqbal Khan. I had worked with Narendra for about three years. He was also like my father. I never felt any kind of discrimination at his home.

I was about 17 years old. I decided to leave that job. So I came back to 'Mandi'. There I got a good job in "Anand Prakash and Company". Mr. Bansi Singhal was the owner of this company. After some time my master Mr. Bansi sent me to work for his daughter. His son in law, Mr. Narayan Das Goyal was a kind hearted man. I worked there for five years. They all were very kind and good to me. Mr. Narayan Das Goyal had a brother named Ramesh Goyal who was a doctor. One day he came to meet his brother. No sooner did he see me, he recognized that I had the symptoms of Leprosy. He stopped me from working there and advised me to go to 'Maharaja Yashwant Rai Hospital' to get the treatment. I went to the hospital and began to take treatment. I needed money for my living so I again went to 'Chhawani Mandi' in search of a job. There I began to work in "Radha Krishna Trading Company" as a commission agent. On addition to that job, I also did the job of a night watchman. Thus I was passing on my life. Then I happened to meet a person, Manoj Verma. He gave me a proposal to open a tea stall with his brother Raju Verma. Together, we ran a tea stall in 'Palda' area for five years.

Outwardly my life seemed good, but I knew that leprosy was spreading its roots in side my body. Deformity in the fingers of my hands and feet was setting in. Noticing my condition, Raju Verma took me to 'Banganga Kushtha Dham'. There I saw a lot of leprosy affected persons. Their condition was worse than mine. On seeing them I became nervous. I began to see my future body position in them. I began to hate myself. I did not find rest or ease anywhere. I could not sleep well at night. All the night I had night mares. I was deeply sunk in the whirlpool of despair and sorrow. I decided to commit suicide.

I heard somewhere that by eating the leaves of 'Tameshar' (a kind of wild shrub) anyone could die. So I took the leaves of Tameshar,

boiled them in water, added some sugar in it and drank it. After some time I began to vomit. Seeing my condition my friends took me to a hospital, where I was treated and saved. The doctor at the hospital warned me that if I ever tried to commit suicide again, they would inform the police and I would go to prison. I came home but, I was so restless and puzzled that, the life seemed to me waste and useless. I thought that it was better to die instead of living as a leprosy affected person with deformity.

I tried once again to commit suicide. I bought the pesticides, which was used in cotton crop. I mixed 'Gur' (Sweet) in it and ate it. This also made my condition worse. My friends took me to the hospital. Thus, once again I failed in my suicide attempt. My friends explained me very much that suicide is a crime. I had tried to die two times but God had saved me both the times. The confidence and faith which was sleeping in me awoke. With firm determination, I took my friend Raju with me and got admitted in 'Ban Ganga Kushtha Asharm.' This time I was determined. Whatever the conditions would be, I will not leave the hospital until I recover. My friends too encouraged me. Their support and love held me together, never letting me to brake down. I remained in Asharm for one whole year.

I had developed an ulcer in one of my feet and it was not healing in 'Kushtha Asharm'. So I decided to go to "Dr. Badorwala Leprosy Hospital," Konthwa in Pune. I reached there and met Dr. Nimbalkar. He assured me that my ulcer would heal completely very soon. The treatment took two years. There I saw a lot of leprosy affected persons, who were suffering from deformity but they all were doing some work or other to earn and spending their life with great satisfaction, happiness and dignity. To see them living so happily, I felt very much ashamed because my physical condition was much better than those of them, yet I was so depressed, so hopeless and tried to commit suicide!!

Getting inspired by them I told my friends that I wanted to work and earn so that I for could lead a contented and happy life. In the matter of friendship I was really very lucky. My friends were always ready to help me. This time also they were ready to help me as before. They collected some money and gave it to me.

I was trying to change my life but unfortunately I fell into the company of some bad people. They were gamblers and sold arms illegally. Caught by greed I began to work for them. I was told to supply the arms, wherever they directed me. By doing this illegal work, I earned handsome money. I knew that these arms were being made in my village too. To earn more money I went to my village, there I bought a handmade revolvers for rupees 300 each, and sold them for rupees 3,000. Thus I earned a lot of money. But my illegal activities were found out by the police. The police caught me and beat me so badly and cruelly that I was half dead. Then they threw me into a jungle. After lying there for one whole day I came to consciousness. I reached home. My family also told me not to do this kind of works.

I again asked for help from my friends. They helped me. I too had some savings. Thus I had 60 to 70 thousand rupees. With this money I started property business. I also invested some money in kerosene oil business which was being done by a friend of mine. I was getting good profit. I had saved nearly one lakh rupees.

Lady luck was smiling upon me and I was very happy. I took a training of 'demolishing work' from Leprosy foundation Sasakawa. After completing this training I began to do shattering work also. Now I was full of self confidence I realized that had my friends not helped and supported me, I would have never reached this position where I was standing. I thought that I too should help those persons who were affected by leprosy. I wanted to make their lives cheerful.

The collector of Indore had allotted some land to the leprosy affected person in 'Ajwasa'. I along with my brothers (leprosy patients) started poultry farm, farming, and goat keeping. This year in 'Ajwasa' we got a harvest of 60 bags of soyabean. It was a great achievement for us. Currently, we are preparing to cultivate grams.

Anyone can see a divine smile on Mangilal Chouhan's face. He says "I have seen both good days and bad days. Life has taught me a lesson- "Those who fight and struggle with self confidence and courage, never fail in their life."

Mangilal Chouhan has only one goal To try his best to help the

leprosy affected persons so that they may be drawn out from the pit of darkness, despair and shame. He is trying to bring back the leprosy affected persons into the main stream of society. He says, "The endless sky is open before us, it is up to us how high can we fly."

*Interviewer's note: Story of success, success which he got after a long struggle"*





## **A RUDDERLESS BOAT, BUT STEADILY REACHED THE SHORE**

**- P. Ponnuthayee**

*Interview by M.S.Rajagopalan*

**P**onnuthayee is a totally illiterate woman. She has no chronological perception, nor can she associate any event with her age. For example she cannot say as to which year she was born or when she was married. Nor can she say at which age she gave birth to her two children. But she is certain about one thing. She tells without hesitation that she got leprosy when she was twenty years old. When confronted, she asserts that elders were repeatedly saying so and she remembers very well their words. All she can do is to write her name in Tamil, that to with great difficulty.

One may wonder as to what eventful things could have taken place in such a woman's life. To them my suggestion is to read the following pages.

Vellaisamy Thevar and Paechiammal were a happily married couple from Erumainayakanpatti of Periyakulam taluk in Madurai district of Tamilnadu. They had five children. The eldest and the youngest were sons and in between three were daughters. The last of the girls was our Ponnuthayee. Neither the parents nor the children ever had any education. The parents were earning their bread by agricultural and other manual labour. Though they led a life below poverty line, they were a contented lot.

But calamity struck the family one after another. The eldest son, who was rather irresponsible, became an addict to gambling, and was of no use when contribution to family kitty was concerned. And he died at the age of twenty seven. The last son followed soon. Having lost both the male off springs the family went into disarray with the big problem of marrying three girls with their meager income.

As if the two deaths were not enough Ponnuthayee accidentally spilled boiling water on her legs and she did not understand how the big blister came. She was twenty years old at that time. Being a tuberculoid type (old classification) she had no patches or other symptoms to suggest leprosy, excepting the total anesthesia in her feet and hands, about which she had no knowledge. The blisters, once healed, left the foot with mild deformity. The parents understood as to what their daughter's ailment was and they started stigmatizing her. In between alliances started coming for marriage of the eldest daughter. When the boy's side came to see the girl, they noticed the deformed leg of Ponnuthayee and started asking questions. An evasive reply that it was due to hot water spilling was accepted by the boy's family.

Sensing that her presence would hamper the marriage process, the parents forced Ponnuthayee to leave the home and take asylum in Pope John Colony, Madhavaram, Chennai. Packing her personal belongings, Ponnuthayee left for Chennai. Pope John Colony gave asylum to Ponnuthayee. Staying in spinsters' quarters she was contributing her might in return. Her tasks were cutting vegetables in the common kitchen, sieving and winnowing food grains and helping the senior in cooking. Besides, she was also doing the sweeping and cleaning of common areas of the colony.

After spending some time in the colony (Ponnuthayee does not know as to how long), she developed an urge to see her parents and sisters and wanted to live with them. So she left Madhavaram Colony and went to her native village. Reaching there, she found that she was not wanted and stigmatization was evident. The sister's husband and his family, in the meanwhile, have come to know the truth about Ponnuthayee's health. The return to the family was not worthwhile.



Soon, her parents arranged and got her admitted into the government home for leprosy affected persons located at Pudukottai.

Since there was no treatment for her disease, she was developing deformities in her hands and claw has set in. Seeing her claw hands, some of the inmates suggested that she go to Sacred Heart Leprosy Center, Kumbakonam, to get her claw hands corrected. She finally reached SHLC, Kumbakonam and got admitted. After due pre-operative physiotherapy, Ponnuthayee was operated upon for her claw hands by D.D.Palande, the surgeon of the hospital. After due post-operative physiotherapy, the time had come for the hospital authorities to discharge her from the hospital. But Ponnuthayee had no place to go and her case was reviewed by Dr.P.K.Gopal, the Social Welfare Officer of the hospital, on whose recommendation she was kept in the female ward, pending decision. She started working as ward-attender.

Palaniappan alias Palani was a leprosy affected person staying outside the hospital premises. He earned his livelihood by helping the inmates of Emmaus Block. While everything, including food, was free for patients of other wards, the inmates of Emmaus Block had to pay for everything except anti-leprosy drugs. Though some had attendants with them to cater to their needs, many needed help, particularly for getting food from Kumbakonam town. Palaniappan took the opportunity and started helping these inmates for a small fee. And he was looking for a spouse. He had approached the Social Welfare Department and asked for help in finding a suitable girl for marriage.

Ponnuthayee was sent for and asked about her consent to marry Palaniappan. Though not impressed much, she agreed to marry Palaniappan. She went to her native village to inform her parents about her decision to marry and seek their blessings as well as some financial help for the marriage. Her sister's husband not only disagreed, but also refused any financial help, and prevented her parents as well from helping her. As they were old and living under the protection of their son-in-law, they were helpless. There was no money with them to help Ponnuthayee. Dejected, Ponnuthayee returned. The marriage took place in a temple with minimal ceremonial functions. The bride and



groom got new clothes and only a handful few were present for the marriage and subsequent dinner. Neither her parents nor the sister and her husband attended the marriage.

With all dreams that belong to the newly weds Ponnuthayee settled in the new house in which Palaniappan was residing. With the passage of days Ponnuthayee found out that married life was no better than her spinster days. The reason was not far to seek. Of course she had no humiliation or insult to face because there were many affected people around, but the problem was with finance. She found out the hard way that Palaniappan was a spendthrift. He had absolutely no sense of money management and spent heavily on smoking beedis. And he purchased a lot of lottery tickets. 'Imagine a day when by the stroke of luck we may become rich through lottery', he used to convince his wife. But unfortunately the lucky day never came.

But Lady Luck did not altogether abandon Ponnuthayee. A group of Belgian philanthropists wanted to help the leprosy and/or tuberculosis affected couple around SHLC, Kumbakonam, by providing them free houses. Ponnuthayee got a house under the scheme. This improved the situation somewhat, since there was no rent to pay now. But a provision was made by the Belgian group that at least one of the couple must be occupying the house. If both decided to leave, then they confiscate their right over the ownership of the house.

