

Leprosy is not a Curse...

Footcare at TLM Hospital, Naini



The Leprosy Mission Community Hospital

Naini, Allahabad. (U.P)- 211008

Submitted to Rotary Club, Allahabad

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The Problem of Ulcer in Leprosy:

Leprosy is a cruel disease. While it doesn't kill directly, it deforms and stigmatizes, leading to rejection by communities, and consequent impoverishment, disease and early death. Leprosy causes both disfigurement and disability especially of hands, feet and eyes. While disfigurement often leads to social rejection, disability reduces the possibility of undertaking productive work. Together, they are a life sentence without surgical intervention. Leprosy is also a neglected disease, ignored or denied in many countries and communities. This denial increases the negative impact of the disease as it is often not treated early enough.

Leprosy is one of the oldest diseases known to mankind. 50% of the world's leprosy cases are in India. Leprosy is caused by a germ - Mycobacterium Leprae. It starts with a skin patch and if not treated promptly can lead to deformities. Leprosy is a disease which has several complications like Deformity, Reaction, Neuritis and ulcer etc.

Among all the complications, ulcers are the commonest and restrict activities. They occur because of insensitive feet and hands. Leprosy affected who suffer from a complicated ulcer have several problems - physical, social, economical, psychological etc

Physical:



Leprosy is a disease which destroys peripheral nerves leading to loss of sensation in the extremities. This results in increased injuries, burns, blisters and ulcers. The ulcers get bigger and bigger and secondarily infected because the patients do not feel pain, continue to walk/work and do not take care of the wound. They come to the hospital when the ulcer is very bad and lots of tissue is destroyed. It takes a minimum of two months for the ulcer to heal and many a time patients need amputation resulting in further physical disability (and psychological problems). The patient becomes unable to move or do any work and becomes dependent on

others and thus vulnerable to his/her caregiver.

This is probably the reason why Dr Paul Brand called leprosy a *Painless Hell*.

Psychosocial:

Ulcers on hands or feet do not only limit mobility, they also cause the patient to be isolated from society. They are smelly and family and friends keep their distance from the patient and even drive them out of the house.

Most general and government hospitals in UP do not provide proper care for the leprosy affected. They themselves are afraid of leprosy – stigma prevails – and patients are discriminated against. This causes the patient to lose dignity and also a host of negative emotions, depression and even suicide. Hence they need not only medical care but also psychological care.

Economical:

The most expensive and probably the most worrying factor today is the cost of health care. The relatively well off find it difficult, the poor, impossible. The patients admitted in TLM Naini for ulcer care are mostly the rural poor. They are farm labourers earning daily wages and the monthly income is less than Rs 2000/month. They have large families and several expenses hence medical treatment gets low priority. They often avoid it and accept the consequences. This is even truer for the leprosy affected.

Admission in most hospitals for an ulcer will cost > Rs 20,000 per month and they would have to borrow from money lenders and be in debt for a very long time. This often causes them to decide to die at home rather than to go for treatment.

IMPACT:

SOCIAL IMPACT:

As mentioned above there still exists a social stigma against leprosy, mainly due to lack of knowledge and the misconception that it is a curse from God. This is worse when the patient gets deformity or ulcers. Even though leprosy is curable, the insensitive foot or hand is always at the risk for ulcers. These can get large, infected and foul smelling, and cannot be hidden from others in the home and community; hence many of the patients have been driven out of their homes and villages just because of their ulcers. They cannot afford treatment in private hospitals and are usually not accepted/treated properly in government hospitals so they continue managing at home with local quacks and come to TLM Naini when the ulcer is very bad or they are very sick. Here they are welcomed, admitted and cared for unconditionally. They get compassionate, holistic care – medical, surgical, psychological..... TLM Naini fills a gap existing in the society for these people who have nowhere to go.

CLINICAL IMPACT:

Leprosy is a disease which is curable with the help of Multi Drug Therapy but the sensation once lost cannot be restored and hence ulcers will recur lifelong. Activities of daily living and their regular work can result in injury and ulcers, however these must be done. During admission they are repeatedly taught about how to take special care of their hands and feet, given booklets, protective appliances etc. so that they can protect themselves from getting ulcers and still continue their occupation.

