7. Leprosy Reaction and its Management

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7.3 Types of reaction
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   7.3.2 Type II Reaction
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7.6 Checklist of items needed to treat reactions at PHC

Objectives:

- Identify reaction/ neuritis in early stages
- Describe Management of LAP with reaction
- Describe monitoring of LAP with reaction
- Enumerate conditions for referral of LAP with reaction
Teaching methodology: Lecture Discussion with power point illustrations

Case Study

Case One: Ram Prasad, 22 years old mechanic came to health center with a hypopigmented skin lesion with scar tissue on his forehead. On asking it was found that he had developed this lesion one year back and took treatment from a nearby doctor who had given him medicine for local application saying that this will cure the lesion by burning it but there was no effect. Now lesion has become red and swollen. Discuss diagnosis and management.

Case Two: Harvinder Kaur, 38 years old female with 28 weeks of pregnancy was referred by the local dai to medical officer. She was suffering from temperature and had developed tender nodules under the skin over trunk and both the arms and leg. On examination eye was found red and painful without any other significant finding. Discuss the case.

Case Three: Kamala 35 years old, (not her real name) did not think anything wrong with her when she saw one morning few nodules on her arms. “Probably mosquito bite” she thought. But when similar nodules appeared on the thighs two days later she got frightened. She confided in her husband. They decided to consult a skin specialist. They went to a well known dermatologist who had retired from services a long time back. He suggested biopsy. The report said neurofibromatosis. The dermatologist was not happy with the report. He referred Kamala to a former colleague of his who had also retired form service. He took smears form the ear lobes, thighs ad arms. It was found to be 5+. He put her on a regimen of daily Rifampicin (600 mg) and Dapsone 100 mg. The condition became worse. She developed new painful lesions all over with high fever and joint pains. The couple became scared. They went to a dermatologist in a well – known corporate hospital. He stared Clofazimine 300 mg a day and prednisolone 40 mg a day. There was improvement for sometime. When the prednisolone was reduced to 20 mg she had flare up. She had such exacerbation about thrice after that. She was referred to leprosy centre.

The patient was anxious. She had developed cushingoid features. She was febrile. She had brownish pigmentation of the skin probably due to Clofazimine. She had painful, tender nodules on the face, neck, arms, thighs and legs. Nerves appeared to be normal. There was no deformity.

- What lesions do we learn from the history of the patient?
- What is the condition that she has now?
- How do you manage the patient?
7.1 Introduction

One of the characteristics of leprosy is the occurrence of reactions that occurs due to immunological response of the body system against M. leprae bacilli. Severity of reaction depends on the presence of bacterial load in the body of the affected person and strength of immunological response. Long term problems related to leprosy (deformity and disability resulting in stigma and suffering for the patient and their family) are due to damage from leprosy reactions.

Sudden onset of acute inflammation of skin lesions, nerves, eyes and sometimes even in other internal organs, in leprosy affected person is indicative of reactions

**Inflammation of skin:** Patients usually report with inflammatory changes in the existing skin lesions with mild discomfort. Usually it is not very serious. Skin lesions become red, swollen, warm to touch slightly tender but not painful.

**Inflammation of Nerves:** Inflammation of nerve is very serious. Swelling of the nerve trunk due to inflammation leads to increased pressure with in the nerve and its ischemia. Clinically it may present as pain, tenderness and impairment of function of the affected nerve. Involvement of nerve trunk requires prompt treatment to avoid permanent disability and deformity. Sometimes, nerve damage may occur without any pain or tenderness; making it much less obvious and is known as ‘silent neuritis’. Early nerve damage is usually reversible. When an affected person comes with symptoms and signs suggestive of recent (appearing within the last 6 months) impairment of function of one or more peripheral nerves; such as numbness or muscle weakness in the hands or feet; suspect reactions that may require treatment with steroids.

**Inflammation of eye:** Eye becomes Red and painful, pupil becomes contracted and non reactive. Colour of iris becomes dull and person complains of photophobia (pain in the eye when it is exposed to light). Involvement of eye is an emergency and need referral to higher centre.

All the people affected with leprosy whether having Pauci-bacillary or Multi-bacillary leprosy are at risk of developing reaction. Lepra reaction can develop at anytime i.e. at the onset of the disease, before starting the treatment, during treatment or after completion of the treatment. Lepra reaction is diagnosed by clinical examination and to prevent any disability and deformity due to leprosy, reactions must be diagnosed and treated promptly. Some people are more prone to develop Lepra reactions:
Persons with following features are more likely to develop reaction:

- Multiple lesions
- Lesions close to the peripheral nerve
- Lesions on the face
- Pregnancy & Childbirth

These patients should be monitored more frequently for early detection of reaction and its prompt management.

People having few skin lesions and no nerve enlargement are at low risk of developing reactions.

### 7.2 Diagnosis & examination of the person with lepra reaction

Whenever leprosy affected person is examined, ask for symptoms related to inflammation of skin lesions, presence of cutaneous nodules, pain and tenderness of the nerve, pain & redness in the eye, weakness in hand and feet, inability to close eyes completely, fever and pain in testes (male patient) etc Always assess the function of the nerves as described in diagnosis of leprosy.

Whenever a person suffering from leprosy comes: Always examine for evidence/signs of reaction:

**Skin:**
- Inflamed skin patches
- Red, painful & tender cutaneous nodules

**Nerves:**
- Pain or tenderness in nerve
- New area of loss of sensation
- Presence of weakness in new muscles
- Increased weakness in already affected muscles

**Eyes:**
- Pain and redness of eye
- Recent impairment/ deterioration of vision
- Recent weakness of eyelid muscles/ inability to close eye

Always assess nerve function as nerve damage may occur without any pain
Facts about reaction

- Even in the absence of pain, tenderness or inflammation of skin lesions; any new sensory loss or weakness of muscle means nerves are being affected by reaction.
- Reactions of recent origin i.e less than six months duration or if time of onset is not known (the patient does not remember the time of onset of reaction – giving benefit of doubt) are treated with steroids because nerve involvement of recent origin is reversible.
- Whenever duration of involvement of nerve is more than six months refer the person to specialist for advice and treatment as they would need specific treatment to prevent further deterioration.

Reactions can occur even after completion of treatment by Multi Drug Therapy

7.3 Types of reactions

There are two types of Lepra reactions. Both types can occur before the start of treatment, during treatment or after treatment has been completed.

**Type 1 Reaction:** Reversal Reaction
**Type 2 Reaction:** Erythema Nodosum Leprosum Reaction

Both types can be divided into mild or severe: only severe reactions are treated with corticosteroids. Patients with single skin lesions are unlikely to get reactions, but most of the affected people have some risk of getting a reversal reaction; only a much smaller group of people with MB leprosy having a heavy load of bacilli are at risk of developing an ENL reaction.
7.3.1 Type 1 reaction

It is also known as Reversal Reaction and can occur both in PB and MB leprosy. It occurs as a result of increased activity of the body’s immune system, fighting the leprosy bacillus or remains of dead bacilli and this presents as inflammation of skin and nerves where leprosy bacilli are present in the body. It usually occurs with in the six months of starting the treatment.

**Clinical features:** The reaction may be the first presenting sign of the disease. The Existing lesions become red, swollen and warm. Lesions are not painful but some discomfort may be felt. Sometimes, only few patches are inflamed. Some previously unnoticed or non visible patches may become visible giving an impression of appearance of new skin lesions. Type 1 reactions last for few weeks only.

Swelling of the limbs &/or face may be present. General condition of the patient is satisfactory. There is usually no fever and patient does not feel ill. Eyes are not affected by a Type 1 reaction but person may develop corneal anaesthesia & lagophthalmos due to involvement of nerves. (Refer POD & pathogenesis of eye).

Nerves are frequently affected in type 1 reaction and become enlarged, painful and tender. Sensory and motor function of the nerve gets affected. Some times, involvement of nerve may be the only presenting feature of reaction without inflammation of skin lesions.

If left untreated, Type 1 reactions usually settle down within six months, but involvement of nerve may lead to permanent loss of function resulting in disability and deformity.