Meanwhile Ponnuthayee got two children, first a boy and five years hence a girl. With Palaniappan's attitude not changing, the problem continued. One day Palaniappan came with an idea. 'In Delhi, a colony cum leprosy hospital is in need of ward-boys and they have asked me. I have decided to go to Delhi. I ask you to accompany me'. Ponnuthayee did not believe a word of what he said. Palaniappan was in not in any way specially qualified that he should be invited for a job. And she also knew that many who leave for Delhi go there for begging which incidentally was very lucrative there. Ponnuthayee categorically refused to accompany her husband to Delhi. She cited that they could lose the ownership of the house if both leave the house. So Palaniappan proceeded to Delhi without Ponnuthayee.

The Belgian group, in the meanwhile, brought out a scheme by which a fixed deposit was made in the names of children of affected couple, which was meant to be utilized at the time of those children's marriage. So, Ponnuthayee got Rs. 40,000/- each for her son Ramesh and daughter Radhika. But this deposit cannot be spent otherwise. Though these deposits did not give any financial relief for day to day activities, it certainly brought some comfortable thoughts on the future of children. With remittances from Delhi being very irregular, Ponnuthayee faced a big hardship and was at a loss to meet both ends meet. Her son was studying for Motor- mechanism diploma and the daughter was in her school days. Paying for their education was a big challenge. But she was determined that she will not do anything which would belittle her dignity.

Balusamy and Vanaja (names changed) were an affected couple who eked out their living by doing septic tank cleaning. They were living in the same colony where Ponnuthayee was also living. The cleaning was done, not by mechanized methods, but manually. One day when his wife took ill and could not accompany her husband for work, Balusamy asked Ponnuthayee if she would like to help him and in the process make some money.

Ponnuthayee was in two minds. To work or not to work, that was her question. Of course, the work would fetch her some money, which shall certainly be handy. But at the same time the nature of work was repulsive. Finally she concluded that she was not doing anything that was below her dignity. And she was doing it for the betterment of her children's education. Her concern for her children over-weighed her hesitation, and she consented to assist Balusamy.

The septic tank cleaning work was always done in nights, when others were fast asleep. Otherwise the repugnant smell would invite objections from neighbours. Starting at about ten in the night, it would go on up to two or three in the early mornings.

First, a big dry pit was dug. Then the cement packing was removed to expose the concrete slabs that cover the tank. When the slabs were shaken loose and lifted, Ponnuthayee was shocked. A lot of insects,

both harmless and poisonous, started coming out. Centipedes, scorpions, crickets, beetles and grass hoppers were there in plenty. Once they all moved away, Balusamy sprayed kerosene on the top surface to quench the odor. Then, with a bucket and coir rope, he started removing water that was stagnating inside, as was done when water was drawn from a well. Ponnuthayee received the bucket and emptied in to the big dry pit. Once all water was removed, the sediments of human excreta were removed the same way. Finally, once the tank's contents were shifted to the dry pit, the pit was covered with mud and closed. The concrete slabs were replaced and cement packing applied.

Ponnuthayee got hundred rupees for the job. And it was quite a sum for her.

After seven or eight such outings, Ponnuthayee decided to quit septic tank cleaning job. She wanted to start selling tea to the inmates of Sacred Heart Leprosy Center. With whatever savings she had made, she added the financial assistance that she received from the Social Welfare department of Sacred Heart Leprosy Center. With this amount she purchased a cycle and a drum with a tap at the bottom. The drum was thermostatic and could contain about sixty cups of tea. As she did not know cycling, she rolled the cycle all the way to SHLC which was one kilo meter away, with the drum full of tea seated in the carrier of the cycle. Inside the hospital she sold her tea to the inmates. By this way she was making some money. Remittances from her husband at Delhi were as usual irregular and uncertain.

Once the hospital opened a canteen of its own Ponnuthayee's business fell off. But she is a determined lady. Her primary concerns are about her two children. Her son Ramesh, now twenty-three years old, is a motor mechanic at Coimbatore, Tamil Nadu, earning a salary of six thousand rupees. The daughter Radhika is a twelfth year student in school, with aspirations for a career in accounts. Ponnuthayee's main worries are two. Money for the education of the daughter is one, and her second worry is getting suitable spouses for her children from families, who would not bother about her leprosy background.

Ponnuthayee may not have achieved great heights in the social

status. But for a totally uneducated woman, she has shown grit and determination in fighting for her existence, not once contemplating to do anything that would be below her dignity.

Now, at fifty-five she is waiting for the tide to turn in her favour.

*Interviewer's Note: Strictly speaking, Ponnuthayee's story should not find a place in Dignity Regained II, for there was no regaining of dignity in her life. But she never lost it, in the first place. So, if a book titled 'Dignity Sustained' is ever compiled, I am sure Ponnuthayee would find her story as the first preference.)*





## **GAVE AWARDS, BUT DEMOLISHED MY HOUSE**

**- Ramesh Bhai Kureel**

*Interview by Manoj Solanki*

**L**eprosy.

On hearing this word a figure comes to our mind; a helpless person begging alms with his claw hands. He too is a creation of God but rejected by all. He wonders as to what was his fault? Why God has given him this? Why has he become so unwanted in this beautiful world?

We take pity on him, we want to help him but we do not dare to go near him: we are afraid that we may be affected with his disease just by touching him. Today in this ultramodern world, we are broad minded enough, but our thinking has not completely changed towards the leprosy patients. To adopt a leprosy affected person, to have matrimonial alliance with the children of leprosy affected and to bring them back to the main stream of our society, all these things seem good to listen, but in reality they are dreams. These dreams are shattered into pieces when we face the reality.

Our society and even the parents and relatives of a leprosy affected person have a deep stigma for this disease. They became so stone hearted that do not agree to keep such a person in their homes, in their locality and in their society. There is a question, if we have such an attitude towards them, where will they go? Who will help them? How

will they survive without our support? We must have to answer all these questions.

This is the story of a man, who was affected by leprosy, but towards him people showed concern. They supported him. Ramesh Bhai Kureel is the name of that person. He never gave up hope nor lost his heart. He not only helped his family but made all his dreams true..

The prestigious Award of "Best Self Employee" was bestowed upon him three times. He got this prize in 1992, 1998 and in 2006. Ramesh was born in a very small village named "Kushalkhera" dist. Unnav in U.P. Since it was a very small and backward village, all the members of Ramesh's family worked in fields and earned their living. The earning was hardly sufficient to meet their needs. Father did not send any kid of the family to school. But Ramesh was an exception. He was the youngest son, very dear to parents, so he had got an opportunity to go to school. But his study stopped in class IV because of poverty.

The financial condition of the family was getting worse. Ramesh wanted to help his family, but he was very young. He was unable to do any hard physical work. He felt very helpless. Many years passed, when one day a relative came to meet them. Seeing their pitiable condition he advised them to send any one of the member with him for employment. With his earning the condition of family will improve. Ramesh who was heartily willing to help the family snatched the proposal. He got his parents' consent with great difficulty.

After getting the parents' consent, Ramesh was very happy. His parents were making preparations but his father had no money for his travel fare, so he took a loan of Rs. 20/- from the village's Patel. Ramesh left the village and went to Baroda with his relative. He was a stranger in that big city but he was determined to fulfill all his dreams. He began to learn the making of leather suitcase which he soon learnt very well. His elder brother was in Delhi and he too did the job of making leather suitcase. So he invited Ramesh to Delhi. Both the brothers started their own business.

They have just started their work, when they got a telegram from village saying that their mother was seriously ill.

Immediately both reached the village and got the mother admitted in hospital. Several days later, their mother recovered and came home. Whatever money both the brothers had, was spent on mother's treatment. So again they borrowed a sum of rupees 800 and left for Delhi. They restarted their work. This time their hard work bore fruits and their little workshop began to run smoothly and successfully.

Unfortunately Ramesh's elder brother was caught by greed. He quarreled with Ramesh and separated him from the business. Ramesh, once again with broken heart and empty handed, came back to village. At home he saw the poor condition of the family. Ramesh gathered up his courage and with a new enthusiasm he came to Kanpur. These he worked for some time.

Then he met a relative of his sister. He had some relatives in Baroda. So Ramesh came to Baroda with him. Ramesh went to those people, where he had learnt to repair suitcase. He got a job. His salary was 125/- per month. His friend also got a job there. They worked there about 6 to 7 months. They saved some money and from their saving took a small room on rent. They started their own work in that room. Gradually their work began to grow. After some time they bought an old sewing machine. They needed some more people in the business. So they called their nephew.

Three of them started a small workshop of suitcase making. Their hard work brought success and they began to earn a good income. Ramesh Bhai started to send money to home. With this help now their family's condition improved.

After some time Ramesh got married. His wife came to Baroda to live with her husband. Ramesh was walking fast on the path of success. Lady luck was smiling upon him. He made his own cottage on a Government plot.

Ramesh opened his workshop in his cottage. His wife also supported him in his work. Meanwhile he was blessed with four daughters and a son. His income was good so the family was happy. But Ramesh's luck has come to test him. Ramesh noticed some colorless patches on his body. He thought it might be a skin disease. So he went to



'Fatehpura Municipal Hospital.' There doctor doubted it as leprosy and suggested him to go to "Shram Mandir Trust", which was a voluntary organization. Ramesh reached the hospital. There, the doctor confirmed that they were the symptoms of leprosy and it was in its initial stage.

Ramesh Bhai was filled with sorrow but he faced this disease boldly. He took the course of MDT for a whole year. His disease was diagnosed as of early stage and he took the treatment regularly so Ramesh recovered without any deformity and got a negativity certificate.

Ramesh Bhai was busy in his treatment so he could not pay attention to his work properly. Getting raw materials has become very difficult. Ramesh got worried. He explained his problems to the workers of "Shram Mandir Trust" but this organization gave only treatment to leprosy patients. They told Ramesh about a social organization named "Gujarat Raktta Pitta Nivaran Sangh."

This organization was indulging in spreading the awareness in society and in rehabilitation of leprosy affected persons. Ramesh Bhai reached the "Gujarat Raktta Pitta Nivaran Sangh" and met its Honorable Minister Mr. Purushottam Panchal.

After hearing Ramesh's story Mr. Panchal assured to help him. A worker (member) went to Ramesh's home, did inquiries and after satisfaction gave a report. On the basis of this report Ramesh's children got help for their study. Ramesh too was granted an aid for his work.

This help proved a boon and Ramesh plunged into his work with a new hope and enthusiasm. Gradually his work began to grow; and his children were also studying well.

Knowing about Ramesh bhai and his hard work, the former President K.R. Narayan awarded him the international Award of 'Best Self Employee' in 1992. He also got rupees 5000 cash along with the award. This money was a great help for his business. He expanded his business and began to supply his suitcases to nearby villages. He earned good money and bought a plot. He made a small home and also opened a



shop. They left their old cottage and came to their new house. He started a provision store in the shop. Ramesh's eldest son left his study after passing class X. He joined his father's business.

Ramesh Bhai's eldest daughter got married in Delhi in a non-affected family. Second daughter passed B.A. after three years; Ramesh Bhai got her married with great pomp and show. Ramesh Bhai's only son was looking after his business very well. He had grown sufficiently old. So Ramesh Bhai got him married too.

With this, Ramesh Bhai had not completed his responsibilities. He had a reputation in society. He was an example for other leprosy affected persons. For them he was an inspiration. Ramesh Bhai was also encouraging the leprosy affected persons to live a life full of dignity. In 1998, the Government recognized his contribution and Social Justice and Co-operative department honored him with 'Best Self Employee'.

Ramesh Bhai had achieved a position which is a dream for any leprosy affected person. He is respected by the people as well as the government officials. To honour his services, his hard work and enthusiasm, the Labour and Employment Ministry of Gujarat Government awarded him 'The Self Best Employee' again in 2006. This was his third award. After sometime Ramesh Bhai got married his third daughter too. His youngest daughter is very intelligent. After her graduation (B.A.) she also completed IT course from NIIT. She got a good job in Tata Consultancy Services. Ramesh Bhai's whole family was very happy and was feeling proud at her achievement.