What more can be done:

An ulcer does not become complicated immediately. It starts as a small simple ulcer, and if not cared for, will turn into a large complicated one. Hence education on how to protect hands and feet and to report early when the ulcer occurs is very important. Prevention is the bottom line.

Community Level:

Community Self Care Groups:

There is a need to form community self care groups consisting of people with anesthetic hands and feet due to leprosy, diabetes etc. of all ages. This group will discuss about leprosy and how to prevent ulcers and even if the ulcers occur what should be done to prevent them getting worse. Group members will motivate each other to take care of their hands and feet and go to a hospital as soon as they get ulcers.

The social worker can be the key person to create such groups and follow-up their activities, with help from nurses and physiotherapists. Monthly meetings should be held. This group can also function as a stigma elimination team. Awareness about leprosy can be done and the social issues regarding leprosy can be addressed.

Hospital Level:

Workshops:

Workshops can be held in the hospital for those leprosy affected people of the nearby villages, on a regular basis. This again is to reinforce education, self care, remove stigma etc and mainly to ensure that

they show a doctor when they get ulcers- in the early stages. This can be conducted by the Training Unit using physiotherapist, doctor, counsellor, nurse and social worker.

At TLM Naini

Out Patient Department:

TLM Naini is continuously battling to remove the stigma and discrimination against people affected by leprosy. The OPD serves approx 300 patients daily, both leprosy and others, all seated together in the same hall. It never segregates leprosy affected.

Doctors:

Most medical professionals do not like to touch a leprosy patient. Here at TLM Naini doctors assess the patient, the wounds and do septic surgery to clean the wounds without showing any fear of touching the patient.



Physiotherapy Unit:

Self Care: The physio department at TLM Naini provides health education on Self Care both to individual patients and in groups. This is a time consuming and difficult task as most patients are illiterate and unwilling to learn.

Soaking/Scrubbing/Oiling (SSO) – To keep the feet clean and prevent cracks and ulcers patients have to soak their feet in water daily, then scrub off the dead skin and massage in oil. The physios demonstrate this to the patients in the OP, practically, again spending a lot of time.

POP: The physios apply Plaster of Paris splints/casts on the feet of patients with ulcers to immobilize the area and take off the pressure from the area; so that ulcers can heal quickly. One POP application costs approximately Rs 300.



Crutch: Crutches are provided to the patients with ulcers, again to eliminate direct pressure over the ulcer whilst walking thereby helping healing and preventing recurrence.

Footwear with Modification:

TLM Naini has a Shoe department where special footwear is made with necessary modifications for individual patient's feet. Microcellular rubber is used for the sole. This is soft and helps distribute the pressure evenly over the sole of the foot whilst walking. The Occupational therapist assesses the condition of the patient and accordingly prescribes the footwear.

Laboratory:

TLM Naini has a well equipped laboratory and performs basic hematology and biochemistry tests. Patients with bad ulcers often have serious medical complications like severe anemia, septicemia etc. and the tests help doctors manage the patient properly.



Counselor:

Leprosy is more of a social problem than a public health problem. Thus the psychological treatment is equally important. The hospital provides counseling service to all the new leprosy affected and some of the e follow up patients who need it. Patients who need to be psychologically prepared for an amputation get special attention.

In Patient Department:

The inpatient care is provided mainly by the nurses, ward aides, doctor, physios and counselor.

Doctors:

For the inpatients doctors are available around the clock. Rounds are done twice a day for the sick patients and once a week for others. On Wednesdays there is an ulcer round with the team of one Doctor, Nurse, physiotherapist, Occupational therapist, Shoe technician and ward aide. During this round all the patient's needs are assessed with special emphasis on footwear and prevention of recurrence.



Physio unit-

Inpatients get regular physiotherapy and education. The physio department conducts self care group discussions with various groups of patients - such as women's group, youth group, old people's group etc. They also supervise daily SSO in the wards.

Laser and Infra Red therapy is given to speed up healing of ulcers. This costs approximately Rs 1000 to 1500.