7.3.2 Type – II reaction (Erythema Nodosum Leprosum- ENL)

Type II reaction is also called Erythema Nodosum Leprosum (ENL) reactions. It occurs when large numbers of leprosy bacilli are killed and gradually decompose. Proteins from the dead bacilli provoke an allergic reaction. Since these proteins are present in the blood stream, a Type 2 reaction involves the whole body, causing generalised symptoms.

People having increased load of leprosy bacilli like those Multi- bacillary/ infiltrative type of leprosy get Type 2 reaction. It may occur in the early stages of treatment and even after completion of the treatment with MDT, because body takes a long time to clear the dead bacilli. Type 2 reaction commonly occurs with in first three years after the start of leprosy treatment.
ENL is a chronic condition that can persist for several years; it may get better or worse from time to time. If not treated, most of the time, a person with type 2 reaction may feel very ill and may even die. Besides skin and nerves other organs such as the eyes, joints, testes and kidneys may also be involved and if not treated may get permanently damaged.

**Clinical features of a Type 2 reaction:**

In the beginning general symptoms like fever, headache, and body ache appear before the characteristic nodules appear on the skin.

Type 2 reactions exhibit the typical signs of erythema nodosum - red, painful, tender and cutaneous (nodules are in the skin and not under the skin/subcutaneous. skin can not be moved over them) nodules that can appear on any part of the body but commonly found on face and outer surface of limbs and less frequently on the trunk. They subside within a few days even without treatment (and appear in crops Nodules are better felt than seen and more likely to recur (episodic).

Nodules may be few or many in number and are not associated with the leprosy skin lesions. **Tenderness of the nodules is an important clinical sign of ENL.** Nodules may ulcerate in severe cases. Involvement of eye in type -2 reactions is a serious condition; it may lead to the development of iritis (inflammation of the iris) and impairment of vision.

**Patients developing reactions are at a higher risk of developing disabilities and deformities compared to people who do not develop reaction.**
7.3.3 Difference between Type I and Type II reactions

Type I reaction is localised where as type 2 reactions is more generalized. The following table shows the differences between the two types of reaction:

<table>
<thead>
<tr>
<th>Signs</th>
<th>Type I</th>
<th>Type II</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of reaction</strong></td>
<td>Delayed Hypersensitivity</td>
<td>Antigen antibody reaction</td>
</tr>
<tr>
<td><strong>Inflammation of the skin</strong></td>
<td>Skin lesions suddenly becomes reddish, swollen, warm, painful, tender but the rest of the skin is normal</td>
<td>Red, painful, tender, cutaneous nodules (deep) appear that are not associated with leprosy patches. ENL may appear commonly on face, arms, legs.</td>
</tr>
<tr>
<td><strong>Nerve involvement</strong></td>
<td>Nerves close to skin may be enlarged, tender and painful (neuritis) with loss of nerve function (loss of sensation and muscle weakness) and may appear suddenly or rapidly</td>
<td>Nerves may be affected but not as common or severe/acute as in Type I</td>
</tr>
<tr>
<td><strong>General condition of the patient</strong></td>
<td>Good, with little or no fever</td>
<td>Poor, with fever and general malaise</td>
</tr>
<tr>
<td><strong>Timing of presentation and type of patient</strong></td>
<td>Usually early on in the course of MDT; occurs in people with both PB and MB</td>
<td>Usually later in the treatment; occurs in people with MB leprosy.</td>
</tr>
<tr>
<td><strong>Eye involvement</strong></td>
<td>Weakness of eyelid closure may occur (nerve involved)</td>
<td>Internal eye disease (iritis) occurs</td>
</tr>
<tr>
<td><strong>Other Organs</strong></td>
<td>Not affected</td>
<td>May be affected</td>
</tr>
</tbody>
</table>

Treat as Type 1 reaction if:

- Presence of new nerve damage with/without skin inflammation
- Presence of inflammation of skin lesion

Treat as Type II reaction if:

- Presence of ENL skin lesions
Both the type of reaction can be either mild or severe

7.3.4 Features of Mild Reaction

- Occurs in the skin only (Other than face)
- Mild swelling of skin lesions without ulceration
- Nerves are not affected
- Mild fever may or may not be present
- Mild swelling (oedema) of the limbs may be present

7.3.5 Features of severe reactions

Reaction is severe, if one or more of the following features is present and needs treatment with steroids.

- Red, painful, single or multiple nodules in the skin with or without ulceration
- Pain or tenderness in one or more nerves, with or without loss of nerve function
- Silent neuritis or quiet nerve paralysis
- New area noticed with loss of sensation
- Increased or new muscle weakness noticed
- A red, swollen skin patch on the face or overlying another major nerve trunk
- A skin lesion that becomes ulcerated or is accompanied by a high fever
- Marked oedema of the hands, feet or face
- Pain and/ or redness of the eyes with or without loss of visual acuity (Involvement of eye)
- Generalized symptoms with painful swelling of the small joints with fever
- Recurrent ENL more than four attacks in a year
- Reaction lasting for more than six months
- Enlargement of Lymph glands /testis with mild pain or tenderness
- Involvement of other organs

7.3.6 Differential Diagnosis

Common conditions that can be confused with reactions are:

- **Drug Reaction**: skin lesions in drug reaction are flat, possibly hyper-pigmented, itch and do not correspond to skin lesions. Itching is not a feature of leprosy.

- **Local sepsis**: local sepsis is usually localized to one part of the body and cause of sepsis like injury or insect bite is usually present.
7.4 Management of the reaction

- If a patient develops lepra reaction during the treatment –
  Do Not Stop MDT (rather complete the course of MDT)
  
  Lepra reactions that occur after completion of treatment must be managed by steroids.
  
  Do Not Start MDT

Management of reaction depends on the following features:

- Type of reaction
- Severity of Reaction
- Any complications or contra-indications affecting treatment.

Principle of treatment of reactions

- Rest,
- Analgesic
- Anti-inflammatory drugs
  (Like any other inflammatory condition)

7.4.1 Management of mild reaction

Reassurance: Patient is reassured that it will subside within few weeks with medicine

Analgesics and Anti-inflammatory agents: Mild cases of both the types of lepra reactions are treated symptomatically with Aspirin (Adult dose 600 mg which can be given upto six times a day)/ Paracetamol (adult dose 1 gm upto four times a day). Steroids are not given to patients of mild lepra reaction.

Reactions, which show no signs of severity but which are limited to mildly inflamed skin lesions may be treated symptomatically with Aspirin/Paracetamol.
7.4.2 Management of severe reaction

If any of the features mentioned in section 7.3.5 are present at the time of diagnosis of reaction or develop later during treatment, means person is suffering from severe reaction and require treatment with steroids and advised:

- **Bed rest:** For the person

- **Splint:** Rest to the affected nerves and muscle is provided by use of splint. Splint is applied to the joint in the vicinity of the affected nerve, to prevent injury to the affected nerve due to repeated movement of the joint. Other adjoining joints are moved twice a day with full range of movement to avoid stiffness. When acute phase is over i.e. pain and inflammation subsides (recovery begins), passive exercises are started to maintain the range of movement of all the adjacent joints. Later, even if there is some permanent nerve damage, active exercises are started to restore muscle strength of the muscles.

- **Analgesics:** Analgesics are given whenever required.

- **Prednisolone:** The main drug for the treatment of severe reactions is corticosteroids
  
  - Prednisolone is the most commonly used steroid for this purpose. It is easily absorbed when taken orally. Must not be taken on empty stomach. Salt intake must be restricted while on steroids.
  
  - Steroids are given to relieve pain and inflammation in the nerve. Prednisolone is a very effective drug and its affect starts in a few days. Prednisolone reduces the inflammation in the nerves resulting in reduction in nerve pain, tenderness & oedema of the nerve and helps gradual restoration of nerve function.
  
  - The usual dose of steroids to begin with is 40 mg daily (up-to a maximum of 1 mg/kg of body weight) duration of treatment is 12 -24 weeks depending on the severity of reaction and response to the therapy.
  
  - If inflammation of skin & nerve is better and there is no new nerve involvement, the dose of Prednisolone is gradually reduced at fortnightly interval depending on the response and eventually stopped.
  