Ramesh Bhai is contented in life. All his children are settled in their lives. Now it is the time for him to take some rest. He had struggled a lot with life, now he wanted to stay at home and wanted to enjoy the rest of his life. But again a big problem was standing before him.

The house in which he and his family were living was situated just beside the main road. The government wanted to broaden the road. He was given a notice that his house was being demolished.

Ramesh Bhai became much worried. He had made that house and shop with great difficulty. These two things were the only source of

their family's income and support. He met with government officials and Municipal Corporation. He requested them, and he went on fast but all in vain. No one heard him. The road which was 50 feet broad was broadened to 100 feet. His house was broken before his eyes and he could do nothing. At present his house remains only 17 feet long and 12 feet wide. The remaining house will also be broken, because the government is planning to construct a traffic circle at the very place where his house is standing.

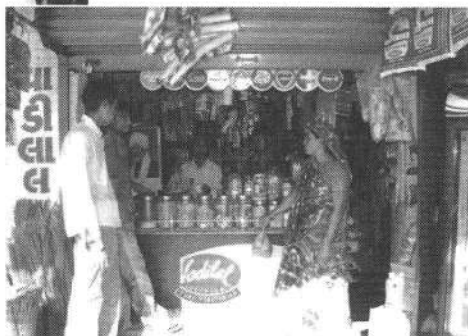
As of now, Ramesh Bhai is living in his house and running his provision shop. But he does not know when his roof would be snatched. He has no savings for his future. He has spent all his saving in his childrens' study and their marriage.

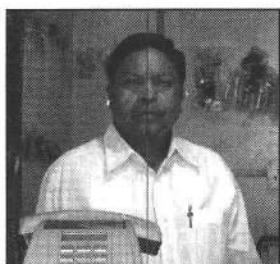
Ramesh Bhai has not given up. He has a hope that central government will help him. He has tears of sorrow in his eyes but has a ray of hope too in his heart. He has full faith in God and in his own hard work. Ramesh Bhai wants that Leprosy affected person should neither lose heart nor give up hope. They should try to live with dignity.

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*Interviewer's note:- "A story of an ordinary person who had seen some dreams and his determination made them true.*

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## **BADLY EARNED MONEY SPENT FOR GOOD CAUSE**

**- Rasul Mulla**

*Interview by Uday Takkar*

**I** am Rasul Mulla. I was born on 1-6-1956 in the village of Waghdari of Sholapur district, Maharashtra. My father's name was Mulka

As far as my adolescent days were concerned, there is not much to speak about. Our family was on the poor side. Like so many other village children I went to school for study and played after school hours with my school mates.

But one thing was puzzling me.

"Mother, why is it that my two sisters are not living with us in this house? Why are they living in an isolated house in the outskirts of the village? They are not even allowed to come and see us."

"-----"

"Mother I am asking you."

"You are too young to ask these questions. You should not be asking them."

"But Why? All the sisters and brothers of my classmates are living together."

After a pause my mother should have decided that I should know the reason.

“It is because both of them have leprosy. They cannot be living inside the village.”

“But, who decided it that way?”

“The village Mukhya and other elders of the village have decided so. You see, leprosy is a dangerous disease and if your sisters stay inside the village others may get the disease. So they have been banished to the outskirts. Strict orders have been passed in the village panchayath that none would also go to visit them.”

I was old enough to know that nothing can be done against the village elders' decisions. But one thing was clear to me. Leprosy is a dangerous and dreadful disease and people with leprosy should be avoided.

It was October-November of 1972. I remember that very well because it was winter and the festival of Diwali was approaching. At this time, it was planned to have a medical checkup of all the school students. In anticipation of the festival, all the children and school students were happy, enjoying the world of sweets, crackers, lanterns and multi colours of rangoli. Also there was an air of expectation as it was being planned to have a medical checkup for all students by the school management. The prior day of Diwali dawned. A set of doctors came to the school and got engaged in the medical checkup. They were going from class to class for check up.

Some Doctors entered into my class room. The teacher was announcing names of students as per rolls.. One after one, examinations were being carried out. Now it was my turn. I stood before the doctor. Doctor started the medical checkup on me. He was examining me for a while, very minutely. He was looking at the patches on my hands and abdomen. In between he was talking to our teacher. I was confused. I was worrying as to why the doctor is examining me repeatedly when other students were getting relieved in a short period of time? I became alert when the Doctor questioned me. He was asking

me very quietly as to how long the patches were there on my body. "Do you remember?" I replied that they may be there for the last 3-4 months. Then he pricked the patches with a pin and tested the pain sensation. By this time there was tension on my mind. At last the Doctor informed the teacher, that, I am having 'Leprosy'.

My mind was shattered when the Doctor pronounced the bitter truth after medical checkup. There was utter consternation in me and was flabbergasted about my future as I was then in 9th standard. There was enormous fear and misunderstanding about leprosy in the society. Isolation of patients and keeping them away from the main stream of life was thought to be the only solution to the problem. That was all the understanding and mentality of the society to the disease.

"Rasul has leprosy".

These words of the Doctor were shattering my heart, whenever I remembered them. Now, I will be side tracked. I shall face isolation aggravated by insecurity and insults. The sight of my two sisters living in the village outskirts flashed in my confused mind. All the relations with them have been broken. They were leading a life of isolation and humiliation. And it is going to happen to me as well.

With the emotionally charged and confused state of mind, I returned home.

The happy atmosphere of the home was changed. Everyone became serious. None was talking to me freely. The enthusiasm about Diwali vanished. Parents became nervous. But at last my father assured me. He started arranging for my treatment. He discussed with the doctor several times and ultimately, I was sent to leprosy hospital at Solapur for treatment.

I get goose pimples, when I remember what I saw that day in the Solapur hospital. We were horrified when we saw the deformed fingers and the ugly faces of the leprosy patients. I went with all the fear inside the hospital to meet the Doctor. He examined me. I was relieved when he said that if I take medicines, I shall get cured. My anti-leprosy treatment was started. I did pass few days in Solapur and then after

meeting the Doctor, we both returned to my village, Waghdari.

I resumed attending the school. But now the behaviour of the school teachers and classmates was changed. I was asked to sit on the last bench with none sitting in that bench. My classmates started teasing me. My friends, who were previously playing with me, were not coming near me. Teachers started avoiding touching me. This atmosphere was beyond my control and I left the school. My dream of becoming highly educated person was thus shattered and I stopped at 9th.

The financial status of my home was below par, the decision to discontinue the education made me undertake manual work for earnings; I wanted to avoid financial pressure on my father. A road was under construction in the village. I started working as a laborer at the construction site. I was asked to dig up the land. One day while doing so, my hand was swollen and I started getting severe pain. My face was looking red. What is happening to me? Shall I become ugly? The mutilated figures that I saw in Solapur hospital flashed in my mind. Should I live with a mutilated body? No, I should not. Let me end my life. These thoughts lead me to think of suicide. I told my friend about this. He discouraged me from any such attempts and gave me a lot of assurances and words of encouragement.

“Let us go to the doctor again. Don't think of ending your life. Your father is backing you. I too will help you.”

This ray of hope gave me mental support in the darkness of nervousness. I immediately met the doctor at Solapur. I was skeptical because my fingers were already affected. Some were deformed and some got absorbed. In these circumstances, my family members will be in trouble because of me, the villagers will isolate me, with these thoughts I decided to leave the village and left my home. With tears in eyes and dejection in mind, I left my village once for all to go to Borivali, Mumbai.

At Borivali in Mumbai, some leprosy patients were staying together where my sister was also residing, having chosen a spouse for herself. I decided to go to Borivali, thinking that, I will be able to earn

a living. I reached Borivali. The residents of this settlement used to beg at the temples, railway stations etc. and with that earning were leading their livelihood. Isolated life and unemployment made me to undertake the profession of begging. I was mentally not prepared for this kind of life. My mind was constantly agitating against this life of begging. Soon I started working as manual worker, and then as a laborer in a wooden mill.

There was famine in Maharashtra at this time. There was restriction on trade of food grains from one state to other. I decided to take advantage of these circumstances and undertook the illegal business of selling food grains. I started selling rice which I used to bring from Gujarat, Dehradun, and Ambala etc. I started traveling day and night. Travel for hours together by passenger trains while remaining hungry, fear of arrest by police, uncertainty of quality of rice grains purchased for resale, all these were raising my mental tension when I undertook this trade. Gradually I started earning good amount of money.

Once I purchased rice from Dehradun. I started my return journey and all of a sudden there was checking by railway flying squad in the train. I had plenty of rice which I could not hide. The police took charge of my quota and I was arrested. I was punished with a jail term of 20 days in Surat, and payment of Rs.20/- as fine. Once the term was over I was released. I tried to overcome such problems and was passing years of my life. The income provided me with some steadiness in life.

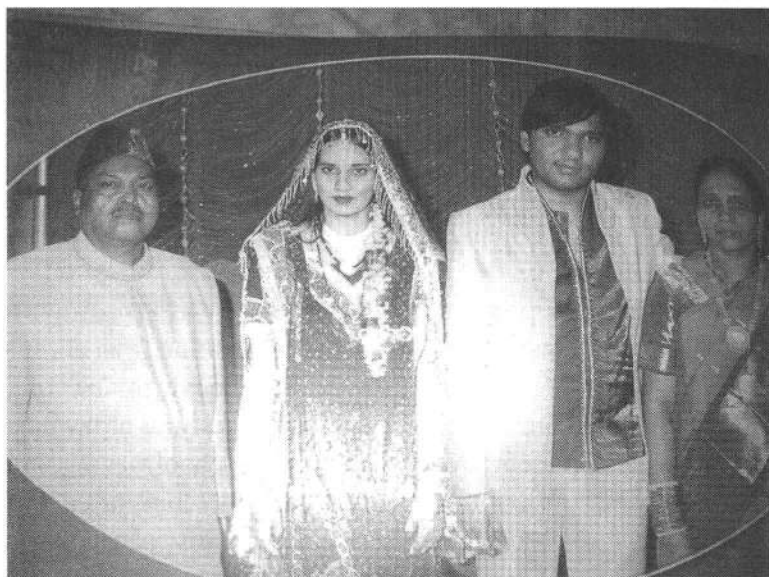
But in 1977 there was flood in Mumbai. All of a sudden our slum was devastated at Borivali. Once again we all started looking for new shelter, struggling for it. Again the same problems were before us. Who will accept us in the Society? Where will we get place to stay? The same bitter experience of unwanted persons was staring upon me. Trombay, an area away from original Mumbai city where my other affected sister was staying along with some leprosy patients, was chosen by me for stay. A leprosy patient allowed me to stay with him but under the condition of doing all the work in his house, including laying the floor with cow dung. In Trombay gradually, I got stability. But as

per local rule, unless one stays for 20 years continuously, the house could not be owned. So I stayed in a rental house. Now people started thinking about getting me married. My friends in Trombay seriously started working on this issue. They started looking for a bride. Of course, in those days marriages were taking place between the leprosy patients themselves or their relatives. So, my colleagues gave me information about a girl from Shram Mandir Hospital at Gujarat. I got married to Rasheeda Beevi in 1979 with the approval from both the sides.

With increased responsibilities of married life, more money was needed for day to day living. There was no chance of getting job due to deformities, and I have overruled begging. These reasons made me join with some bootleggers selling illicit liquor in Trombay settlement. There was no alternative. I started helping in the profession. Gradually, I knew ins and outs of this business. Once, while I was distilling, a tin full of hot liquor fell on my leg. The skin of the entire leg got peeled off. It was difficult to do any kind of work. Once the burn injury healed I undertook the responsibility of transporting illicit liquor from one place to other. There was plenty of money in this profession but there was no peace of mind and no self esteem. Besides my children were growing up gradually. I started thinking of having a change of profession and life style that would have self respect instead of having illicit liquor business. So, I started working in that direction. I got success in it. First I acquired telephone booth on the ground that I was physically handicapped. Then I purchased an auto rickshaw and started leading life on its earning and successfully got rid of illicit liquor business.

