Is Leprosy a curse?

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Leprosy has tormented humans throughout recorded history. Throughout its history, leprosy has been feared and misunderstood. For a long time leprosy was thought to be a hereditary disease, a curse, or a punishment from God. Before and even after the discovery of its biological cause, leprosy patients were stigmatized and shunned. Even today after a huge anti leprosy campaign and programmes initiated by the government many people have fear of leprosy. The result of this fear can be easily seen – Leprosy beggars in the community, Leprosy colonies, ostracized leprosy affected and many more.

The Leprosy Mission Community Hospital Naini is serving the people affected by leprosy for over 136 years. This hospital provides holistic care to the people affected by leprosy which includes- Multi Drug Therapy (MDT), Ulcer care, Reaction management, Reconstructive Surgery, Special footwear, Splint, Occupational therapy, Physiotherapy, Nursing care, Counseling and many more.

**SNEHALAYA—**

Snehalaya is a hindi term which means a house of love. This particular cottage patient service (snehalaya) was started for those leprosy affected who had been ostracized by the society due to their disease of leprosy.

There are 14 patients with leprosy who live in the campus, many with crippling deformities of hands and feet. They were admitted to the snehalaya decades ago when they were rejected/thrown out by their family and the community due to leprosy and disfigurement. Their average age now is above 60 years. There are 11 male and 3 Female inmates and the average duration that they have been here is 40 years.

As they grew older, routine tasks and activities of daily living became even more challenging. Common Toilets were situated far away from their quarters, and connected by mud roads. It was difficult especially for those in wheel chairs and those using crutches, and even more so in the monsoon when the mud was slushy and slippery. Hence they became partially dependent on others to help them.

To maximize their independence and make life easier for them, changes were made to make their living arrangements disable friendly. These included:
Activities:

- Health Care—

  Doctors:-
  - Based on the daily report of the nurse, doctors see the condition of the inmates and provide treatment if there is any need of medical attention to be provided.

  Geriatric nurse:-
  - One full time nurse has been appointed to take care of their medical needs which include daily dressings, medicinal care (distributing medicines, taking their blood pressure, sugar test etc) and giving their proper health report to the concerned doctor.
  - She occupies the inmates for the whole day by spending time with them, listening to them and make them feel at home.
  - Organize some group games which again motivate them and alleviate their anxiety.
  - Sometimes feed the inmates when they are sick or not able to eat by themselves.
  - Ensure daily calcium supplement and fluid intake.

Physiotherapist:-
- Physiotherapy department makes regular visit to Snehalaya and provide them physio assistance to maintain and increase their endurance and fitness. This includes-
  - Exercise, self care teachings.
  - Prevention of Impairments & Disability (POID) activities.
  - Providing Micro Cellular Rubber (MCR) sandals, regular checkup etc.

Occupational therapy:-
- There is an Occupational therapist who visits the inmates of Snehalaya to teach & help them for their Self care & Activities of Daily Living.
- It is one of the most integral part of Snehalaya care because most of the inmates are fully deformed (absorbed fingers and toes) and hence the inability to do things and the risk of getting injury is more.
- ADL teaching helps them to be self dependent in most of their daily activities and also saves them from getting injuries.
Counsellor:-

- Visits them regularly to meet their psychological and emotional needs.
- Many activities like
  - Group therapy- group discussion, sharing of experiences etc.
  - Individual counselling,
  - Spiritual nurturing etc are being performed by the counsellor.
  - All these activities help the patient to be occupied and bring the inmates close to each other.

1. RECREATIONAL ACTIVITIES:-

Picnic:-

- A special picnic is organized twice a year for the inmates of snehalaya so that they may enjoy one whole day out from the hospital campus.
- They really enjoy this trip where they play-badminton, throw-ball and other board games like ludo, chess etc. and enjoy meals cooked at the picnic site.
- In this picnic some of the hospital staff accompany them - nurse, counsellor, physio or occupational Therapist, a cook and driver.
- This picnic is meant to provide them psychological release of stress, an opportunity to get away and make this just their special day. It takes their mind off from being ignored by their own family and loved ones just because of their disease - Leprosy.