  - For the maximum recovery, it is essential to complete the course of prednisolone.
  
  - In case of neuritis, (inflammation of peripheral nerve trunk) the period of treatment may be prolonged according to the response. From 20 mg onwards the dose for each period would be for 4 weeks.
  
  - Response to steroid therapy is generally assessed within two weeks. Review the progress every two weeks. If there is favourable response, the dose may be tapered according to the schedule. If there is no response, the same dose is continued and person is referred to higher centre.
  
  - In case of type – I reaction not responding after 2 weeks of treatment with prednisolone or at any time showing signs of deterioration, the patient is referred to the referral center. (District Hospital).
The standard treatment for PB & MB patient with severe reaction is as follows:

<table>
<thead>
<tr>
<th>Prednisolone regimen</th>
<th>Added with clofazimine in ENL (Type 2 reaction)</th>
</tr>
</thead>
</table>
| 40 mg O.D. for first 2 weeks  
30 mg O.D. for weeks 3 & 4 | One capsule (100mg) 3 times a day x 4 weeks |
| 20 mg O.D. for weeks 5 & 6  
15 mg O.D. for weeks 7 & 8 | One capsule (100mg) 2 times a day x next 4 weeks |
| 10 mg O.D. for weeks 9 & 10  
5 mg O.D. for weeks 11 & 12 | One capsule (100mg) once a day x third month |

**NOTE:** Start MDT, if person has come for the first time & MDT not taken previously. People still on anti-leprosy treatment (MDT) must continue their treatment. However, those who have completed their course of MDT do not need anti-leprosy treatment while suffering from lepra reaction or on steroids.

### 7.4.3 Management of severe type II reaction

Type 2 reactions can often last for months or even years and so there is a risk of people becoming dependent on steroids. It becomes difficult to taper steroids and eventually terminate the treatment. These persons need drugs other than Prednisolone like Clofazimine, Thalidomide for the management of the reaction. Though Clofazimine is less potent than steroids and often takes 4 – 6 weeks to develop its full effect; it is extremely useful for reducing or withdrawing corticosteroids in patients who have become dependent on them. Total duration of clofazimine Therapy should not exceed 12 months.

You may start Prednisolone for persons suffering from severe reactions and refer them to referral centers for management by experienced staff,

### 7.4.4 Counseling to the patient with reaction

Before starting treatment with steroids, complete information must be given to the patient regarding:

- The reason for the treatment
- Duration of the treatment
- The importance of taking the correct dosage
- The fact that treatment must never be stopped suddenly
- Conditions to be reported immediately
- The possible side effects of the treatment
The reason for treatment: Explain that the drugs are being given to reduce pain (if present), inflammation and restore function of the affected nerve that is likely to improve in one to two weeks. Person must come for follow up after two weeks. If left untreated nerve damage can lead to permanent disability and deformity. Also tell the patient that recovery may be partial and some symptoms might remain after treatment (for example, sensory loss or muscle weakness) but treatment is essential to prevent worsening of the disability.

Duration of the treatment: Duration of treatment depends on severity of reaction and response of the reaction to drugs. Minimum duration of treatment is twelve weeks (PB cases) or twenty-four weeks (MB cases).

Taking the correct dosage: To get the best results, medicine must be taken daily and in the prescribed doses for the recommended duration.

Treatment should not be stopped suddenly: Steroids have a powerful effect on the body. If it is stopped suddenly person may become seriously ill. Blood pressure may drop and may feel weak. Drug once started must be reduced gradually. It is important to take the complete course of treatment without interruption.

Conditions to be reported immediately: Tell the patient that they are at risk of recurrence of reaction and new nerve damage. Any impairment of nerve function must be reported immediately. If, at any time pain increases or pain starts in another nerves, area of sensory loss increases or new area with sensory loss is noticed or new muscle develops weakness/ paralysis or weakness increases in already affected muscle, skin ulcerates, eye becomes red and painful, develops impairment of vision/ vision deteriorates further or develops lagophthalmos; it must be reported immediately as in such situations person may need higher dose of steroids or same dose for a longer duration. In case of deterioration of condition always refer the affected persons to higher centre for more specialized care.

Possible side effects: Tell the patient that certain overt diseases may manifest by taking steroid treatment and must report if any of the following is noticed to prevent further complications.

- Worsening of cough
- Excessive thirst or urination (symptoms of Diabetes)
- Pain abdomen
- Worsening of sepsis
- Diarrhoea / Dysentery
- Swelling of face, increased hair growth, acne

7.4.5 Monitor the progress

If nerve gets involved in mild reactions, steroid therapy is started and effect of the therapy is assessed every two weeks. Record all the clinical findings as these are required to assess the progress (detect any deterioration early/ taper the dose of steroids) in the condition of
the person. Patient is advised to come after 2 weeks for follow up but tell person to report immediately to the health center if at any stage there is worsening of the condition. (refer above - condition to be reported immediately) other wise, person is asked to come after two weeks.

**Person on steroids is reassessed every two weeks while on steroid therapy** or on every visit

- Assess general condition of the patient
- **Watch for side effect:** As already mentioned person on Steroids may have a number of serious effects, for which further investigation would be required. Ask the person to report development of any side effects/ any other problem (refer possible side effects).
- **Monitor nerve function:** By conducting detailed examination for sensory and motor function and comparing it with the pervious report. Response of the treatment and appearance of any new symptom/sign is assessed. If definite deterioration in nerve function or severity of reaction is discovered at any time after starting steroid therapy, refer the person for specialist advice. Meanwhile, continue the same dose of prednisolone.

**Prescribe prednisolone for the next two weeks if there is**

- No deterioration in the nerve function
- No evidence of involvement of new nerve
- No involvement of eye

**7.4.6 Follow-up after treatment with steroids**

People who have been given a course of steroids for reaction or nerve damage are followed closely because of the risk of recurrence.

Make sure that each of them understands that a reaction or new nerve damage can recur. Tell them how to recognise the early signs of nerve damage and how important it is to return promptly to the clinic for treatment. These signs include pain or tingling sensations, further loss of feeling or loss of muscle strength and inability to close the eye (refer section ……).

People still on MDT and come to collect their medicine are checked every month for effect of treatment on nerve function and referred immediately in case of any deterioration in the nerve function.

People who have already completed MDT by the time they come to the end of a course of steroids are asked to come back every three months after the completion of the course for review and nerve function assessment.

People who still have lag-ophthalmos (weakness of eyelids) after completion of treatment with steroids are referred to a specialised centre.
While referring the person, details are noted in the referral register; this will help you to keep the track of the person referred by you and provide follow up treatment as advised by the referral centre. Person is also given referral slip, giving the details of the condition of the referred person and treatment given. Person would be referred back with details of the follow up treatment required for the referred person.

**Contraindications to Prednisolone in presence of NFI:**

- **Nerve abscess:** Presence of abscess along the course of the nerve needs surgical evacuation.

7.4.7 **Management of person on interruption of steroid therapy**

Some times, patient may not come back for next dose of therapy, try to retrieve the patient with the help of the health worker. Explain the importance of continuing the therapy. When ever patient returns after interruption in the steroid treatment:

- Find out the duration of interruption
- Assess their nerve function.

If duration of interruption is **less than four weeks**, continue with the next dose that should have been given at the missed appointment and follow the standard course.

If duration of interruption is **four weeks or more** management will depend on the condition of the patient.

- If the original problem does not exist (no sign of reaction), stop the steroid treatment.
- If nerve damage of less than six months duration and sign of reaction still persists, restart the whole course of steroids. Make sure that the person understands the importance of completing the course without interruption.
- If the nerve damage has worsened, restart the course of steroids and refer the patient to a specialist.

7.4.8 **Referral of patient with reaction**

Patient may need referral before starting the steroid therapy or during the treatment.

**Referral before starting the treatment with steroids:**

As already mentioned some people are more vulnerable to side effects of steroids and need specialized care. Before starting the steroids assess the person for presence of the hypertension, diabetes mellitus, peptic ulcer, tuberculosis, ulcers, osteomyelitises, and eye ailments. If any of these conditions is present, leprosy affected person require treatment for that particular condition along with steroids and is referred to higher center (District
hospital) because they will need additional resources such as inpatient care, laboratory facilities, services of ophthalmologist, radiology & surgical facilities during steroid therapy. Pregnant women & children under 12 years requiring steroid therapy are also referred to higher center.