It was all the time pricking in my mind that I was kept away from getting education. I started a school with co-operation from all, in the Duttanagar colony of Trombay in order to remove trouble of our children getting education. Thus I would make best use of my earned money. Also another thought behind starting the school was that in this said school, children from other areas would also join for education along with our children and the rift between the leprosy patients and the society at large would narrow. Today 3000 students are undergoing



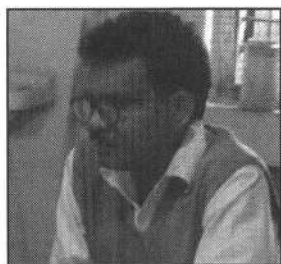


education, where only one class was started at the beginning. Today I am working as a Vice President of the School. After starting the school, my participation in several social undertakings went on increasing. Some of the cognizable items are shown below.

1. Trustee & Vice President, right from the beginning of Abhinav Dhyan Mandir School.
2. Recipient of Dr. Ambedkar National Fellowship award for 2010 for social work.
3. Active participant in the work of Maharashtra Kushtpidit Sanghatana since its initiation and at present facilitator.
4. Member of religious unity committee of local area.
5. Collection and Donation of Rs. 10 lakhs to Chief minister's Fund for the treatment of injured soldiers in Kargil War.
6. Collection of donation from cine actor Mithun Chakravorthy for school fund.
7. Visit to Governor of Maharashtra, Chief Minister of Maharashtra and the Prime Minister of India regarding anti leprosy work and its follow up..
8. Fasting to draw attention of the Government for the problems of patients at Dattapur Leprosy Asylum.
9. Guidance to leprosy patients for acquiring Sanjay Gandhi Yojana (Pension Scheme).
10. Active participation in arranging cricket matches between leprosy patients' settlements.

As I undertake welfare activities for the leprosy patients and Society at large, I have not neglected my family, and I am giving medical education to my daughter- in- law. She will serve the people at grass root level in the Society in future, this is my day dream. With this I am continuing my life journey.





## THE DREAM OF BACHELOR DEGREE COMES TRUE

- Shaligram Tondon

*Interview by Sabir Husain*

**I**f Ever you happen to go to Dhanbad in Jharkand state don't forget to go to Barmasia Rehabilitation Training Centre. I have got an opportunity to go there. I was told to take an interview of some Mr. Shaligram Tondon, who was working in BRTC.

Mr. Shaligram Tondon was once leprosy affected person. I was curious to know about him. When I reached B.R.T.C and told people there and told them that I am curious to know Mr. Tondon, I was told that Mr. Tondon was not living in B.R.T.C. campus. He lived in his own house just a little distance away to B.R.T.C. I moved to that address. I was quite surprised to see that nice home adjoined by a big kitchen garden. A noticed a name plate put on the wall. I read in bold letters-

**"SHALIGRAM TONDON B.A Hons. (HINDI)**

**ADMINISTRATOR BRTC DHANBAD"**

His two sons took me inside the house. Sitting in the room, I was totally confused. Who is this man? How has he acquired such a position, so much honour and high education? After a little time Mr. Shaligram Tondon who was nearly 56 years old entered the room. He had an attractive personality. After introduction I told them the purpose of my

visit. After some hesitation he was ready to tell me his story, the story of success. Shaligram Tondon turned over the pages of his past memories and I began to write them on paper.

A peasant Family lived in a Village 'Charpada' dist Janjgirchama in Chhatisgarh state. The head of the family Mr. P.Tondon, his wife Mrs. Bhuri Tondon and their three daughters Bhagwati, Padmini and Komal were quite happy with their lives. Their happiness knew no bounds when a male child was born in their Family on August 01, 1955. The parents named their beloved son Shaligram Tondon. Shaligram was loved not only by his parents but also by his three sisters.

The time went on and Shaligram started going to school. Being an intelligent student he became popular and dear to both his teachers and his friends. He was good at studies and he also gave a helping hand to his father in his fieldworks. All were very happy. Shaligram was a meritorious student. He had got merit scholarships in Class IX and X. Everybody felt proud of his achievement.

Shaligram had passed class X in 1974 and scored very good marks. At that time when all were very happy and making merry, Shaligram feel ill. His loving father took him to many doctors. But no allopathic doctor or native medicine man could diagnose his disease. His father gave him herbs, roots and homeopathy treatment. But all these went in vain. Shaligram was growing weaker and weaker with each day. When all the savings exhausted his father sold his fields too for his son's treatment expenses.. Shaligram, lying on bed, cursed himself. He was helpless; he was ashamed of himself because most of the fields had been sold for his treatment. He had given up hope for his recovery.

One day one of his classmate's sister K.P. Bharti came to see him. His teacher Mr. Ramlal yadav also came with her. Both of them felt very sorry to see Shaligram's pitiable and miserable condition. They told Shaligram about sister Leoni, a much experienced person. They brought sister Leoni to Shaligram's house. No sooner did sister Leoni see Shaligram, she recognized his disease. She told him that he had been affected by Leprosy. He had border line leprosy, and he could recover if he would take treatment regularly.

Hearing this news all the family members as well as Shaligram's friends were shocked. Shaligram was afraid that the society will not allow him to live in the village. They will move him from his house to live in the forest or a lonely place to live a solitary life.

Sister Leoni was a kind hearted lady. She advised Shaligram to take treatment and finally shaligram got admitted in "Nirmala Leprosy Hospital" in Govindpur in Dhanbad district. There he stayed for about two and half years. He was all alone their. Day and night he wept bitterly, remembering his sisters, mother and father.

Many a times he thought of running away from the hospital, but the sisters who worked there were very gentle and loving to the patients. They always took care of Shaligram. So he stayed there and took the anti leprosy drugs.

Now Shaligram was free from leprosy. It was time to take leave but he was so attached with the staff members of the hospital that he wished to stay there. Considering his desire, the doctors allowed him to stay there. He began to learn how to take care of the other patients. But the environment of the hospital did not suit him. He became ill again.

So father Hunt sent him to BRTC. There too he became ill for some time. In 1982 some hand looms were installed in BRTC and the in charge Mr. Frank made Shaligram the operation in charge of the hand looms. Thus a new chapter, a new path had opened for him. He was getting a salary of about 4000 to 4500 rupees per month.

Shaligram was very happy in his new life. Shaligram now began to think of completing his study which was interrupted because of his disease. He again passed matriculation with 58 percentage marks in 1983. Then in 1985 he passed Intermediate with 58 percentage marks and then in 1988 he got his bachelor's degree in Hindi Hons. Shaligram's dream came true. Shaligram's salary had been increased too. He got married with Rani in 1989.

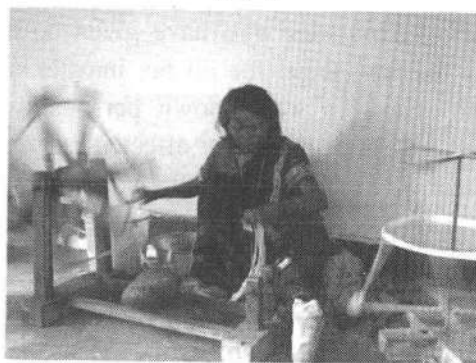
After marriage Shaligram went to his ancestral village. He came to know that all of his sisters got married and were living happily and his parents were no more. Shaligram could not forget the hatred and

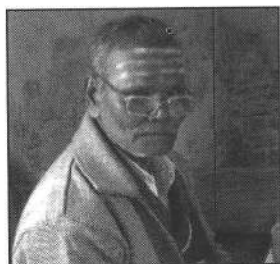
discrimination showed to him by the villagers. He did not want to stay in the village. He sold the rest of the family land and came back to Dhanbad. From this money he bought a plot. After some time he took a loan and constructed a home on this plot. This house contains two bedrooms, one dining hall, Kitchen and a bathroom. He has also made a beautiful Kitchen garden on the rest of the land.

Shaligram Tondon has two sons. The elder son Abhishek Tondon is studying in SFS College Nagpur. He is a student of B.A. Eng. Hons. The younger son Vinay Prakash Tondon is studying in Class XI in a English medium school in Dhanbad.

Shaligram Tondon is happy in his life. He says that God has tested him many times but he has also blessed him with happiness, peace, contentment and a beautiful family.

*Interviewer's note:- Dreams may shatter. Wishes may die. But success is his, in whose eyes the ray of hope lie.)*





## **NONE IS SUPERIOR BY SIZE, BUT BY PURPOSE**

- Shivlingh

*Interview by S S Rajput*

**“A** little lamp can do which the big sun can't do, It gives light at Night. No one is superior by size but by purpose.”

In Faridabad a little lamp named 'Shivlingh Lohar' is giving light to those leprosy affected persons who have given up hope. Shivlingh Jagdev Lohar is like and angel for all the inmates of 'Bharat Mata Kushtha-Ashram.' He is a well known personality in Faridabad. Shivlingh himself was once a leprosy affected person but now he is healing the wounds of his fellow brothers and sisters with his whole heart and spirit. He has been doing this noble work for the last thirteen years.

Shivlingh was studying in class IV in the local Govt. School in his village when he noticed some patches with sensory loss on his body. Three years passed away but no one did ever make out that he was caught by leprosy.

Although his school teacher was giving him medicines, they were not anti leprosy drugs. They were some home remedies, herbs and roots. His teacher was giving him that treatment but all in vain. Gradually Shivlingh got his fingers of hands deformed. He was feeling weakness in his body. Everyone in his school talked about his unknown

disease but no one knew that he was affected by Leprosy.

On the other hand, Shivlingh himself was not aware of his health, so he was passing his time with his friends. He had lost his mother in his early childhood. He helped his father after school. His father was a blacksmith; he looked after him but being an uneducated, village man, he too could not treat his son properly. Shivlingh had two elder brothers. Both died because of this disease. He had two sisters, who were married, so Shivling was all alone to support and look after his father's business.

Shivlingh's father had chosen a girl for Shivling. She was living in the same village. All the things were going well but Shivling was very anxious about his disease. Whenever he saw his deformed fingers, he became restless. One day he went to the tea stall with his friends. The owner of the stall gave tea to his friends but refused Shivlingh by saying that he had deformity in his fingers and by touching the glass of tea anyone might get the infection of that disease. Friends rebuked that man but he did not agree to give tea to Shivlingh. That instance left a deep impression on his mind and heart. He was hurt so badly that he shut himself in his home. He did not even meet his friends.

When his teacher came to know the instance of that tea stall, he too become very worried. He was very sorry for Shivlingh. He sent for Shivlingh. Shivlingh came and told that he did not want to live in village. His teacher convinced him that leaving the village is not the solution of his problem.

He should take the modern and latest drugs for his disease. At last Shivlingh was ready and thus he started taking Depsone drug. He took the Depsone drugs for two years. His disease was cured, but still his fingers were deformed.

During his treatment, the members of medical unit suggested him to go to 'Konthawa Hospital,' Pune, to get his fingers treated properly. Shivlingh, who did not want to live in the village because of the rejection and discrimination, immediately got ready to go to Pune.