Christmas Dinner:-

- A special Christmas dinner is organized for the patients and staff every year. This dinner is different from other routine meals as it not just the special food but a time of fellowship with the entire hospital staff & their families, Guests and other short-term in-patients of the hospital.
Sports:-

- The need for the elderly to have some activity and exercise is important. Hence, this is encouraged among the Snehalaya patients and supervised by the nurse and therapists.
- To promote this, a Special annual sports day is being organized every year. In this many outdoor games like throw-ball, number games, hitting the bars etc. are organized for the Snehalaya patients. This event is held during the Christmas season.
- Exciting First, Second & Third prizes is also given to them to motivate and make them feel happy.
- Daily games (indoor games) organized by the Nurse and counsellor helps them to communicate, exercise and get together.

2. Spiritual Nurture

- By the grace of God almighty TLM Naini has a nice Chapel where Christian activities take place the whole year and patients are encouraged to join in.
- Snehalaya members help in church activities like ringing the church bell, arranging bibles and song books in the chapel.
- Some of them participate in Sunday service, Christmas, New Year and Easter services.
- They have Daily prayers too.

3. Accommodation, Maintenance & other facilities

Here in Snehalaya the hospital tries to provide a comfortable and pleasant stay and hence many changes/Renovations have taken place time to time. Some of the features of their accommodation and other facilities are-

- Well illuminated quarters and surroundings
- Neat & clean rooms (cleaned by the hospital cleaning staff twice daily)
- Attached latrines & bathrooms. (cleaned by the hospital cleaning staff twice daily)
- Separate beds with good quality mattress, pillow, quilts etc.
- Air Coolers in summer (temperature goes 45° to 48° C in Summers)
- Sufficient water taps in bathrooms, with disabled friendly access.
• Purified water (Aqua guard) for drinking purpose.
• 24 hours electricity (Using Power Generator during 5-6 hours of power cut daily)
• Cemented pathway
• Clothes distribution twice a year (Summer and winter).
• Blanket distribution once a year.
• Bathing & washing soap, oil distribution once a month
• Pocket money of Rs 100/- per month.

WORK RELATED ACTIVITIES:
Most of them are kept occupied doing work suited to their age and disability and thus also helping the hospital. They do jobs like gardening, making dressing sets, packing medicines, helping other ward patients and supporting the nursing department. Some are used to provide health education & self-care teaching to the ulcer in-patients.
Over the years the stigma has reduced, and some of their family members visit them regularly – though not willing to take them home. This really helps make them feel loved at least for a few hours in a year. Some patients also visit their homes once in a while especially to attend functions like marriages and festivals.

DIET:
A good diet is very necessary for health. Here in TLM Naini the hospital provides a balanced diet to the members of the snehalaya. To provide variety and maintain taste there are different menus for each day. The diet provided to the patient is carefully cooked by the kitchen staff and then the quality of the food is being checked by the hospital staff. There is regular inspection in the kitchen to have a good control over the quality of food.

Following is the menu of food being served to Snehalaya.