Nurses:



TLM Naini provides 24 hour nursing care to the in patients. Patient with ulcers have dressings done twice a day, get medicines and general nursing care. They do not have family members staying to take care of them; hence nurses have to attend to all their needs. Nurses are friendly, caring and compassionate. They look after the patients as if they were their own family.

Counselor:

Ulcer patients need long duration of stay as the healing of the ulcer takes time. Because of this they worry about their family, home and other social issues, including their future. The counselor provides the psychological support that they need. Group counseling is also done. This helps to boost their morale and motivates them to get back to their community with full confidence. The counselor also addresses other psychological problems that they may have and helps with regular counseling sessions, and, if necessary also counsels family members.



Ward aids:

These work closely with the nurses and provide the basic level care to the patients. Many leprosy patients lose their limbs or fingers and are significantly disabled and cannot take care of themselves. The ward aids help in feeding them, bathing, cleaning of their utensils etc. and also help the nurses during the dressings and in the septic surgery.

Other hospital activities

Ophthalmic Care:

TLM Naini has an eye technician and a visiting ophthalmologist. They examine and treat eye complications due to leprosy thus preventing blindness. They also treat other patients with eye problems. Cataract surgery camps are organized at TLM Naini and many leprosy patients and other poor patients benefit



Rehabilitation Unit:

TLM Naini has a rehabilitation unit attached to it which is run by the Comprehensive Rehabilitation Programme of The Leprosy Mission Trust India. This helps the dehabilitated leprosy affected (deformity/ulcers) people to start income generation programmes. The disease, stigma, deformity, ulcers, long hospitalizations etc increase poverty and often this affects the children's education also. Comprehensive rehabilitation programme helps such families and provides financial support for children's education.



Surgical Intervention:

TLM hospital Naini provides good surgical intervention for ulcers. The hospital has two major operation theatres and one septic operation theatre with latest equipment. Approximately 700 septic surgeries are done per year.

All dead tissues (slough and gangrenous tissue) need to be excised. It is not enough to take antibiotics alone. The infected and non viable bony sequestra needs to be removed.

Procedure of Surgical Intervention:

All patients with complicated ulcers have septic surgery done within 48 hours of admission so that the infection does not spread further. This is done by the doctor with help from the nurse. The time taken depends upon the severity of the wound, on average 30 to 45 minutes per patient.

PREVENTION

Footwear:

Shoes are vital to any campaign to save the feet of leprosy patients. In countries where most people walk barefoot it is not enough to provide shoes—the patient has to wear them, and wear them all the time except in bed. The function of shoes is to protect the feet and to spread the strain of weight-bearing over all of the good sole, sparing the scarred areas and pressure points.

As the foot walks on a yielding material so the pressure point of the foot sinks into its deeper part and the soft material comes up into the arch of the foot and takes weight everywhere. Spring material spreads the strain of weight bearing both in space and in time. It spreads



it in space by allowing all parts of the foot to share the weight, thus reducing the strain on localized pressure points. It spreads the strain also in time because if a patient lands heavily on his foot as from a jump, the springy material slows down the rate of deceleration and thus slows the impact.

Statistics:

Outpatients Department:

The Leprosy Mission community hospital Naini is one of the largest referral hospitals of the state treating a large number of leprosy patients. Patients come from far and wide - Uttar Pradesh and even other states like Bihar, Madhya Pradesh, Chhattisgarh, and Jharkhand etc. Every year nearly 22,000 leprosy patients are seen, out of which approximately 3000 are new patients and 19,000 revisits.

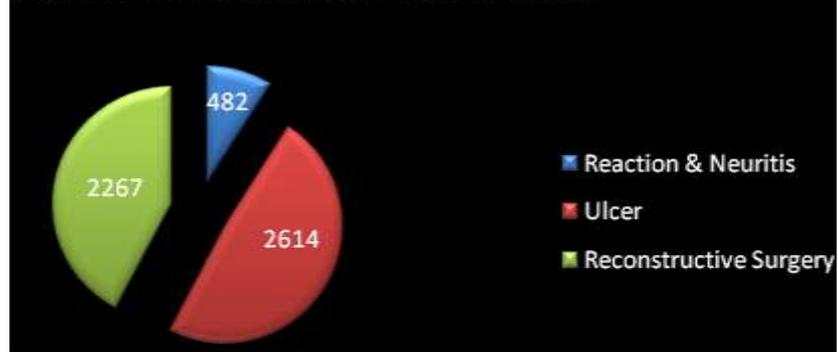
Sl. No	Year	New patients registered	Revisits of leprosy patients.
1	2010	2,847	19,888
2	2009	3,112	19,761
3	2008	3,275	19,203
4	2007	2,768	14,122
	2006	2,304	13,602