After treatment at Pune, Shivlingh's fingers became normal as they were before. After recovery when he was asked to return his village, he



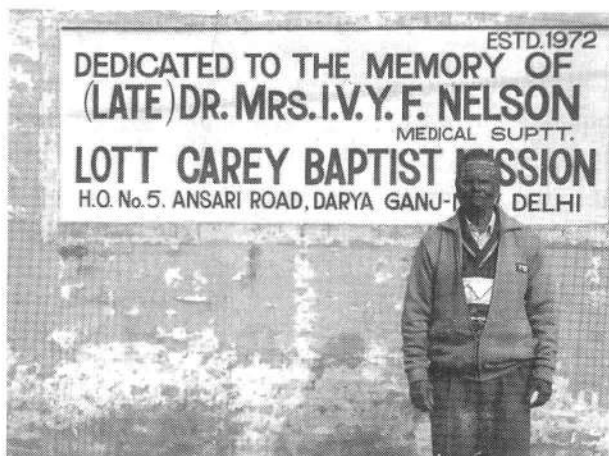
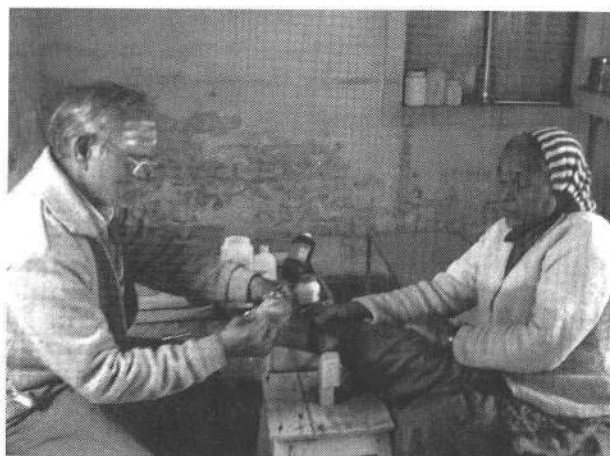
refused to go there. He was afraid that the villagers will not accept him. He would have to face the same discrimination, hatred and ignorance. He requested the hospital administration to let him live there. He wanted to learn the work of a compounder. Doctors happily agreed and he began to learn this work.

Mean while Shivling happened to meet father Christ Das. Father proposed him to come to Kolkatta and spend his future life there. Shivlingh accepted his proposal and reached Kolkatta to start a new life. He got a job of compounder in 'Mother Teresa Hospital'. He worked there from 1974 to 1996. Shivlingh was very happy there. A girl named Nirmala came to hospital to learn dressing, and during her training period she met Shivling. Both began to like each other. Nirmala too was a leprosy affected person, cured after treatment.

Shivlingh had to think a lot. He thought that if he marries the girl, whom his father had chosen in the village, may be, she would desert him once she knows about his disease. So he decided and married Nirmala in 1977. Shivlingh and Nirmala are spending a happy life. The couple is blessed with four children, three sons and a daughter. The eldest son Jaishankar passed 12th class. He does not live with his parents. The second son Ratan left the school after passing IX class. He works in a factory. He got married. His wife Sarita is learning sewing through Sasakawa India Leprosy Foundation. Youngest son too left the school after IX class. He is learning mobile repairing work. His only daughter Guddi is also learning sewing with the help of SILF.

During the interview Shivlingh expressed his sorrow that he could not give his children higher education. He advised his fellows and friends that it is good that children are learning some job oriented work but they should study, at least they should be graduates.

In Kolkatta Shivlingh was getting six hundred Rupees per month. After marriage it was difficult for him to manage the house in such low salary. So in 1996 when he got an opportunity to go to Delhi, he went there. He started attending the leprosy colonies there and bandaged the leprosy patients' ulcers. Although this new work was very tiring, he earned rupees 200 per day. Shivlingh did his work with devotion. His



affectionate behaviour and devotion made him dear among many people. He became popular day by day. Once leprosy affected persons' leader Gurappa came to Delhi. By luck he happened to meet Shivlingh. He admired Shivlingh's work so much that he offered him to come to "Bharat Mata Kushtha Ashram" in Faridabad and work as a compounder. So at last Shivlingh moved to Faridabad (Delhi) in 1998. Since then he is serving in 'Bharat Mata Kushtha-Ashram.'

Shivling is getting 4,000 rupees per month from the "Lot (carry) Kerry Baptist Mission Society". From the state government, both husband and wife get the ration worth rupees 600 per month, free of cost. Thus Shivlingh and his wife Nirmala are leading a life of satisfaction and peace.

Shivlingh says that the most pleasant and memorable moment was that when he went to Kolkatta and did his first job. He told with pride that after leaving his village, he never lost his heart, never gave up hope. He never thought of begging. He fought with the critical situations and finally won the battle against discrimination, rejection and hatred.

Shivling told me, "Now whenever I go to my village, all the villagers welcome me with great love and respect. The same person of the tea stall offers me tea with great affection and respect."

Shivlingh says with pride and happiness that when he sees the love, affection and respect in the eyes of people, he feels that he has won the battle against the hatred, ignorance, stigma and discrimination.

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*Interviewer's Note - Shivling was lucky enough that he did not face much stigma and rejection by his society and village. Just one instance at tea stall moved him from head to toe. He ran away to escape but when returned, brought honour and respect along with him. The most important thing is that shivling never thought about begging and never indulged in any crime. He fought against critical circumstances and has come out as a winner.)*



# 11



## **A LIGHT HOUSE SPREADING THE RAYS OF HOPE**

**- Shyam Kishor Mandal**

*Interview by Kamelesh Divyadarshi*

**T**he juvenile days of Shyam Kishor were a very uneventful and uncomplicated one. Born in 1972 to Tulaknath Mandal of Baladih of Areriya district in Bihar, he was like so many other kids of this small village. Education was never given importance in that village, like so many other Bihar villages, and as such our Shyam Kishor was also denied education and never saw the school building in his youth. The whole family depended on agriculture as the source of livelihood.

“Go, take the cows to the field and graze them“, his father told him one day when he was eight years old. Thus he became a contributor to the family work, bidding goodbye to his playdays. This cowherd work continued till 1983. Taking the milch animals to the banks of Kosi river, he let the animals graze, while he watched the gushing river, standing along its banks. He was not aware that soon this river is going to play havoc in their lives.

In 1983, the embankment of the river collapsed and a huge breach developed. Water with its full velocity gushed thro' the breach sweeping away everything in that village. People, including the family members of Shyam rushed to the highland of Parbisgang, for the safety of their lives. Deprived of their livelihood, Shyam started working as a labourer assisting a mason.

On 10th May 1985 Shyam got married to Manju Kumari at the age of 13. It was a certain case of child marriage, not permissible by law, but was an accepted practice by the village traditions and customs. No one dared to complain and every one aided and abetted it. The marriage was performed with all pomp and show with all family and village members attending it. Our friend Shyam got as dowry, ten thousand rupees, a bicycle, and a wrist watch besides many other things. Raina was the pet name given by Shyam to his new wife. After marriage the family returned to Balidih village. Shyam continued to work as a laborer and his wife was happy.

Came the first vijayadasami day and the newly married couple went to the bride's home for celebration. Many relatives attended the function and greetings and pleasantries were exchanged by the relatives. The newly found honor of a bridegroom played a heavy role in Shyam's mind. Also the total loss by river floods should have been working in his mind. He resolved that he would work hard, earn more and attain a better standard of living and thus keep this wife happier. Once the festivities were over, he went to Saudala (famously known as Bihari Basti in Rajasthan) along with a contractor. And the trouble started.

His mother had a lesion on her hand which was leprosy, but the lady never thought of it as leprosy and hence did not take any treatment. Thus Shyam should have contacted the disease from his untreated mother.

Striving to achieve a better livelihood Shyam worked hard with his contractor, which started complications. After fifteen days' of heavy work Shyam developed high fever and cold. Fever prolonged and heavy swelling developed in both hands and feet.

"Hey Shyam, What is this ? Your health is not good for quite some days, and you are not taking any medicine. Come, let us see a doctor."

A friend suggested and a few others supported his view. So Shyam, together with his friends went to the village hospital. Shyam was checked by the doctor.

"I am sorry to tell you this young boy. But you have leprosy"

"What nonsense ? How can that be ?"

"He cannot be having leprosy. How can that be?"

"Doctor Saheb, you are making a mistake."

His friends started talking all at once.

"But the fact is that he is having leprosy." said the doctor.

"Look here, Doctor. We know what leprosy is. Leprosy patients have claw fingers. Some even lose their fingers. But there is nothing of that sort with this fellow. So don't tell us again that he is having leprosy." shouted one friend as he attacked a nearby attendant. Bedlam was let loose. The hospital staff got frightened and suggested them to go anywhere for a second opinion and treatment. The group left the hospital refusing to accept the diagnosis and refusing to take any medicine from the hospital.

As days passed by his friends started believing that Shyam did have leprosy and slowly one by one they distanced themselves from Shyam.

With dejection, Shyam left immediately for Delhi where his cousin brother lived. Shyam was taken by the cousin to a nearby medical center where the diagnosis was confirmed and a bed was given to him in the verandah. After eight days, he got himself admitted in AIIMS and within next eleven days both hands and feet became inactive. Added to his misery was the absence of visits from any of his family members or friends, except the cousin who helped him. Loneliness, and rejection, more than the disease frustrated Shyam and he always cried. The doctors and nurses always consoled him. At last there was a good news. The doctor said that his hand can be surgically corrected after one year and suggested his return to his house.

Shyam could not effectively use his hands and feet. Added to this he had no money. On doctor's recommendation, he was provided with 225 rupees. Buying a ticket at concessional rate Shyam returned home.

On reaching the village, Shyam was subjected to stigma and discrimination at its peak. The entire village was against his return and

insisted that he leave the village. They could not understand as to why the operation could not be performed immediately and why one year hence. He was put in isolation, with separate tumbler and plate. None of the villagers, friends, relatives, parents, not even his wife ever visited him. Basic requirements like a bathing soap and a good food was denied to him. People who have heard of this dreadful disease and its effects on human hands and feet, but have not actually seen one, flocked in front of his isolation place to have a glimpse of an actual sufferer. Thus he became an exhibit, but none to show any empathy. Dejectedly, he used to imagine as how it would have been had he had enough money and a son. At least his son would have given him a glass of water. This torture went on for eighteen days, after which he could not tolerate any more.

He wanted to commit suicide. So he took all the anti-leprosy drugs given to him in one dose, expecting that it would kill him. Whether the drugs killed the lepra bacterium or not, it certainly did not kill him! Dejected with his failure, he made his second attempt by hanging himself. As the noose tightened around his neck he could not help moaning. Hearing his moaning sound some villagers saved him by cutting the rope and bringing him down. His third attempt was a jump into the river Kosi and gets drowned. Again failure is what he met. A farmer saw him drowning and saved him. Bitterly he thought that not only life but even death has betrayed him. He cried and longed for the day when his relatives, parents and wife would all live happily together.

One relative by name Radha Mandal of Dumgarh heard about Shyam's health and visited him. Seeing his pitiable condition, he took Shyam to Viratnagar, Nepal and there Shyam met Doctor Richer. Dr. Richer gave a reference letter to Dr. Walter Kerketta of The Leprosy Mission, Muzaffarpur. Also he provided Shyam with bus ticket and a sum of rupees 100 towards his travel expenses to Muzaffarpur.

Dr Kerketta admitted Shyam for an initial treatment period of two months. But it somehow lasted for three years. As part of treatment injections were being given to him in buttocks. One day, unfortunately the needle broke inside the buttock and pus formation leading to



jaundice resulted. The ordeal was unbearable and he was not able to eat anything. All his hair dropped and he felt he was close to death. Dr Kerkette changed his menu and gave Shyam plenty of fruits, glucose and Horlicks, as per the wishes of Shyam. And medication also continued. Later an operation was performed on his buttock. Many in the hospital provided him with fruits, and at one stage he was eating 10 kilograms of fruits. Soon he recouped well and his health improved.