Eye involvement: Involvement of eye / muscles of eye lid whether before or during the treatment; is considered emergency and must be referred immediately because it may lead to impairment of vision and even blindness.

Type –I reaction, which occur after the completion of treatment, must be referred and managed at the referral centre.

Referral during the Steroid therapy

- Patient is also referred to secondary referral unit (District Hospital) if condition of the patient does not improvement after two weeks of steroid therapy
- If condition of the patient worsens at any time during treatment
- If develops side effects of steroid therapy (Refer Monitoring)

Referral after completion of steroid therapy

- People who still have lagophthalmos (weakness of eyelids) after completion of the treatment with steroids should be referred to a specialist centre.

7.4.9 Treatment with surgery

In some cases with Chronic nerve pain i.e. if inspite of the treatment with steroids pain lasts for more than four weeks. To relieve nerve pain and restore nerve function; nerve pressure is relieved by surgery called nerve decompression. Nerve decompression is an out door procedure.

7.4.10 Recording steroid treatment

Information regarding lepra reaction and details of steroid therapy are filled in lepra reaction/ neuritis form (form PIII) kept at the PHC to monitor the nerve function by comparing the current findings with that of the previous visit. If steroids are being given, record the details in the Leprosy Treatment Register and on the Patient Record Card by red ink. To ensure regularity of the treatment, in people on steroid therapy, who have completed course of MDT, add their names in the treatment register with old registration number in red for the duration of the steroid therapy. Details of the referred person must be recorded in the register (P- V).
7.5 Precautions with treatment with Prednisolone

7.5.1 Conditions that worsen with steroid therapy
If any of these conditions is present, Treatment for the condition can be started along with the steroids.

<table>
<thead>
<tr>
<th>S. No</th>
<th>Condition</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Worm infestations</td>
<td>Mebendazole (100 mg twice daily for three days)</td>
</tr>
</tbody>
</table>
| 2.    | Diarrhoea, with blood and/or mucus      | * Amoebic dysentery: Metronidazole 800 mg three times daily for five days (adult dose)  
* Bacillary dysentery: ciprofloxacin 500 mg twice daily x 5 days or 
Trimethoprim 200 mg twice daily x 5 days; 
Co-trimoxazole 960 mg twice daily x 5 days |
| 3.    | Conjunctivitis/trachoma                 | * Conjunctivitis: Tetracycline eye ointment twice daily for five days.  
* Trachoma: Tetracycline eye ointment twice daily for three to six weeks |
| 4.    | Fungal infections                       | Clotrimazole cream (apply twice daily for at least three weeks).           |
| 5.    | Scabies                                 | Benzyl benzoate Application                                                |
| 6.    | Epigastric pain                         | Ranitidine 75-150 mg twice daily                                          |

When there are no contraindications to steroids, Mebendazole is given to treat any worm infestation (if not taken during the last six months) and steroids started.
7.5.2 Persons with following conditions are referred to higher centre before starting steroid therapy because they need additional resources, precautions and monitoring during steroid therapy.

<table>
<thead>
<tr>
<th>S. No.</th>
<th>Conditions</th>
<th>Reason for referral</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Pregnancy</td>
<td>Affects Foetus</td>
</tr>
<tr>
<td>2.</td>
<td>Children under 12 years</td>
<td>Effect on growth</td>
</tr>
<tr>
<td>3.</td>
<td>Diabetes</td>
<td>All worsened</td>
</tr>
<tr>
<td>4.</td>
<td>Hypertension</td>
<td>Presence of any infection</td>
</tr>
<tr>
<td>5.</td>
<td>Eye involvement (red eye)</td>
<td>Corneal ulcers and keratitis is made worse. Iritis, uveitis, iridocyclitis and scleritis need specialized care</td>
</tr>
<tr>
<td>6.</td>
<td>Ulcers &amp; Osteomyelitis</td>
<td>If started before specific treatment makes sepsis worse</td>
</tr>
<tr>
<td>7.</td>
<td>Tuberculosis</td>
<td>Specific treatment needed before starting steroids</td>
</tr>
<tr>
<td>8.</td>
<td>Severe depression/ psychosis</td>
<td>Worsen</td>
</tr>
</tbody>
</table>

Person with recent nerve damage not having any of the above mentioned conditions (requiring referral) can be treated with steroids at PHC.

7.5.3 Monitor the patient for side effects of prednisolone

Side effects of prednisolone therapy can be serious and sometimes even fatal. Before starting the treatment with steroids, exclude medical conditions (See Section 7.5.1 & 7.5.2) that make a person more vulnerable to side effects of steroids. Treatment for some of these conditions can be started along with the steroid therapy (See section 7.5.1) where as other need referral for specialized care
If steroid therapy is given for prolonged period i.e. six months or more, monitor the person for hypertension, diabetes, peptic ulcer, osteoporosis, growth retardation, cataracts and glaucoma. If suspect any of these conditions refer the person to higher centre.

**Make sure that people with Lepra Reaction / Neuritis are treated as early as possible –**

1. Make sure that effected person & their family members have learnt to suspect reaction
2. Service providers are capable of managing reactions & neuritis
3. Prednisolone is available to treat reactions
4. Proper counselling is done to assure adherence to treatment regimen
5. Cases with poor compliance are reminded / retrieved in time
6. Proper referral of cases in time and its follow up is done.

### 7.6 Checklist of items needed to treat reactions at PHC

**For the diagnosis and treatment of mild reaction**

- Ballpoint pen for testing sensation.
- Routine care forms for monitoring progress.
- Acetyl-salicylic acid (ASA, Aspirin) to treat mild reactions.

**For treatment with steroids**

- Testing strips for examining the urine for glucose.
- Mebendazole to give to all patients who will be treated with steroids.
- Metronidazole and co-trimoxazole (tablets/capsules).
- Tetracycline eye ointment
- Benzyl benzoate lotion.
- Clotrimazole cream.
- Antacid tablets.
- Prednisolone tablets.
- If possible, laboratory facilities for examining sputum for TB, stool for ova & cyst.

The above mentioned items can be made available at PHC/ CHC through general supply.
Type I reaction before & after treatment with steroids

ENL reaction before & after treatment

Type II Reaction
8. Prevention of Disability & Medical Rehabilitation

Structure
8.1 Introduction
8.2 Common disabilities due to leprosy and their Prevention
  8.2.1 Common physical problems faced by leprosy-affected person
  8.2.2 Prevention of Disability
8.3 Diagnosis and treatment of leprosy in early stages of the disease
8.4 Early diagnosis and management of lepra reaction and neuritis
  8.4.1 Assessment of Disability and risk status of the LAP
8.5 Protection/Care of limbs with Nerve function impairment
  8.5.1 Self care procedure for limbs with loss of sensation
  8.5.2 Characteristics of appropriate footwear
8.6 Care of eyes
8.7 Prevention and Management of ulcers, callosities and injuries
  8.7.1 Callosities & cracks
  8.7.2 Ulcers & Blisters
8.8 Care of the limbs with weakness/paralysis of muscles (Physiotherapy)
8.9 Monitoring of self care
8.10 Interventions managed at referral centre
8.11 Surgical Treatment of Leprosy
  8.11.1 The conditions that require surgical intervention:
  8.11.2 Referral of person for Surgery
  8.11.3 Criteria of selection for Reconstructive Surgery
  8.11.4 Facts must be known about surgery:
  8.11.5 Priorities for reconstructive surgery
8.12 Support to LAP with disabilities
8.13 Community based Rehabilitation
  8.13.1 Components of CBR
  8.13.2 Organisation of CBR
  8.13.3 Steps for establishing CBR
  8.13.4 Advantages of CBR
  8.13.5 Monitoring and evaluation of CBR

Objectives:
- Enlist common disabilities due to leprosy
- Describe procedure for prevention of disability in LAP without disability & worsening of the existing disability
- Demonstrate self care practices for LAP
- Enlist criteria for reconstructive surgery for LAP with disability
- Describe procedure to establish community based rehabilitation
Teaching methods- Case demonstration, group exercises, group discussions and role play

Case study:

Case one: Santi, 42 years old female came to the health worker and requested her to write some good ointment for healing of the wound. On examination it was found that she has an ulcer on the hypo-theneral eminence of left hand. ulnar nerve was thickened muscle weakness was obvious in left hand On exploration it was revealed that such wound appears repeatedly specially after working on chara (manual grass cutting machine for cows) machine. On examining the hand it was found that her ring finger and little finger is bent, about which she told the worker that it is like this since four months, after she had fallen from the steps. HW referred the person to the doctor and found left ulnar nerve thickened and sensory loss on the medial 1/3 of the palm. Discuss the management of the case.