In Patient Department:

Every year nearly 1300 leprosy patients get admitted for treatment of various problems like Reaction, Neuritis, Reconstructive surgery, Ulcers, care of physical disabilities and other general medical problems. The following table shows the number of admissions of leprosy patients with number of bed days utilized by them.

ADMISSION DETAILS - SHORT TERM LEPROSY (2010)					
	No. of Admissions	Actual Beddays utilized	Average duration of stay	No. of Discharges	No. of Deaths
Eye	78	771	10	78	0
Reaction & Neuritis	64	4126	64	80	1
Ulcers	540	21404	40	506	3
Reconstructive surgery	525	14195	27	508	0
Other Surgeries	2	11	6	2	0
Medical	223	6309	28	205	7
OG	2	24	12	2	0
Care of Physical disabilities	0	0	0	0	0
Others	0	0	0	0	0
TOTAL	1434	46,840	33	1381	11

Patient admissions 2006-2010



The above graph clearly shows that the maximum number of admissions is for Ulcers. The number of bed days utilized by them is also large. The average stay of a patient for treatment of an ulcer is 40 days. During admission the patient is given medical treatment, surgical treatment (debridement/amputation etc), daily dressings, physiotherapy, food, counseling and other facilities all adding to the cost.

Diet:

A good diet is very necessary for health. Here at TLM Naini the hospital provides a nutritious diet for the IPs. The menu is varied and tasty and the quality checked by the hospital staff. There is regular supervision of the kitchen for hygiene etc. The weekly menu is as follows:



Sl. No	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Breakfast (8:00 am to 8:30am)	Suji, Tea	Bun, Eggs, Banana & Tea	Chana Desi & Tea	Dalia & Tea	Bun, Eggs, Banana & Tea	Chana Desi & Tea	Bun, Eggs, Banana & Tea
Lunch (12:30 pm to 1:00 pm)	Rice, Dal, Vegetable & Pickle	Rice, Dal, Vegetable & Pickle	Rice, Dal, Vegetable & Pickle	Rice, Dal, Mutton/Chicken & Paneer	Rice Kabli chana, pickle	Rice, Karhi & Pickle	Rice, Rajma & pickle
Evening (4:00 pm to 4:30 pm)	Tea	Tea	Tea	Tea	Tea	Tea	Tea
Dinner (7:00 pm to 8:00 pm)	Roti, Dal & Vegetable	Roti, Dal & Vegetable	Roti, Dal & Vegetable	Roti, Dal & Vegetable			

There is a provision for Special high protein diet (milk, egg, gram, protinex etc) which is given only to those who need it - recommended by the doctors. The average expenditure on patients food per year is nearly 21, 00,000/- rupees however 50% of the inpatients are ulcer patients so some 10, 50,000/- rupees is being spend on food for ulcer patients.

Outcome Indicators

Statistics alone will not be sufficient to measure the impact of ulcer care services being provided by TLM Naini hospital. Since leprosy ulcer affects life in many ways the impact on the various aspects of life should also be measured.