Now Dr. Kerkette wanted him to go home. But Shyam went to Dr. Richer of Viratnagar. On examination, Dr. Richer said that one of his legs was normal but the other leg needed further treatment at Kathmandu. Shyam went to Kathmandu and met Dr. Ruth and Dr. Des. They opined that his problem leg could be cured in next 3 years. Surgery was performed on his right leg. During those three years, not only his health was taken care of, but also his studies. Private teachers came to teach him three times a day, and he reached up to IX standard.

After getting well, Shyam asked for a job, but Dr. Ruth could not give him any as he was an Indian and hence could not be employed as per the laws of Nepal. Instead he gave a letter of recommendation and sent Shyam to TLM, Muzaffarpur. But at Muzaffarpur, he was told that affected persons could not be given any job.

Another event has developed in the meanwhile. A letter from his wife was waiting him at Muzaffarpur. She wanted Shyam to meet her immediately, as her second marriage with another person was being decided by her parents. Dr. Kerkette gave some money to bring his wife back, with an assurance that accommodation would be provided for them on their return.

“Will you all please come with me to my village ? “ Shyam asked some of his Rajput friends.

“Why ?” they asked.

“Because my parents in law are contemplating a second marriage to my wife against her will and I want to stop it.”

“Alright. We shall help you to stop the marriage and see that your wife is brought back.”



“Come on. Let's get going.”

But it was too late for the group and Shyam. As they reached the village the marriage has already been solemnized. It was a clear act against the provisions of Indian Penal Code, a case of polyandry, but in a village setup, neither the police nor the law of the land can prevail over the village panchayath leaders' dictum. Also, anticipating trouble from Shyam, the girl's parents had arranged for some muscle men to prevent any forceful intervention by Shyam. As they reached, the girl was leaving with her new husband, right in front of Shyam's eyes. The formalities of Dwiragaman (departure of newlywed bride) were going on. Shyam and his friends returned empty handed. Dr. Kerkette had clearly told him to return to Muzaffarpur, if his wife does not accompany him. On hearing the whole event, Dr. Kerkette assured him of some work in days to come.

On returning to the village, he called for the village panchayath and requested them for a land of ten dhur. He got the land and with the help of some kind villagers, constructed a cottage for him. Though land and permission to construct a hut there was approved, water from common sources was denied to him. So he put up his own hand pump and started cultivation. And he started indulging on something illegal. He started making and selling illicit liquor. This business, as expected, thrived and Shyam made good money. He took three acres of land on lease and started farming. Again this venture gave him good returns. His mother started making occasional visits, but father never came.

Shyam's courtship with Muzaffarpur never seemed to end. He developed an ulcer and needed hospitalized treatment. He went to TLM, Muzaffarpur for ulcer treatment. He stayed there for seventeen days. Not only did the healing of ulcer take place, but also another wound of his mind healed. Separation from his wife, because of disease, was torturing his mind. A nursing attendant, who was a leprosy affected person, developed a liking for him and proposed marriage. Shyam also developed a liking for Phool Kumari.

Out went Manju Kumari permanently.

In came Phool Kumari permanently.

The marriage was a registered one in a court of law. But somebody misinformed Dr. Alomani that Shyam had taken some dowry for the marriage. On hearing this the doctor got angry and scolded him when the couple went to seek her blessing.

“Today you take dowry for marrying her. Tomorrow, who knows, you may engage her in begging.”

Shyam had to explain that he has never taken any dowry. All he wanted was a life partner. Once convinced the doctor gave the couple her blessing to live happily together and never get separated.

Returning to his home village of Azeria with his new wife, the couple started a happy life. In 1998 Veena Kumari was born at Muzaffarpur hospital followed by Binitha Kumari in 1999 again at muzaffarpur. During the period from 1999 to 2004 he worked in Muzaffarpur hospital. At home the illicit liquor business was thriving.

“Look Shyam. I want to talk to you.” said Dr. Kerketta one day.

“Yes doctor.”

“You know that you have more responsibilities now. You have your wife and two daughters to take care of. Besides you have to look after your health as well. Don't you ever think that you should not indulge in such type of activities any more which could put you and your family in jeopardy?”

“I don't follow you, doctor. What do you mean?”

“I mean your illicit liquor business. What you do is illegal. It can land you in jail any time. If such a thing ever happened, what will be the fate of your wife and daughters? Don't you think that you should refrain from that business? My advice to you is to leave the liquor business immediately.”

“I understand doctor.”

That night Shyam could not get sleep. The words of Dr. Kerketta were ringing in his ears. After giving serious thought, Shyam decided to give up liquor business. Once the decision was taken, sleep was easy to come.

As per the advice of Dr. Kerkette, Shyam shifted his residence to Muzaffarpur. His father had died in 2004. At Muzaffarpur, he constructed a house for himself in PWD land (Government land). In the meantime Shristi was born. His mother who had a lesion in her hand, but never believed that it was leprosy, had now developed leprosy in full scale. She came to her son at Muzaffarpur, started on anti leprosy treatment at TLM and got cured of the disease.

One day Shyam saw a paswan about to throw and drown a small baby boy in the river Kosi. Shyam stopped the man from doing so and prevented the killing of the infant. It was a poetic justice that Shyam, who once wanted to commit suicide by throwing himself in to the river, should now save a baby from Kosi river. His wife wanted to adopt the boy as their son. After completing the legal and social formalities, Pritham became the fourth member of Shyam's family. He is now five years old. The first two daughters study in class II and the third in class I. Pritham's schooling has not yet started. But Shyam is determined to give as good an education as is possible within his means.

Lady luck continued her smile on Shyam as TLM gave a sum of rupees 45,000. To that Shyam added his own savings of rupees 55,000.

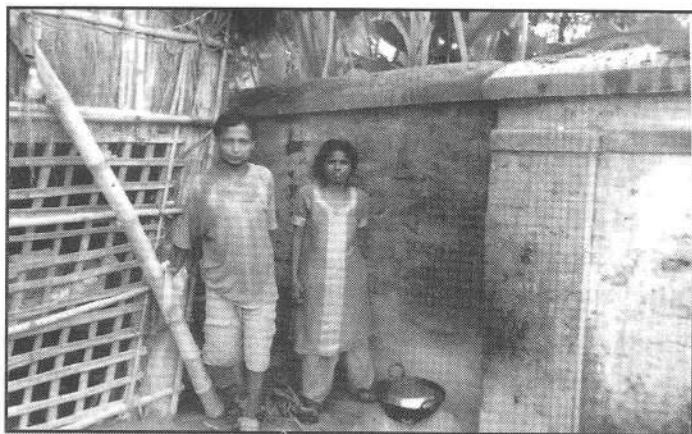
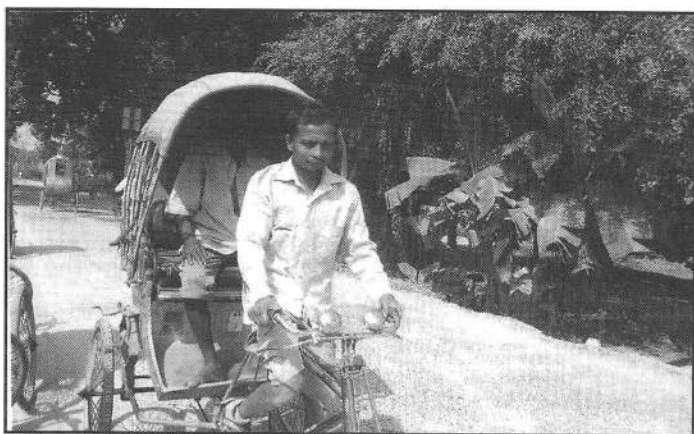
Presently, Shyam has an investment of two cottages, a shop, a hand pipe and a rickshaw, giving him a monthly income of rupees 5,000. He now leads a respectful life. Members of the public patronize his shop without any inhibition or stigma. Also his opinion is sought and respected in community related problems and invited to participate in functions and other occasions. Overall, one can say that he regained all dignity that he has lost in his earlier days. Hearing about his developments and achievements, his first wife wanted to come and live with him. But Shyam was cautious not to invite any complications or troubles and turned down her offer. She has been banished from his life permanently. Recently, when asked about his first wife's name, Shyam could not even recollect her name.

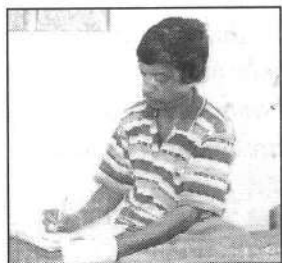
Today, at the age of 38, Shyam has to bring up his young kids, with due respect from society. But a day will come when we would see in that cottage, an elderly Shyam, with four well educated children, and each

occupying important position in the society they live. And his house would be brimful with happiness, laughter and contentment to its maximum.

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*Interviewer's note: Struggle, grit and determined attempts gave Shyam wonderful success and glory. Snatching of his wife right in front of his eyes and hatred by all relatives, parents and in laws was all over weighed by the good help and advice of some good doctors which was a boon in his life's unbelievable attainment and development which are unique and splendid.*





## **BOUNDARIES UNLIMITED BEFORE PEOPLE**

**- Tarun Mukherji**

*Interview by S S Rajput*

**T**arun Mukherji was born in Bengal but made his abode in Jaipur, Rajasthan. He feels much happy to be called himself a 'Rajasthani' instead of a 'Bengali'.

Tarun is leprosy affected person. He is having a loving wife and they both are leading a life full of dignity, contentment and peace. They live in 'Navjeevan leprosy home' in Jaipur.

When I asked him as to how he reached Jaipur from such a distant place like Bengal, he became thoughtful, recollecting his past memories. He began to tell his story of misery, grief and struggle.

I was born in 'Bankura' a small village of West Bengal. We were three children. I was the youngest in the family. Our home was run by our mother. At the age of eight I came to know that our father Ram Mani Mukherji was insane. He wore only a towel and spent the whole day roaming on the roof. He came down only for meals which he took in his separate room and then slept silently. In fact he never bothered anyone and his activities never suggested any mad person's.

My grandfather had constructed a large house. My father owned a portion in it. There were two sets in this portion, each had contained three rooms, a kitchen, latrine and bathroom. It had water supply

connection too. My father could not support my family, so my mother had given one portion for rent. From this money she met our needs like food, clothes and the expenses of our education. Two of my uncles also gave some financial help. Thus the life was going on.

One day my mother took us to her brother's house that was a kilometer away from our place. There we happened to meet our aunt, whom we had never seen before. The reason was that she was suffering from leprosy and was getting treatment at the leprosy hospital at Gouripur, which was 8 kilometers away from our village. Luckily, she was free from the disease and had a negative certificate.

This hospital was not very far from our village, so we could see the leprosy affected persons roaming frequently in and around the village begging for alms. I have no shame to admit that at that time I too hated those persons because they had deformed legs and hands.

While I was studying in class V in Goyanka High School, Bankura, misfortune came silently and knocked at my door. It was winter and my legs started to develop cracks. My mother did not take it seriously, thinking that the cuts were due to cold. Every night she washed my legs with lukewarm water and applied massage with Vaseline. While going to school, I had always put on socks. Two years passed in this way. I was in the seventh standard, I noticed swelling on my toes and fingers and also on my face and eyes.

Seeing this, my mother got worried and anxious. She took me to a dermatologist Dr. K P Bhutp. He examined me and diagnosed them as symptoms of leprosy and revealed to us so. He advised us to go to leprosy hospital as soon as possible.