Case two: Suru 18 years old female, registered for MB leprosy came to the health center with complaint of redness & pain in the right eye along with deterioration of vision. On exploration, history of appearance of tender nodules on both the arms 15 days back was extracted. Discuss the case.

Case three: Mr. Haribhau Hatkar 52-years had developed tingling sensation in the right leg about 6 months back. He went to a local practitioner. He assured him that it was not serious. He was prescribed some B complex. He became worried when a blister appeared on the underside of his right big toe. His son’s friend who was a soldier advised him to go to a reputed medical college hospital. He consulted the neurologist. He was subjected to various investigations and pronounced normal. He was prescribed injections of B. complex. About 6 weeks later he found that his right foot was not holding on to the Chappal and it was slipping out of his feet easily. He met a friend who noticed multiple skin patches and brought him for advice to health centre. Discuss the management.
8.1 Introduction:

Leprosy is considered a dreaded disease for its potential to cause permanent and progressive disability and deformity in the affected person. Disabilities/ deformities in leprosy patients can occur as a result of nerve damage or infiltration of tissue by the bacteria. Damage to the nerve results in impairment of its sensory, motor and autonomic function; leading to loss of sweating, anesthesia, weakness/ paralysis of muscles of eyes and extremities. Loss of sweating makes skin dry and liable for development of fissures/cracks/ulcers over extremities.

Delay in treatment of leprosy, lepra reaction and neuritis are the main causes of development of disability. If neglected these disabilities/ deformities may worsen gradually and even lead to dehabilitation of the affected person

Most of the disabilities due to leprosy are preventable

And occur as a result of
Direct/ indirect effect of damage to peripheral nerves supplying eyes, hands and feet
As part of
<Lepra reactions with signs of acute inflammation
<Insidious process during the course of the disease with out any obvious signs & symptoms of inflammation

Disease produces certain changes in the structure and functioning of the affected part of the body e.g damage to the nerve/body tissue directly e.g. eye. Changes in the tissue directly due to the disease process like damage to the nerve and anaesthesia produced due to damage of the nerve are called primary impairments

Neglect, excessive use /careless use of the insensitive hand or foot leads to development of cracks, ulcer, wounds, septic hand/ foot, shortening of fingers / toes, even mutilation of hand or feet and disorganization of the foot or wrist. Similarly, improper care of weak/
paralysed fingers results in **Joint stiffness or formation of contractures.** These ulcers, contractures and disorganised joints are **secondary impairments.**

Due to presence of primary and secondary impairment, a person is disabled and is unable to perform certain activities like writing, weaving etc (skillful use of the affected part) and is handicapped to carry out certain responsibilities in the society eg economically support the family; starts loosing the social status and become isolated gradually and may even leave the house (**dehabilitation**) and becomes **destitute** without food and shelter

**Fear of developing disability and becoming handicapped, dehabilitated and destitute gives rise to stigma against leprosy that is often seen in the society**

Efforts must be made to prevent occurrence of disability/ prevent worsening of the existing disability by identifying the people at risk of developing impairments and monitor the identified high risk person for early detection lepra reaction / neuritis and take immediate corrective action.

**By prevention of disability we mean:**

- Timely detection of disease and its effective treatment
- Care of insensitive hands, feet and eyes for prevention of secondary impairment (through self care)
- Early identification & treatment of relevant impairments such as neuritis, ulcers and injuries
- Improving the permanent disability and making handicapped person able again.
- Prevention of dehabilitation and destitution by instituting measures to over come handicaps.
- Salvaging the destitute by providing them with shelter and sustenance as well as restoring self-esteem/human dignity and fellowship to them.

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**Success of management of leprosy depends on the ability of prevention of development of disability and deformity**
8.2 Common disabilities due to leprosy and their Prevention:

8.2.1 Common, physical problems faced by leprosy-affected person due to disease are:
(Refer pathogenesis, Diagnosis & management of leprosy)

**Problems with blinking & closure of eye:**

Infrequent blinking or loss of blinking and weakness/paralyses of muscle that close the eye; means cornea is constantly at risk of exposure. Damage from this exposure leads to dryness and ulceration of the cornea. These ulcers may heal leaving a scar (opacity). If opacity is central in location, it may interfere with vision, leading to blindness. Vision may also be affected due to direct involvement of ocular tissue. The aim of POD interventions is to preserve sight.

**Loss of sensation in the hand**

Loss of sensation is usually accompanied by loss of sweating and therefore dryness of the skin predisposing to recurrent injury, cracks and ulcer. These in turn lead to chronic infection, stiffness and loss of tissue, making the hand more and more disabled. POD interventions are needed to keep the skin in good condition and avoid injury, if necessary by adjusting routine activities.

**Weakness and deformity of the hand**

Muscle weakness leads to imbalance of muscle power around a joint leading to disability and deformity and if neglected, it often leads to the formation of contractures and fixed deformity over a period of time. POD activities help to preserve muscle strength, prevent contractures and fixed deformity.

**Loss of sensation and ulceration of the foot**

The same problems of dryness, recurrent injury (especially from walking) and development of cracks/ulcers occurs in the insensitive foot. Late complications include chronic infection (osteomyelitis), which may sometimes need amputation. Interventions for POD target to keep skin in good condition and appropriate footwear to prevent injury and formation of ulcers. Changes in the routine activities may also be required.

**Weakness and deformity of the foot**

Muscle weakness affecting the toes is quite common, but it usually does not affect walking. A foot-drop leads to problems with walking.
8.2.2 Prevention of Disability:

Prevention of disability Comprises of all the activities undertaken at individual, community and program level which are aimed at preventing impairments, activity limitations and participation restrictions’ of an individual.

Prevention of disability means:
- Prevention of occurrence of disability
- Prevention of worsening of existing disability (limitation of disability)

Diagnosis and management of leprosy, lepra reaction and neuritis in the early stages is basis of Prevention of occurrence of disability. Prevention of worsening of the existing disability is possible by taking proper care of their insensitive hands, feet and eyes. Identify the relevant impairments such as neuritis, ulcers and injuries at an early stage and manage these appropriately. Following steps if followed would help you limiting the disability in leprosy affected persons:

8.2.3 Steps for prevention of Disability/disability limitation are:

Prevention of occurrence of disability
- Diagnosis and treatment of leprosy in early stages
- Early diagnosis and management of lepra reaction and neuritis supported by counseling, assessment of risk status

Limitation of disability means:
- Early diagnosis and management of deterioration in disability status supported by counseling, assessment of disability & risk status
- Protection/Care of limbs in persons with Nerve function impairment through self care
- Protection of eyes through self care
- Care of cracks, callosities and ulcers
- Reconstructive surgery & aides and appliances

8.3 Diagnosis and treatment of leprosy in early stages of the disease

Identification of leprosy affected persons, before disabilities and deformities set in (early diagnosis of leprosy) and treating them with MDT is the most crucial step for prevention of disability. All the efforts must be made to encourage self reporting of the affected person for treatment by increasing the awareness in the community and training the staff members in identification of leprosy affected person.
Early diagnosis and management of lepra reaction and neuritis:

Diagnosis of lepra reactions and neuritis and other complications during early stages is facilitated by:

- **Identification of high-risk persons**
- **Adequate counseling of high-risk persons**
- **Frequent and periodic monitoring of high-risk persons for appearance of lepra reaction and impairments due to nerve damage**

**Assess the risk status for each leprosy affected person and repeat it at frequent intervals to monitor and diagnose impairments in early stages.** People with following features are more likely to develop disability and deformities compared to others.