Physical Outcome

- Healing of the wound.
- Restoring/Improving cosmetic appearance
- Prevent recurrence of wounds

Psychological Outcome

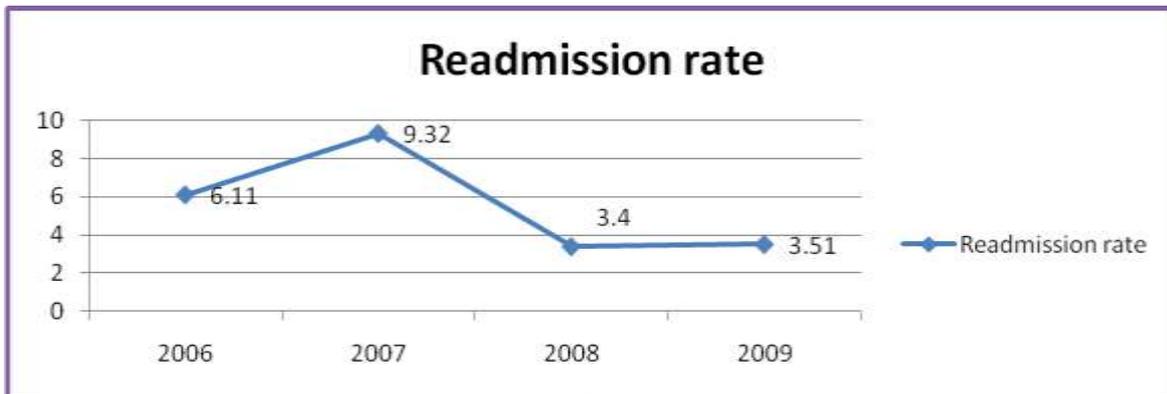
- Increased Self-Confidence in Patients to face the community
- Build Self-esteem of the patients to have a desire to be a productive member of society

Social Outcome

- Ability to do daily work
- Eligibility for Education
- Re-union with family
- Marriage
- Employment / Employability
- Improved Socio-economic Status & Social participation

Statistically

Sl. No	Particular	2006	2007	2008	2009	2010
1	No. of ulcer admissions	564	589	461	460	540
2	No. of readmissions (among above)	42	36	43	16	19
3	Readmission Rate	7.44	6.11	9.32	3.4	3.51



The above graph shows clearly that the rate of readmission for ulcer is reduced. It shows a positive result of the extreme hard work and excellent ulcer management and patient education done by The Leprosy Mission Hospital, Naini.

Costing:

Cost of Footcare at TLM Hospital, Naini

Sr. No	Cost of Footcare	Net value
1	Medicine / Medical supplies {600 admissions} (includes Antibiotics/ IV Fluids/ Betadine/ Gauze Bandages/ Baematinics supplements)	23,07,300
2	Surgery {800 surgeries per year} (wound debridement inside theatre)	8,18,000
3	Ulcer prevention / Healing aid {600 admissions} (MCR Chappals/ Special footwear, Prosthesis/ POP/ Walking cast with iron/ splints/ Self care teaching)	18,47,300
4	Food (Material/ preparation/ maintenance)	21,59,400
5	Bed cost {approx 25,000 bed days for 600 admissions} (Clothing/ Bedding/ Cleaniness/ Nursing care/ Maintenance/ Electricity/ Water supply/ Sanitation/ Admin exp/ Ulcer rounds)	88,10,700
6	Laboratory {600 admissions}	5,84,600
(TOTAL)		1,65,27,300

Cost of Footcare at TLM Naini - ₹ 1,65,27,300

Cost per ulcer patient - ₹ 27,546.00
{ ₹ 1,65,27,300 / 600 admissions }

Cost per ulcer patient / day - ₹ 689.00
{ ₹ 27,546 / 40 days }

Why we need your support

TLM Naini's work depends heavily on external funds which have been drastically reduced both due to the financial crisis and waning interest in 'Leprosy'. HIV/AIDS and Rehabilitation attract the donors today. However, this work is still much needed and any form of support- financial, equipment, prayer... is needed, so that the work can go on without compromise.

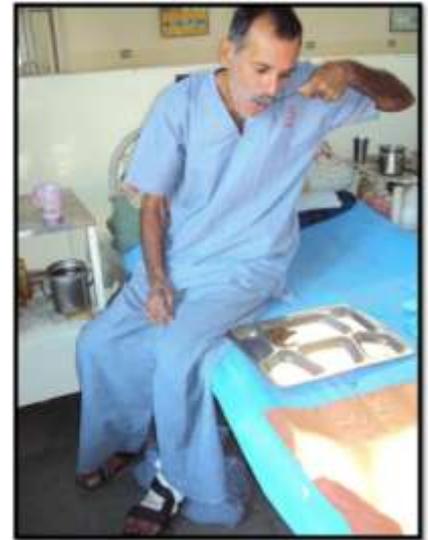
Annexure

Stories of Beneficiaries

Ganga Pandey (checked)