<table>
<thead>
<tr>
<th>Sl. No</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
<th>Sunday</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Breakfast</td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Halwa, Tea</td>
<td>Bun, Eggs,</td>
<td>Bengal Gram &amp; Tea</td>
<td>Wheat porridge &amp; Tea</td>
<td>Bun, Eggs, Banana &amp; Tea</td>
<td>Bengal Gram &amp; Tea</td>
<td>Bun, Eggs, Banana &amp; Tea</td>
</tr>
<tr>
<td></td>
<td>(8:00 am to 8:30am)</td>
<td>Banana &amp; Tea</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lunch</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rice, Dal, Pumpkin-potato &amp; Pickle</td>
<td>Rice, Dal, cauliflower-potato &amp; Pickle</td>
<td>Rice, Dal, Brinjal (aubergine) &amp; Pickle</td>
<td>Rice, Dal, Mutton/Chicken &amp; cottage cheese</td>
<td>Rice, white chickpea gravy, pickle</td>
<td>Rice, Curd based pakauri gravy &amp; Pickle</td>
<td>Rice, Red kidney beans gravy &amp; pickle</td>
</tr>
<tr>
<td></td>
<td>(12:30 pm to 1:00 pm)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Evening</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tea + Pakora</td>
<td>Tea + Biscuits</td>
<td>Tea + Bread pakora</td>
<td>Tea + Biscuits</td>
<td>Tea + Bread pakora</td>
<td>Tea + Biscuits</td>
<td>Tea + Samosa</td>
</tr>
<tr>
<td></td>
<td>(4:00 pm to 4:30 pm)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Dinner</td>
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<td></td>
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<tr>
<td></td>
<td>(7:00 pm to 8:00 pm)</td>
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</tr>
</tbody>
</table>
Special high protein diet (milk, egg, gram, protinex etc) is given to those who have been recommended by the doctor. The average expenditure on Snehalaya patient’s food per year is nearly ₹ 29,200 per Snehalaya inmate.

**Schedule of Snehalaya:**

<table>
<thead>
<tr>
<th>Sl. No</th>
<th>Timings</th>
<th>Activity (Monday to Saturday)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>8:00 am</td>
<td>Breakfast</td>
</tr>
<tr>
<td>2</td>
<td>8.30 am to 12:00</td>
<td>Working in their respective area- kitchen, workshop, different wards, garden, pharmacy etc.</td>
</tr>
<tr>
<td>3</td>
<td>12.30-1:30</td>
<td>Lunch</td>
</tr>
<tr>
<td>4</td>
<td>2:00-4:00</td>
<td>Working in respective areas.</td>
</tr>
<tr>
<td>5</td>
<td>4:00-5:00</td>
<td>Evening Tea + Snacks</td>
</tr>
<tr>
<td>6</td>
<td>7:00 pm</td>
<td>Dinner</td>
</tr>
</tbody>
</table>

Sunday is a holiday for them also when they take complete rest, enjoy the food, watch television play games and have some fun.  
The television was donated by a former staff (Occupational therapist) who migrated to Ireland to earn enough money to get his sister married. Inspite of his financial needs, he was so attached to the Snehalaya patients (over the 3-4 years with them) that he donated two television sets, clothes and a special meal on his first visit back to India.

**DONATION APPEAL:-**

By the grace of God Almighty we were able to meet the expenses of the Snehalaya members for the past decades, which included their Food, Accommodation, electricity, Medical care, Staff cost and other expenses. Due to the economic recession of the year 2008, many of our donors across the world find it difficult to donate freely as they used to. Hence we request you to support the Snehalaya and its members-

- *These are aged parents and grandparents who have been neglected by their own families.*
- *“We all wish we could have done more for our elders and this is an opportunity to do something in their memory”*
**COSTING:-**