My mother was shocked. How could it be? But realizing the truth she did not lose heart and mustered courage to take me to the leprosy hospital, Gouripur. People had stigma against the disease and as such the affected persons were not allowed to travel by bus. Hence my mother engaged a rickshaw for our trip to the hospital. The doctor gave me D D S tablets and advised me to take them regularly. In those days D D S tablets were the only available anti-leprosy treatment for the affected persons. In spite of taking medicines my disease was not

responding to treatment. My hands and legs were still swollen. When people around me came to know about my disease, they distanced themselves from me. I went to school, hiding my hands, but I could not keep it a secret for a long time. Almost all people knew about my disease. Shopkeepers refused to sell me things and also refused to take money from my hands. I was not allowed to travel by buses. I had some close friends in my neighborhood like Devdas, Pankaj, Santhi and Lalit. When their parents came to know about my disease, they rebuked me a lot and told my mother to keep me away from their houses. They were worried about their kids.

Meanwhile my aunt got a government job in Gouripur hospital, by the help of the Superintendent of the hospital. She built a cottage in Kalyanpur, near Gouripur, and started living there. She took us the three brothers to Gouripur hospital where we were examined. I and my elder brother were started on treatment. My elder brother was lucky enough to get rid of the disease in six months and became negative. At that time, according to a government order, an able and negative leprosy affected person, after due treatment could get a government job. Thus my brother got a job! But I was not so lucky.

In 1976, when I was in class IX, the headmaster of my school called my mother and asked about my ailment. Once told, he bluntly told my mother not to send me to the school till I recovered completely. When I heard those words, I felt as if I was thrown into a sea of miseries and sorrows. I was totally boycotted by all my friends, by the society and now from my school as well. I was mentally disturbed and I could not understand as to where to go and what to do. How could I lead a life of isolation? How could I bear the hatred and ignorance of people? All day and night, I only thought about these questions.

One can imagine the state of mind of a boy who was all alone. He was forcefully subjected to bear the inhuman behavior of the society, with no right to oppose these things. My mother told my uncle about what the headmaster said. My uncle took me to the Kalighat temple in Kolkata, where he made me wear a sacred thread. Returning home, he gave a feast to five Brahmins. Then he took me once again to Gouripur



hospital, got me admitted there, with strict instructions that I should not return home, till I got a negativity certificate. I have never been away from my home. I always remembered my mother, my home, my friends the food cooked by my mother etc. After a few days, after quarrelling with my aunt, I slipped out of the hospital without informing the administration. At that time I felt like a free bird without any bonds.

I rushed to Chhawana railway station, which was just 2 kilometers away from the hospital. I took a train and within next 30 minutes was at my home. When my mother and brothers came to know that I have run away from hospital, I was rebuked a lot, beaten a lot and refused any food. Though my mother was a lot worried about me she could not allow me to stay at home because of the social stigma. At that young age I failed to understand that my mother and my brothers were all my well wishers and was doing what they all did for my good. I thought of them as my enemies. I was immediately taken back to the hospital.

There was a patient by name Mastan in ward No 2. He talked in Hindi and I loved talking to him and soon he became my friend. Mastan told me that he had been to various leprosy colonies in Punjab, U.P, Delhi and Mumbai. He also told me that there was no need for leprosy affected persons to buy any railway tickets! Mastan was begging, but he never looked like a beggar indeed!

One day we decided to leave the hospital. We reached Chhawana railway station. Mastan was with me. We reached Asansol Junction and from there we boarded Mumbai mail and headed for Mumbai without any ticket.

Ville Parley is station in Mumbai. There, behind a petrol pump, lived some leprosy affected persons from Tamilnadu and Andhra. Most of them were completely deformed and earned their livelihood by begging. Some able bodied and good looking persons were selling illicit liquor in local trains. I met one Abdul. Mastan arranged for my food and accommodation and left away.

Narrating about those days I feel sad and sentimental. I did not know as to where I was heading for. There was neither any road before me nor any destination. I have left behind my mother, my brothers, my



friends, my school, everything! I had only one thing in my mind and that was that I have to live alone and far away from them. I too joined those people and started selling liquor in the trains. One day while walking along the railway track, I got injured and developed wounds. Blood started gushing out of the wounds. I remembered my mother. How she washed the cracks in feet when I was young and massaged with Vaseline! How much did she love me! To day I find that I am all alone in this strange city, with no one there to care for. Seeing my pitiable condition one kind person advised me to go to Konthawa leprosy hospital at Pune. I went there and got admitted. But after a few days I got bored there. From there, along with a leprosy affected sage I went to Dehradun. There I went to Nanapali Road leprosy Udyog Kendra and I met Subart Chattarji, a Bengali person. On hearing my story, he took me to one Fr.Degraze. Father took pity on me, gave me some money and sent me to Shahjahanpur for some Khaddi training. But I could not stay there for a long time I came back to Mumbai

There I saw a lot of leprosy affected persons, getting free food and sleeping on foot paths at night. I started to live like them, eating and sleeping on foot path. There was no difference between me and a stray animal. My soul, my dignity, my self-respect were all dead. Wandering here and there was my way of life.

One day I met Sajal Chakravarthi, a Bengali, who was earning his livelihood by liquor selling. He disclosed that he too is a leprosy affected person and had been wandering here and there after leaving his home. But he was taking treatment regularly and now he was a cured person. He was living in Mumbai, in his own house, having a happy life with his family.

On hearing his story I got inspiration, I decided that I too shall take regular treatment and lead a happy life as leprosy cured person. Sajal helped me. He gave me a letter to one Shivnarayan and told me to go to the leprosy hospital at Purana Ghat, Agra Road, Jaipur, Rajasthan. He also gave me a sum of two hundred rupees. I left Mumbai and came to Jaipur. I reached the hospital and gave the letter to Shivnarayan. At that time the night had already fallen. But Shivnarayan was kind enough to

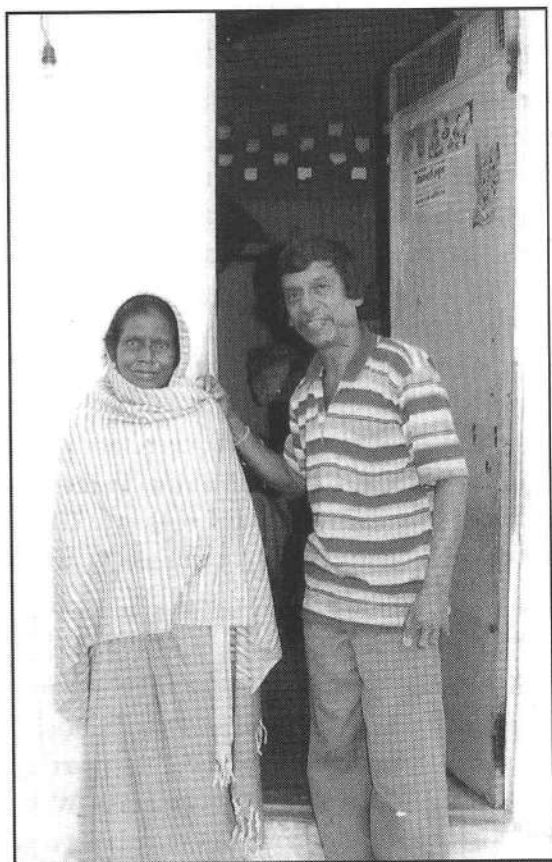
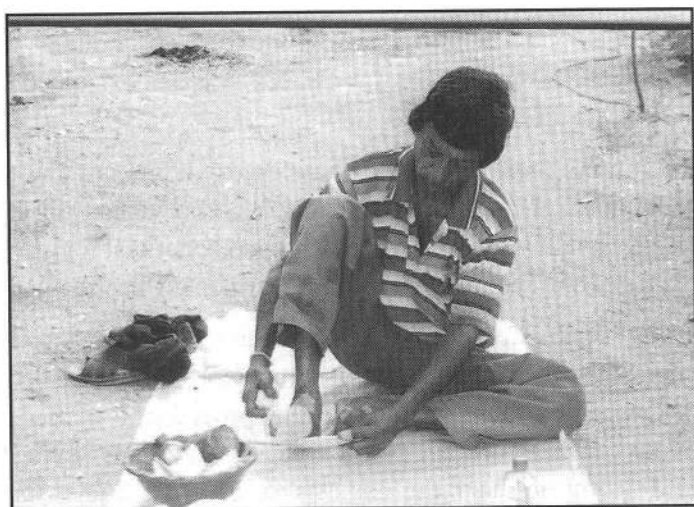
me to give food and arranged a bed for me to sleep, though I was not admitted into the hospital. Next day Dr. K C Sharma examined me and admitted me into the hospital.

At that time, there was neither any leprosy home nor any locality around the hospital. But some kind donors who visited the hospital helped a lot. Here my school education proved beneficial for me. Under the guidance of one Sayyed Rehaman, I learnt many useful things.

Sayyed often went to Collector's and Tahsildar's office in connection with processing of petitions from leprosy affected persons. I often accompanied him and learnt the procedures of processing applications for ration cards, pension papers etc. Thus, living in the hospital I learnt to help the inmates of leprosy homes in those governmental paper works. In helping them I found happiness and satisfaction. I started spending most of my time in leprosy homes.

Some Bengali families also lived in that leprosy home. Seeing them, the loving memories of my family members, which I had since buried deep in my heart awakened. I yearned to meet them. So I wrote a letter to my family. I told them all about me. I also told them not to worry about me. I gave them my address so that they could reply. Reply did come, but was discouraging, as I expected. Both of my brothers were married now, with their own families and they had no time to think about me. They were not willing to have any relationship with me whatsoever. On reading this letter I became very sad. But there was one consolation. The people of leprosy home were always with me. So I decided to leave the hospital and go on to live in the leprosy home. I found out that I was very happy in their company. There was not any kind of hate, disgrace or dislike. All were living with love and in peace.

After some years a leprosy affected person, with his wife, from Shahjahanpur, U.P came to settle in our leprosy home. Unfortunately the person died, leaving his widow alone. She belonged to a small village in Bengal. The people of the leprosy home took initiative and negotiated her marriage with me. Eventually, the marriage took place, and as couple we shifted to Navjeevan Kushtashram. We were provided with accommodation by some donor. We started our new carrier. We



started getting ration as inmates and are living happily. After this I never entertained the idea of going elsewhere. Earlier because of my negligence I could not save my fingers and toes. But now my attitude to life has completely changed.

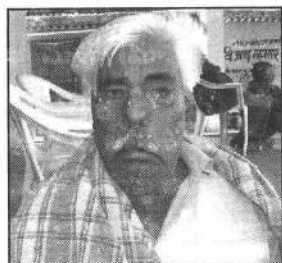
I wanted that my brothers, their wives and my mother should meet my wife. So, we went to Kalyanpur. All members of the family came and met us. The people of my village and my society did not know that I was alive. For, they only knew that after running away from my family I never had any contact with my family. I felt hurt to see the strange behavior of my family members. So, after that meeting, I never went to Kalyanpur and met them. I realized that in fact the people of Jaipur are more valuable to me. They have a unique place in my heart and in my life. I feel proud to be called a 'Rajasthani'. On the recommendation of the Chairman of Sarthak Manav Kushtashram, Jaipur, a donor helped me construct a verandah in front of my home.

To recollect the entire life, I had to leave my family, because of leprosy. I have spoiled almost half of my life. But God took me out of that hell. And it was his plan to send me to Jaipur. Here, in Jaipur, I got so much affection, love and help that I have forgotten all the miseries and wounds inflicted on me by my own people. I was spending my life as if I was walking on the hot sands of a desert. Some good and kind people came in my life. It was their love affection, sympathy and mercy that brought fresh blossoms in my life, the blossoms of joy and happiness.