Ganga Pandey is a 55 year old man from Bihar. He has 3 sons. He lived happily with his family before he got leprosy. He worked in the field and earned a living for his family. He was unaware of his disease in the beginning. Soon after his fingers started getting affected an ulcer occurred on his left foot. He was diagnosed as leprosy. Once his ulcer got bigger his family started keeping their distance from him. Ganga Pandey realized that his family members had changed their attitude towards him.

He felt a terribly discriminated against in his own home. After some time the condition became so bad that his family members stopped touching him or even his belongings. No one from the family or the village would sit with him and talk to him. He was asked not to stay in the house and given a separate bed outside the door.



For a father the most exciting moment is to see his children's marriage, but Ganga Pandey was unfortunate; he was asked by his son and wife to stay away from home during the wedding preparations and ceremonies. This really upset him. He stayed outside the village for three months in a mud house until his son got married. He is currently admitted at TLM Naini hospital and waiting for his ulcers to heal. He is deeply hurt by the behavior of his family and says that after he is discharged he will move somewhere away from home. However the team will counsel him and motivate him to be strong and get back into routine life and also call the family for counseling.

Paramhans

When I was 18 years old, I came to know that I got leprosy. My right hand and right foot did not have any sensation. I completed leprosy treatment from the local government hospital for two years. Initially I did not get ulcers, so I was actively involved in household responsibilities and in agricultural work. For the past 15 years I started getting recurrent ulcers on the foot and hand and slowly started losing fingers and toes. I was completely unaware about what precautions to take. Gradually the foot ulcer became worse. I went to private hospitals and local clinics for dressings.

For many years I did dressings myself at home. Due to lack of proper care the ulcer got worse and my family members kept me in a separate room with everything separate for me (utensils, towel etc). They treated me like an untouchable person.

I wanted to sit with them, I wanted to play with my grandchildren but the family members did not allow me to do such

things. I longed for some amount of love, affection and compassion from them but they isolated me and left me with tears. Even I started worrying that my disease would spread to them. For the past 15 years I have been experiencing so much pain & rejection, no one will accompany me for treatment. For the past 6-7 years I have been completely isolated from family. My daughter only gives me food and goes away. My family hates me, because of bad smelling ulcers. No one comes near me.

Since the past two years I have been going to TLM Faizabad hospital for ulcer treatment. They admitted me for a month for ulcer care but since it was getting worse they referred me to TLM Naini hospital for further management. I have come here with much hope that I will be healed here with medicine and love & compassion.



Aditya Kumar

45 years old Aditya Kumar says that this is my first visit to TLM Naini hospital for leprosy treatment. Doctors advised admission because I had an old non healing ulcer on the right foot. 15 years ago I was diagnosed to have as leprosy at TLM Faizabad hospital; I had only three months treatment from there because I did not have any leprosy complications like ulcer, clawing fingers or other visible deformities. But at that time my feet were anesthetic. I did not continue the treatment because at that time I had several other responsibilities.

I was a daily wage laborer, and had three children. My wife knew about my disease. She was little bit supportive as long as I could work and earn money for the family but as soon as I became unable to earn because of the ulcers in both feet she started keeping her distance from me. Somehow I managed to continue working even though I had ulcers, because I needed to be part of the family and see them happy. Once my health deteriorated and I was not able to earn my wife said to me “Now you are a leper and you cannot do anything for us. ” and left me alone and went off with another man.

I was completely brokenhearted and depressed. For the past four years I have been going to various government and private hospitals for ulcer treatment. Even though I needed admission the doctors never admitted me. They didn't even look properly at my ulcers. When I asked for admission they refused to get admission because I was a leprosy patient.

This is my first admission in any hospital

(TLM Naini) for ulcer care. I feel so happy and excited that the doctor understood my problem, explained my condition to me and advised admission. Truly this is first time I am experiencing that I have been accepted and loved by people. I do not have any permanent residence, sometimes I stay with my old parents in a slum near a government hospital in Mainpuri district and sometimes in the temple.