- Multi-bacillary leprosy
- Multiple skin patches
- Past or present thickened/painful/tender nerve trunk
- Past/present reaction, lesion near/on the nerve trunk,
- Skin lesion on face
- Pregnancy with or without thickened nerve trunk

**These high risk people are counseled frequently especially** at the time of registration for treatment, during treatment and on completion of treatment regarding **possible signs and symptoms of reaction** and need to report immediately for treatment/appropriate referral for prevention of further damage; in case of nerve pain, loss of sensation, weakness of muscles, appearance of tingling/paraesthesia in the hand, face and foot, involvement of eye. Those who come with disability are told to recognize signs and symptoms of worsening of disability.

**Frequent monitoring of high risk persons:** Monitor these identified people more frequently at regular intervals for early detection of impairment of nerve function. Persons at risk are assessed on every visit to health centre i.e. every month till taking MDT and every three months after completion of the treatment. Examine, at risk people for development of lepra reaction (refer lepra reaction), neuritis, any nerve function impairment (refer involvement of nerve, examination of nerve function including sign for recognizing early nerve damage) & involvement of eyes (Refer pathogenesis: involvement of eye, examination of eye, examination of individual nerves). Assess and record the findings of disability status.

People with lepra reaction and acute neuritis are treated with rest to the affected part, analgesics and steroids.

**8.4.1 Assessment of Disability and risk status of the LAP:**

Risk status of the affected person changes with the disability status of the person. After diagnosis of leprosy is confirmed, assess the disability status and also identify the risk status of each person for development of impairment & disability.
During every visit of the LAP for treatment or follow up, assess the extent of disability and record the findings in the form P-II for future reference. This helps in early detection of any deterioration of NFI, recognize the changes in the disability and decide the line of management to prevent further treatment.

**Procedure of assessing a disability and risk Status of a person:** (for more details refer diagnosis and treatment of leprosy, lepra reaction)

**History taking:** always ask for

- Duration of disease
- Duration of treatment i.e. MDT,
- History of reaction / neuritis and treatment
- Duration of Disability if disability is present
- Progress of disability
- History of repeated ulcers/ injuries
- History of use of any protective device in the past
- History of prior surgery (nerve decompression/ reconstructive surgery) etc.

**Physical Examination**

**Observe for:**

- Condition of the skin (dryness, cracks, callus, wounds),
- Swelling and redness on skin patches and joints
- Appearance of new lesions
- Absence / infrequent blinking of the eyes
- Redness, pain and watering in the eyes

**Palpation:**

- Palpate peripheral nerves for thickening and tenderness
  (Ulnar; Median; Radial;Lateral Popliteal; Posterior Tibial;)

**Examination:** (Refer diagnosis of leprosy)

- Sensory testing for hands (palm), feet (sole)
- Voluntary muscle testing - Abduction of little fingers, Abduction of Thumb and Extension of wrist, Dorsi-flexion of foot, closure of eye lids
- Examination of eye for any change
- Stiffness of joints
- Impairment of vision
8.4.3 Grading of disability: Refer diagnosis and treatment of leprosy

Assessment of Risk Status for development of disability and type of monitoring required:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Risk status</th>
<th>Monitor</th>
</tr>
</thead>
<tbody>
<tr>
<td>* PB leprosy, * Skin soft &amp; supple * Normal sensibility * No thickening of nerve</td>
<td>No risk</td>
<td>* Need NFI once in six months * Counsel early reporting on development of sign and symptoms of impairment of nerve function</td>
</tr>
<tr>
<td>* MB leprosy. * Multiple patches * Nerve trunk thickened or tender but no sensory loss * pregnancy</td>
<td>At risk of developing NFI (Nerve function impairment)</td>
<td>*Follow up the person frequently every month if taking MDT and *Assess NFI every three months after completion of recommended course of treatment. * Counsel for early reporting on development of sign and symptoms of impairment of nerve function * Refer, if NFI develops after the completion of the recommended course of treatment.</td>
</tr>
<tr>
<td>* Only impaired sensation</td>
<td>Risk of injuries or burns, blisters and ulcers Risk of involvement of more nerves</td>
<td>* All the above, * Self care to keep skin of the affected part soft and supple, * Early detection of any abnormality and treatment</td>
</tr>
<tr>
<td>* Blisters, * callosities, * scars, * cracks, * weakness of muscles, * deformity</td>
<td>Risk of progressive damage and disability</td>
<td>* All the above including Self care * Active and passive exercises to maintain rang of movement Improve strength of the muscles</td>
</tr>
</tbody>
</table>

Those who have already developed some impairment and disabilities are in great danger of developing new disabilities as well as worsening of existing ones and need urgent specific action. Such persons are identified and monitored more frequently. Hence, risk status of a person must be revised frequently during assessment of disability and affected person is counseled and monitored accordingly.

Presence of disability at the time of diagnosis of leprosy or its development during and after the completion of treatment is a measure (indicator) of quality of services being provided
8.5 Protection/Care of limbs with Nerve function impairment:

Even after treatment with steroids damaged nerve may not recover completely and some loss of sensation, loss of sweating and weakness of muscles may remain for rest of the life. LAP are trained to take care of their insensitive hands/feet and weak muscles to avoid wounds, skin cracks, and stiffness of joints to prevent further deterioration of structure and function.

Insensitive limbs are protected by practicing self care. Person with nerve function impairment are trained and encouraged to manage their disabilities by practicing self-care.

8.5.1 Self care procedure for limbs with loss of sensation

Aim of Preventive Care of the limbs with NFI/(Principles of self-care for limbs) are:

- Care of skin to keep it soft & supple to avoid skin cracks by practicing Soaking, Scrubbing and oiling
- Protect insensitive limbs from injury, burns & blisters and ulcers
- Early detection of blisters, wounds and injuries by daily inspection of affected hands and feet
- Provide early and correct wound care
- Practice active exercise to retain the strength of weak muscles & make weak muscles stronger
- Practice passive exercise to prevent contracture in paralysed muscles and maintain full rang of movement of the joints

First three points will be discussed here and rest of the three points will be discussed in individual sections of the same chapter.

Keep skin soft and supple: (Skin care procedures)

Sweat keeps skin soft and elastic. Absence of sweating causes skin of palms and soles to become dry and brittle. Dry skin cracks easily (esp at digital crease & on margin of the heel). These cracks / fissures may extend and become deeper to develop into palmer/plantar ulcers. To keep the skin soft people with impairments must practice soaking, scrapping and oiling preferably thrice or at least once daily

Procedure: Train the person to:

- Soak dry hands and feet in a bucket of water for 20 minutes / until any hard and dry skin becomes soft.
Rub off the surface layers of keratin by pumice or rubbing stone/rough cloth. In the presence of a crack, thin the edges of the crack by rubbing it along the edge and not across the edge.

Rub in oil like neem oil or liquid paraffin or any other bland oil that will not attract insects, vermin or rats; immediately after soaking without wiping. This helps to retain water and keep skin soft. Tell person not to apply oil without soaking. Eatable oil if used may attract rats and insects that is specially dangerous to insensitive limb.

If hard and thickened skin develops, at pressure points or site of old healed wound, scrape it layer by layer over a period of time/number of days and avoid its development in future.

For hard calluses, keratolytic ointment (6% salicylic acid or Whitfield ointment) can be applied.