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*Interviewer's note:- There are a number of young people like Tarun, who could not bear the hate, ignorance and stigma shown to them by their own relatives. Dejected and deserted, they spend their lives in footpath. Today there is a need to create an awareness and reforms in the society, so that the leprosy affected may get proper concern, guidance, proper treatment and the most important, a loving and caring atmosphere. It is our duty to look after them and do the needful to bring them back to the main stream of the society.*





## A FIGHT FOR DIGNITY AT LEAST IN DEATH

- Vishwanath Ingale

*Interview by Uday Takkar*

**H**e was returning by train from Chandkuri leprosy asylum to Kothara leprosy asylum. As the train stopped in a station in between, he alighted to give his legs some movement. He at once noticed a group of persons around a man lying on the floor. Going near and parting his way through the crowd, he saw that a dead man was on the floor of the railway platform and he was a leprosy affected person. All were mute watchers and none were forthcoming to give any help.

The man felt wretched and disgusted. He decided to abandon his further journey.

"Sir, I need your help," said the man to the chief officer of the railway police.

"What do you want?" the officer asked in an irritated voice.

"A leprosy affected man is lying in the railway platform and he is dead."

"What can we do about it?"

"Please arrange a decent burial for this dead man."

"What is your concern about him?"

“I am a leprosy affected person. And I want a decent funeral for my fellow sufferer. While alive, we are being discriminated. At least in death give us some dignity.”

The officer silently got out of his seat for arranging the funeral of the dead man.

Having accomplished his task, the man now started proceeding along with his journey. Oh! We are sorry that we did not mention his name!

Vishwanath Ingale

15 years old Vishwanath presented himself to get admitted in the N.C.C camp at Begumpura, Amravati district of Maharashtra State. All the candidates were being subjected to medical checkup. In this checkup, it was detected that Vishwanath was found to be having leprosy. Due to this diagnosis Vishwanath and his family members had to face major mental trauma.

Death of his own mother immediately after his birth, step mother's torturous behavior and suffering from a disease having social stigma, all these three were the impediments before him. But in spite of these horrifying circumstances his father arranged treatment for him and sent him to a leprosy asylum at Kothara of Paratwada for admission.

Educated up to Matriculation, Vishwanath was started on treatment for leprosy in 1957 at Leprosy Asylum at Kothara. Here he got a teachers' job. Time was passing at its pace. Fever, with ulcers on feet was the physical problems of Vishwanath which continued to trouble him. Going back home was impossible because that would have created problem for his sisters' marriage. That was also his fear. He got admitted in Chandkuri Leprosy Asylum from Kothara asylum for few days. After healing of his plantar ulcers, it was on his return journey to Kothara, when he noticed the dead man, described at the beginning.

This episode was lingering in his mind for a long time. He visualized himself in place of that dead leprosy affected person. His mind was constantly under turmoil. Mental tension, bodily limits and anonymous fear made him move from asylum to asylum in search of

mental peace. At times Anandwan, at times Tapovan and at times Kothara were the places where he took shelter and tried to regain mental peace. But he could not stay longer in Kothara asylum on account of his basic sharp intelligence, independent way of thinking and stubborn attitude to fight against injustice meted out to affected persons. At last in 1965 he took a decision to leave Kothara asylum and to go to Bhilai, Durg (Madhya Pradesh) in search of a job. He got a job immediately on account of his intelligence, efficiency, self confidence, mental preparedness to undertake any job and straight forward nature. But on account of his independent line of thinking, he could not enjoy this job too and at the end he started an independent profession and got well established in it.

Sensitive minded Vishwanath was taking cognizance of his fellow brothers' and sisters', sufferings due to social ostracism, discrimination and hatred. Either begging or undertaking illicit liquor business was the ways and means of livelihood for the leprosy affected persons. Vishwanath was constantly contemplating about doing something that would bring changes that would get them rid of this improper way of life. This was the paramount thought that was haunting his mind.

In 1965, on the ground of cemetery, he started building huts at Shardapara, Bhilai by organizing a group of 8 males and 6 female affected persons in spite of opposition and non-cooperation of people, compounded by financial deficit. With all the patience and courage he completed this work. For that he mortgaged his golden chain. Into existence came Ashadeep Leprosy settlement, a world created by his own efforts. The struggle for existence started from here. The challenge before him was that of organizing all the leprosy patients together and changing their mentality for good, which he gladly accepted. Vishwanath started his work the correct way by establishing an organization of all the leprosy affected persons of Madhya Pradesh.

In order to gain protection and to fulfill the needs of his fellow sufferers, and to solve the problem of education of their children, Vishwanath undertook several agitations and fasts. He met political leaders, ministers, Government officers in this connection and did not



leave any stone unturned to achieve these needs. On one occasion he underwent a term of stay in prison. He continuously agitated, struggled to meet his just demands and achieved them at the end. His efforts brought improvement in the living condition of affected persons, like road facilities, water supply, toilets, and development of cultural activities in the settlement for affected persons. The houses in the colony came under revenue tax. That was in a way good for one reason. The ray of hope was a vision for the integration of these people in to the main stream of the society. But that was not to be. Again he faced grave problem because of the affected persons' economic viability in life at Sharadapara. Taking into consideration this fact, the Government decided to dismantle this settlement of leprosy patients in 1984, in order to safeguard the health of people staying around this colony. Orders were passed to that effect. Vishwanath and his associates resorted to agitation against this order and sought the help of District Health officer. The District Health Officer reported that all the concerned inmates of the settlement have taken treatment and are cured. This report helped to a very great extent in the agitation by Vishwanath and ultimately the Government withdraw the order.

Mr. Ingle continued his efforts in order to gain social status and prestige in life. He started production of brooms and dustbins after due vocational training. For the sale of these products in the colony of the workers of Bhilai Steel plant, he prepared a plan. Every sector of the Steel plant colony was adopted by a particular family in his settlement. Thereafter he purchased 6 'galas' in the market and made permanent arrangement for the sale of these products. Even while undertaking this task, he was also paying special attention to the primary and higher education of children, along with vocational training with the help of 'The Leprosy Mission'. In spite of his advanced age of 70 years, he realized the importance of empowerment of women and organized them together. He formed a group of 20 women after great struggle and got it registered with the concerned Government Department. He made arrangement for the vocational training of these women on embroidery and hand loom trade and encouraged women to undertake this vocational training. Not stopping at this, he acquired five handlooms





from the Government. The production of tenable cushions mats from wasted sarees started. This activity flourished so much that on any day this women's group has advance work orders for next 6 months. The Sasakawa India Leprosy Foundation recognized this tenacity of work of the female group and offered a hand of help with 10 handloom. The production increased and so did their daily wages.

To-day is the age of advertisements and competition. In order to withstand this cut throat circumstances, he sent the women concerned with this production, at his own cost to Ludhiana and Panipat to learn the latest trends in the trade for having novelty in the production. The Chhattisgarh Government took cognizance of this work and the handloom department of theirs gave order for the production of mats. Recently these empowered women were felicitated by the Chief Minister of that State. The untiring comprehensive efforts of Vishwanath resulted in higher education of several youths of this settlement. Some are medical graduates. There is social acceptance of those who were formerly ostracized and isolated. There are weddings between these two sections. Leprosy patients in large number are becoming independent and are living a life with self esteem.

In order to recognize this task, the minority commission of Government of India has awarded 'Mother Teresa' award to his organization and has felicitated him and his organization. Those who suffered from torture of having leprosy and assimilated hatred on account of that, with all the patience and sustainability, have now created a position in the society and amongst patients are given Welesly Bailey award at the world level. The struggle for existence by Vishwanath was taken into account with full cognizance in 2007 A.D. and he was nominated for that award. Vishwanath always tells his followers and friends that when you ask for your rights, then be prepared to bear the responsibilities as well and only then you will get self-esteem.

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*Interviewer's Note: We salute Mr. Vishwanath Ingle, the lamp of hope of Leprosy patients, who really throws a ray of hope in the life of leprosy patients. He is a cyclonic personality constantly in search of self esteem.*



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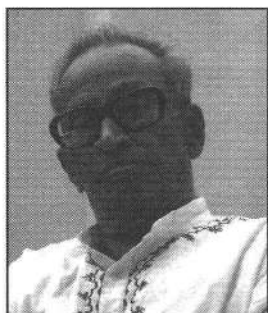
## MEN BEHIND THE BOOK

*Born in 1959, S.S. Rajput is now a state government servant based at Ajmer. His qualifications are M.A., L.L.B, DLL, DCCA, and JMC. His marriage with Smt. Madhu took place in 1987 and their only son, born in 1988, is an MBA student at Pune University. He is a devoted personality, working selflessly for the*



*welfare of Leprosy Affected Persons, through "SARTHAK MANAV KUSHTHASHRAM," Jaipur, since 1980. He is also giving his services as the Editor of "MITRA", a news letter, which is dedicated to the Leprosy affected persons and he is trying his best for their welfare.*

*Born in 1941, M S Rajagopalan got his Degree of Commerce in 1960 from Calcutta University. In 1965 he joined a bank as officer, got leprosy, and consequently was thrown out of employment. After struggling against the disease and its consequential stigma for a decade, in 1971 he got the job of bio-statistician at Sacred Heart Leprosy Center, Kumbakonam, Tamilnadu. Serving this institution for 25 years, he took voluntary retirement in 1996, and committed himself to working for the welfare of leprosy affected people, first through IDEA INDIA, Erode and then the physically handicapped as*



*well through Sarthak Manav Kushtashram, Jaipur, for whom he is a co-ordinator. While at Sacred heart Hospital, he met Sulochana, also a leprosy affected person, who was working as a microbiologist and married her. Their only son, MR Ashok is a post graduate in commerce and a chartered accountant, working in a*

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*computer software multi-national company. The boy is married and is having a son.*

*M S Rajagopalan's short stories in Tamil, have been published in journals like 'Anandha Vikatan' and 'Thamarai'.*

*Born in 1947, K N Madhavachari contacted leprosy and enrolled himself for treatment with Sacred Heart Leprosy Center, Kumbakonam in the year 1967.*



*After completing his treatment in 1977, he was sponsored for training at WORTH by Dr. P K Gopal, the then social welfare officer of SHLC. Successfully completing his training, he is now the proud owner*

*of 'Annai Designs', a digital printing unit, Chennai and is having a very successful career. He has printed this book. In 1983 he got married. He says that all credit goes to the Rev. Sisters (Particularly Rev. Sr. Maria Noel), Mother superior and Dr. P.K. Gopal.*







Reading books like this will bring out that the disease is curable and the affected people could lead a normal life. It will also remove the ignorance about leprosy among the readers. So definitely this kind of book if written and published in an interesting way would surely make people interested to read, like any other story books. It is important that they should make available to the people. Around the world now there is this inclusive approach to work commonly with the differently abled people also. In such meeting they interact without hesitation and share their experience. The organizations of differently abled people are very much interested to know about this and they appreciate the leprosy affected people for their success in their life. They want leprosy affected people to motivate others to come up in the life. So what I want to say here is that opportunity should be given to the leprosy affected people to come out to say about their own success stories. They should be taken as role models by the other differently abled peoples' organizations. Books of the kind like Dignity Regained should be sent to the organizations of differently abled in India so that they would learn the success of the leprosy affected people.

Since I myself was affected by leprosy I am having the pride to say that for the first time the Government has given padmashree award to a leprosy affected person. I consider



the award given is not only to me but all the leprosy affected people and as recognition for the services all those institutions who work for many years to improve the quality of life of leprosy affected people.



**'Padmashree'**  
**Dr. P.K. GOPAL**

The success of this marvelous work is not only by me but by the collaboration of people around the country who worked with me jointly. So instead of saying that I worked, I would say we worked. We have achieved this now all over the country. The work has been started and it is going on, but this is a very crucial period and the work has to continue at least for a minimum of 5 to 10 years. Then we will see the great achievement, the great results of removing the stigma and discrimination and the life of the affected people would benefit.

Thank you.

Publishers



**Sarthak Manav Kushtashram, Jaipur, INDIA**

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