<table>
<thead>
<tr>
<th>Sl. No</th>
<th>Particular</th>
<th>No of Patients</th>
<th>Cost</th>
<th>Total Cost</th>
<th>Particular</th>
<th>Amount</th>
<th>Specification</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Food for Snehalya Patients</td>
<td>14</td>
<td>80</td>
<td>408,800</td>
<td>Food provided to Snehalya patients is free of cost (includes Breakfast / Lunch / Dinner / Tea)</td>
<td>29,200</td>
<td>For Prem Masih</td>
</tr>
<tr>
<td>2</td>
<td>Pocket Money</td>
<td>14</td>
<td>100</td>
<td>16,800</td>
<td>(Snehalya patients use this money to entertain their self)</td>
<td>16,800</td>
<td>For all Snehalya Inmates</td>
</tr>
<tr>
<td>3</td>
<td>Clothes</td>
<td>14</td>
<td>10,500</td>
<td></td>
<td>Clothes provided to Snehalya patients twice a year (during summer &amp; winter) (i.e. July &amp; December) Kurta / Payjama @ Rs 250 * 14 = 3500 Pant / Shirt @ Rs 250 * 14 = 3500 Woollen Shawls @ Rs 250 * 14 = 3500</td>
<td>10,500</td>
<td>For all Snehalya Inmates</td>
</tr>
<tr>
<td>4</td>
<td>Bedding</td>
<td>14</td>
<td>11,200</td>
<td></td>
<td>Bedding provided once in a year to Snehalya patients (includes Blanket @ Rs 500 Bedsheet @ Rs 200 Pillow @ Rs 100)</td>
<td>11,200</td>
<td>For all Snehalya Inmates</td>
</tr>
<tr>
<td>5</td>
<td>Soap &amp; Washing</td>
<td>14</td>
<td>15,000</td>
<td></td>
<td>Requires Bath Soap / Washing soap / Detergent powder for their daily needs Lifebuoy Bath soap Detergent powder Rin Soap</td>
<td>15,000</td>
<td>For all Snehalya Inmates</td>
</tr>
<tr>
<td>6</td>
<td>Medicine / Medical supplies</td>
<td></td>
<td>180,00</td>
<td></td>
<td>All Snehalya patients are &lt;60 years, some of them are &lt;80 requires loving &amp; medical care. One nursing staff is always with snehalya patients to provide better care to them.</td>
<td>13,000</td>
<td>For Prem Masih</td>
</tr>
<tr>
<td>7</td>
<td>Picnic for patients</td>
<td>14</td>
<td>10,000</td>
<td></td>
<td>Picnic for Snehalya patients arranged twice in a year (approx cost - Rs 5000) includes Special food Vehicle Fuel</td>
<td>10,000</td>
<td>For all Snehalya Inmates</td>
</tr>
<tr>
<td>8</td>
<td>Special Food on Festivals</td>
<td>14</td>
<td>14,000</td>
<td></td>
<td>Special food provided to patients on New Year Day / Republic Day / Holi / Independence Day/ Diwali / Dusherra/ Christmas (approximate cost of Special food @ Rs 2000)</td>
<td>14,000</td>
<td>For all Snehalya Inmates</td>
</tr>
<tr>
<td>9</td>
<td>Repairs &amp; Maintenance</td>
<td>14</td>
<td>57,000</td>
<td></td>
<td>Repairs &amp; maintenance required for Snehalya quarters, water pipe line, Electricity</td>
<td>57,000</td>
<td>For all Snehalya Inmates</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td></td>
<td>723,300</td>
<td></td>
<td></td>
<td><strong>176,700</strong></td>
<td></td>
</tr>
</tbody>
</table>
**Prem Masih**

Prem Masih is 76 years old and was born in Naini, Allahabad in the year 1936. His family belongs to Purulia (a district in West Bengal, India). His father was also leprosy affected and was a permanent patient of TLM Naini hospital. His mother used to help the leprosy patients admitted in TLM Naini hospital. He has 3 brothers and one sister.

Prem was just 10 years old when he was diagnosed with leprosy. He was not at all aware of his disease and was thought this would be like other common illnesses and he will be alright soon. Anti-leprosy treatment was not available then and only much later was DDS mono-therapy introduced. He studied till 7th standard and then did a 4 years apprentice training in electrician trade from Allahabad Agriculture University. He worked in few companies as well. When he was 30 years old he was brought to TLM Naini hospital with high grade fever and stayed here for the treatment. Soon he developed ulcers due to anaesthetic hands & feet. After his first surgical intervention he became very upset as he found his future bleak.

He turned to his brothers and sister but no one accepted him due to the prevailing stigma of leprosy. He then found nowhere to go, preferring to return to TLM Naini. He is since then staying in TLM Naini’s Mercy Home (Snehalaya).

He is very impressive with his commitment and sincerity. He is very much involved in the church activities like ringing the church bell (daily morning devotion for staff + Sunday church service), arranging the bibles, song books and chairs in the chapel etc. He knows electrical work and hence helps in the hospital workshop.

The Snehalaya at TLM Naini has given Prem Masih a new motive for living. Today he is not unwanted and rejected but among his new family and has made himself useful, in spite of his disability. He is an example of being “differently abled’ and not “disabled”.