In case of foot, apply oil well beneath or under the toes

Straighten the toes to prevent stiffness of the toes

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**Teach Person to inspect the hands & feet daily/frequently:**

**Tell them to look for:**

- Signs of impending ulcers like redness, swelling, blister, Dry hard skin, cracks in the skin

**Teach them to Feel for:**

- Warm spots by holding insensitive hand against sensitive area like other hand or cheek
- Press gently, to find any sore spot which may occur due to prolonged pressure while working

**Train them to think and learn:**

- Why did they get the wound?
- How can they give rest to the injured part?
- How can they avoid the similar injury in future?
Avoid injury to insensitive parts:

Protection of insensitive limbs from injury:
- Person is made aware about the insensitive part of the body and sensitized to avoid using that part while using objects (rough/sharp objects) that may cause injury.
- To avoid injury to insensitive parts, sensitize person regarding possibility of sustaining injury with out knowing about it, to think critically to recognize injurious actions, practice protective behavior to avoid injury, develop alertness to recognize injuries promptly and develop skills to manage injuries properly on their own.
- Teach and encourage person to use safe methods of handling hot, hard or sharp implements by using simple protective devices (like a hand towel, insulated handles for kitchen implements, protective gloves, MCR covered handles for work tools etc.)
- Tell person to develop habit of automatically inspecting their insensitive hands after work both at home and at work place, for signs of fresh injury
- Teach cleaning of wound with soap and water, removal of any foreign body, keep wound clean, moist (but not wet) and covered.
- Tell to seek medical advice, if wound gets infected/worse

Method of protecting insensitive hands: Person is taught to:
- Keep away the insensitive hand from fire, use stick/tongs to poke the fire
- Hold hot objects using gloves/cloth/insulated handles/holders
- Avoid washing in hot water/check temperature with sensitive part and then use for insensitive part
- Avoid doing one type of job for a long duration/change job/give rest/inspect hands frequently for any redness to avoid blisters
- Always think about the type of injury they may get due to an activity and how can it be prevented.

Methods of protecting insensitive foot: tell person to:
- Use appropriate foot wear (soft inside but hard sole, never tight but not very loose.) or MCR foot wear for even distribution of body weight
- Avoid walking for long distances/for long duration and on rough surface. Take frequent rest. Walk slowly (they must feel comfortable while walking) do not walk more than 20 minutes at a stretch, take rest and then walk, use bicycle.
- Take small steps, walk slowly, use a vehicle when ever possible (Persons will know the suitable distance for walking by experience)
Care of the foot wear: Teach person to:

- Check footwear daily for presence of any damage i.e. cracks, torn, embedded sharp objects, gravels/dust that may injure the foot.
- Clean inside of the shoe daily/ frequently by piece of a cloth

Always use a foot wear that is neither too tight nor too loose

8.5.2 Characteristics of appropriate footwear are:

- Shoe must fit well, neither tight nor loose usually one size bigger than the required size so that it has plenty of space for clawed toes. It may be designed with adjustable strap to allow adjustment for bandage.
- Hard outer surface that is not pierced by thorns and protect the foot from external injuries
- Soft insole of Micro-Cellular Rubber (MCR) of 1cm thickness (known as 15 shore) to provide cushioning to the foot and to avoid pressure on specific points and thus reduce risk of ulceration
- Metatarsal bar (If needed) fixed obliquely across the outer sole about 2.5 cm proximal to the metatarsal heads
- Arch support (if required)
- Insole molded to the contours of the weight-bearing sole for badly deformed foot
- Velcro straps instead of buckles
- Back strap to be able to retain footwear
- No use of nails

Note: Special MCR footwear is not recommended routinely for all the leprosy patients. A comfortable, locally available, socially acceptable foot wear with the above mentioned characteristics is recommended to those who can afford.

However, MCR shoes are also available under NLEP; for those with insensitive sole of foot and cannot afford to buy appropriate foot wear; Ask District leprosy officer or medical officer District nucleus team to make it available.

8.6 Care of eye:

Leprosy affected person is unable to blink/ close the eye/s completely due to damage to the 5th & 7th cranial nerve affecting the protective mechanism of eye and predisposing it to
dryness and injury. Direct involvement of the eye tissue may also occur. Proper care and early detection of eye involvement is essential to preserve the eye and avoid impairment of vision and ultimately blindness.

**Principles of eye care are:**
- Protect eyes from dryness, sun and dust
- Avoid injury to the eye
- Identify signs of irritation and injury
- Identify early involvement of eye tissue

**Protect eyes from dryness, sun and dust and avoid injury to the eye:**

People protect their eyes from dryness, dust, insects and external injury by blinking during the day and closing their eyes during sleep. Persons with sensitive cornea cannot blink and those with Lagophathalmos cannot close their eyes and are taught to protect their eyes by:

- **Think- blink:** LAP who cannot blink automatically must develop a habit to blink voluntarily i.e think- blink for which they are taught to remember to blink and make an effort to close their eyes forcefully. To remember to blink, ask person to develop a habit to blink every time they pass a tree/ house/ person/ while eating every time they swallow the food or when ever they see another person blinking. To blink voluntarily LAP must close their eye forcefully. Even if LAP is unable to close the eyes completely, on closing the eye forcefully, eyeball rolls up and get wiped by the upper eyelid. People with normal facial muscles are taught to push their cheeks up/ use other facial muscles to close their eyes.

- **Eye shield: person is taught to:**

  Protect eyes from dryness, dirt, insects, by using head cloth/ sunglasses with side pieces/ hat with broad rim to shield the eyes during the day.

  Not to rub their eyes on irritation but close the eyes / assist closure of the eye by pulling the skin at the outer corner of the eye upwards and backwards at the same time.

  At night, close the eye completely by hand and tie the eyes with sheet of cloth. A wet pad may be used to protect the eye from dryness.
Identify signs of irritation / injury / early involvement of eye tissue

- Inspect eyes daily to detect any redness of the eye/corneal injury/dust/ eyelashes touching the bulbar conjunctiva or cornea/ injury to the eye. Teach person
  - To inspect the eyes and to wash the hands with clean water before touching the eyes.
  - Use a mirror / take help of a friend or relative to look for any redness
  - Remove any spec of dirt with a piece of clean and soft cloth gently
  - Epilate the eye lash touching cornea
  - Wash frequently with clean water/ Instill oil/ drops to keep the eyes moistened
  - Not to rub the eye
  - To develop a habit to observe a few selected objects placed at a distance daily, for early detection of any deterioration in the vision.

- Report to the health center if notice any of the following
  - Itching, redness, watering,
  - Unexplained pain in the eye,
  - Difficulty in keeping eyes open in the sunlight and
  - Any deterioration in vision

8.7 Prevention and Management of ulcers and callosities and injuries

Leprosy affected people with dry skin (decrease sweating) are liable to develop cracks/fissures that may develop into ulcers. Delayed treatment / neglecting these injuries results in tissue destruction, stiffness of joints and contracture of the soft tissue. To prevent recurrent ulcers and worsening of deformity; detect and manage these cracks callosities, blisters and ulcers during the early stages.

Whenever a leprosy-affected person comes to the clinic examine the condition of the skin, whether it is dry, rough, hard and also for presence of

8.7.1 Callosities & cracks:

Skin of insensitive hands and feet is prone to abnormal pressure and repeated friction and becomes thickened and hardened in localized areas. More over, skin of insensitive part is dry and elastic due to loss of sweating. Presence of callus makes it drier and less elastic. Skin lying opposite a joint breaks open on repeated movement of the joint. If neglected these cracks can develop into ulcer and may even get infected. Hence, always examine the condition of skin of a person.
Prevention of occurrence of callosum/crack and its treatment requires:

Interposing a soft cloth or Pad between the hard surface of handles of tools used by leprosy affected person and insensitive hand, soft cloth/cushion between hard surface and body parts to reduce the pressure and friction.

- Keeping hard skin with callosity soft and supple by soaking, scrubbing and oiling (refer self care)
- Applying softening ointment (6% salicylic acid) and rubbing it over the hard area 2-3 times a day.
- To prevent infection and hasten healing, covering cracked skin by dry dressing

8.7.2 Ulcers & Blisters:
Reasons of ulcer formation in leprosy: (why do ulcers occur in leprosy?)
Ulcer develops due to:

- Neglected cracks and fissures in dry and hard skin (due to loss of sweating) and external injury/burns in the insensitive hands/feet
- While walking, pressure on insensitive feet is normally countered by contraction of intrinsic muscles which elevate the MTP joint region upwards & forwards. When posterior tibial nerve is affected this mechanism is not available due to paralysis of small muscle. More over, there is sagging at MTP joint resulting in increased pressure at localized areas causing local ischemia and traumatic inflammation & breakdown of subcutaneous fat underneath the MTP joint. If sensation in the foot is normal it is recognized as fatigue but persons with insensitive skin can not realize the situation and continues to use the foot causing further damage to the tissue. Area of traumatic inflammation undergo necrosis & liquefaction resulting in formation of blister, if neglected covering skin of the blister may break down resulting in formation of ulcer.