Bhoori

Last year I was at TLM Naini for more than five months. At present I have been here for around 1 month. This time I had an operation for a complicated ulcer, I had septic surgery.

I've been having this problem [leprosy] for more than 10 years. I'm getting ulcers over and over again. I'm doing all the household activities and looking after my child while I'm at home. I did not understand how I got these ulcers. What can I do now; god has given me this disease. However, TLM Naini staff explained to me how I got ulcers and how to protect my hands and feet in the future.

I get regular counseling at Naini. I am very sad and often cry because I miss my small son very much. For the moment I feel happy that at least someone is listening to me and sharing my pain, but it's difficult to keep going. My mother-in-law is looking after the baby while I am away.



Due to the stigma against leprosy we don't go to other villages like other people do and I don't interact much with other people in the village. Inside my family it's all ok.

Both my hands and feet are anesthetic. In spite of doing self-care I'm still getting burns sometimes.

My first marriage was 4-5 years back. Because I had leprosy my first husband's family took me and dropped me at my mother's home. But after that my brother and sister-in-law helped me find another husband.

My husband now has no problem with the fact I have leprosy, because he is a Pandit (priest). He is looking after the temple – he is educated and understands it is not passed by touch. So he eats the meals I cook.

Prevention of Disability due to Ulcers in Leprosy

The Foot in Leprosy

By far the greatest proportion of the troubles of the foot in leprosy patients is not due directly to leprosy at all: it is due to the loss of sensation which results from nerve damage in leprosy. This nerve damage is irreversible. The posterior tibial nerve which is most commonly affected in the lower limb leads to loss of sensation of the sole of the foot and paralysis of all the intrinsic muscles of the foot. Sweating is also lost, resulting in dry cracked skin and fissures which also leads to ulcers. Plantar ulcers occur due to various reasons.

Plantar ulcer

The basic cause of all plantar ulcers is loss of sensation. Various other mechanisms are involved in developing and healing of plantar ulcers. Foot without ulcers and/or with minimal deformity can be managed with regular Micro Cellular Rubber (MCR) sandal's with orthosis if required. Those with severely deformed foot require special attention and custom made footwear. The major cause of ulcers is the previous ulcers. Once a patient develops an ulcer he/she is more likely to develop next ulcer soon and it becomes a vicious cycle. It is this phenomenon that causes destruction of tissue, tendons, bones and ultimately deformed and short foot and it reaches the point where it seems hopeless even to try to save the foot and ends in amputation.



Ethylene Vinyl Acetate (EVA moulded sandal)

Moulding is the ideal method of spreading the strain of weight-bearing to reduce the risk of developing ulcers due to uneven pressure. If every part of the foot is taking equal weight then no part will be exposed to excessive weight bearing. Thus, shoes for badly deformed feet may be made from plaster casts of the patient's feet. Moulded sandal/shoe is used to fit exactly into every hollow and bulge of the sole of the foot. Various materials have been tried and used in making sandals to protect severely deformed feet from developing ulcers. Ethylene vinyl acetate (also known as EVA) is soft, flexible, yet can be processed like other thermoplastics. EVA foam is typically used as a shock absorber. Therefore, it is widely used in

slippers and sandals because of its properties like light weight, easy to mould, odorless, and cheaper as compared to other rubbers with similar properties (Fig 3). This makes EVA foam an ideal material for feet with high risk of developing ulcers due to anesthesia because of leprosy and other mechanical factors. This material is being used in making sandals for short and severely deformed foot, rigid soles when foot is not capable of dispersing weight and as padding materials in orthosis. In all the above mentioned conditions it disperses the weight equally over the entire foot. Therefore, it greatly reduces the risk of developing repeated ulcers due to uneven pressure and prevents patient from needing an amputation.



Fig 3 (a): Cut EVA sheets, (b) EVA mould over patient's moulded foot
(c) EVA moulded sole for sandal (d) Completed EVA moulded sandal

Annual Report 2010

(Attached separately)

Donation Appeal

(Attached separately)

Training Unit Brochure

(Attached separately)