Ulcer is a wound that are caused due to gradual breakdown of tissue which is subjected to increased pressure. Ulcer usually heal by secondary union and process of healing begins only when causal factor is removed. if factor causing ulcer persisits it becomes chronic non healing ulcer. ulcer may return on continuation of the causal factor.

Stages of ulcer formation:

Formation of ulcer passes through the following stages:

1. **Stage 1 (stage of threaten ulceration):** stage of ischemic and inflamed which is recognized as fatigue by normal feet. Rest to the injured tissue at this stage gives it time to repair itself and return to normal.
People with insensitive feet are not able to realize the warning and therefore, taught to inspect their hands/feet frequently and regularly. You can identify this stage by presence of the following features:

1. Presence of deep edema recognized by increase gap between toes/fingers
2. Deep tenderness
3. Local warmth
4. Possibly puffiness over the corresponding site on the dorsum of foot/ hand

**Manage the stage of threatened ulcer by**

1. Absolute rest to the affected part to allow healing
2. Elevation of the affected part for 48-72 hours to prevent further tissue damage & permit resolution of traumatic inflammation
3. Examining foot for any deformity
4. Educating & demonstrating foot care to the person
5. Providing protective foot wear (MCR foot wear)

**Stage 2 (stage of concealed ulceration/ blister formation):** if rest is not provided and stress continues inflamed tissue under goes necrosis and liquefaction. Skin over it remains intact and is identified by presence of blister (necrotic tissue under intact skin).

**Teach people to management of Blister (Concealed ulcer) at home**

- Avoid breaking of the blister
- Clean the skin over and around it
- Pad the lesion well and cover it to avoid injury
- Bandage firmly
- Rest for three weeks to allow healing
- Elevate the affected part

If necessary, blister could be snipped away and the area covered with sterile Vaseline gauze dressing. It may need below knee plaster cast with provision of walking made after 72 hours, retain plaster cast for 3 weeks to allow blister to heal.

- Examine foot for any complicating factors
- After healing teach foot care & provide protective foot wear

If blister is between the toes or close to a toe put some padding between all the toes so that toes are kept apart and do not rub against each other. Provide rest to the foot for at least 72 hrs or use crutches with sling. Blistered foot should not be made to bear weight, instruct patient to keep the foot elevated re-examine after 72 hrs. if improved, continue the treatment.
**Stage 3 (stage of overt ulcer)**

Blister may break open due to external injury or continued use of the affected part or increased pressure from inside due to oedema and breakdown of tissue resulting in ulcer thus, damaged tissue gets exposed to external environment.

Early signs of breakdown are considered as emergency. At this stage ulcer is simple and not infected and is managed by

- Rest
- Elevation of affected part
- keeping wound clean and covered
- No local application/wound kept wet by normal saline

**Process of healing of ulcer and Management of ulcer:** During initial stage of ulcer formation, broken down tissue is removed by body through process of debridement called active phase of ulcer formation. Surrounding tissue is normal, edges of ulcer are undermined, entire area around the ulcer is elastic and ulcer moves on underlying tissue when pressed from side to side with slight force (Ulcer not fixed). At this stage increased discharge of clear straw coloured transudate can be seen which mixes with products of tissue breakdown and turn into creamy discoloured thick sticky fluid with distinct odour called exudate. Usually exudate is sterile and must not be confused with infected discharge. Antibiotics are not needed at this stage. Amount of discharge reduces in around one week. Unnecessary use of antibiotics may result in development of resistant organisms.

Under favourable conditions (cause of ulcer removed and hygienic environment provided), ulcer starts healing (**Rapid Multiplication Phase**), during this stage moderate amount of transudate is present. Edges of the ulcer are not undermined but sloping. Granulatertion tissue (gel like bright red substance consisting of mass of blood vessels and lymph vessels) starts forming at the base of the ulcer which gradually fills the cavity of the ulcer to the level of the surrounding tissue and epithelization begins giving it slightly bluish hue. Though wound appears healed but strength of the tissue is less than the undamaged tissue which improves with time (**Remodelling Phase**).

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**Available options for resting the blistered foot caused by walking:**

- Resting foot in a plaster cast
- Using a sling for the foot and crutches during walking
- Using crutches during walking, keeping the foot off the ground
- Walking on the unaffected part of the foot, using a cane or stick
While treating the ulcer determine whether ulcer is simple (management already mentioned), acute, chronic, complicated, recurrent

**Simple ulcer:**

For uncomplicated superficial (Simple) ulcer part is rested, principles of foot care followed along with SSO, strips of zinc oxide coated adhesive plaster are applied directly on ulcer that are changed every 2-3 days (frequent changes interfere with healing), dressing is continued even after healing for 2 wks. Person is encouraged to wear protective footwear

**Chronic ulcer:**

If the cause of the ulcer is not removed repeated micro-trauma interferes with process of tissue repair leading to uncontrolled inflammation / if favorable conditions for wound healing are not provided, tissue regeneration is delayed. Ulcer does not heal and become chronic. Production of fibrous tissue ties ulcer with deeper structures (ulcer becomes fixed), surrounding area becomes stiff, a ring of callous forms around the edge of a chronic ulcer due to lack of production of chalone.

**Chronic ulcers** are Quiescent with Scanty discharge, hyperkeratotic edge, hard fibrosed base and pale unhealthy granulation tissue. Ulcer looks static with no signs of healing.

If ulcer is not infected, granulation & epithelial tissues of ulcer is protected from damage by encasing the affected part in a plaster cast / below knee cast (for planter ulcer) for 6 wks which is repeated for another 6 wks if ulcer does not heal. Person is trained in Foot care and use of protective footwear

**Recurrent ulcer:**

Most plantar ulcers recur on return of the cause of ulcer or may recur despite adequate care even on walking for a small distance. These ulcers need special care to prevent recurrence.

Causes of recurrence are:

- Factors of ulcer formation continue to operate
- Brittle scar from healing of ulcer is unable to withstand stresses generated during walking
- Deformity produces excessive stress on scar
- Flare of lingering infection in deeper structures

Recurrence is prevented by:

- Reducing of stress on foot by limiting walking & using protective footwear
- Eradication of infection in deeper structures
- Improve the quality of scar by excising scar & closing gap by resuture, skin grafting, use of local flaps including myo-cutaneous flaps and free flaps
• Reduce the load on the scar by modifications in footwear (metatarsal bar, arch support, molded insole)
• Surgical procedures: minor shaving of bone through tendon transfer, osteotomy and triple arthrodesis
• Preventive care to the foot including skin care, injury care and walking care

Acute infected ulcer

Ulcer may get infected. During acute phase affected part become swollen and hyperemic; lymph nodes draining local area become enlarged. Patient is toxic febrile (Gen. signs and symptoms of acute infection) wound has edematous edge, Dirty slough at the base and Copious discharge. For control of infection such wounds need systemic antibiotics after culture and sensitivity, irrigation with Eusol bath & (12.5g boric acid + 12.5g bleaching powder in 5 l tap water, freshly prepared) and Surgery for removal of dead & non-viable tissue and drainage procedures. Such cases are referred as need surgical drainage and debridement.

Complicated ulcer:

Unhealed ulcer may get infected and may extend beyond dermis into tendon, tendon sheath, bones and joints. Pockets of pus are formed and may get connected to the wound through sinuses. Presence of bright red tissue may bulge out of ulcer (Hypergranulation tissue) denotes presence of sequestra.

Tissue around the wound is hot, red and swollen. Draining lymph nodes become swollen & tender. Exudate becomes foul swelling and ultimately disuse Osteoporosis, osteomyelitis with sequestra, disintegration and absorption of bone and destruction of joints sets in. In later stages it may even lead to septicaemia. Septic arthritis, septic tenosynovitis may be present due to spread of infection into joints and tendon. Person with complicated/infected ulcer are referred.

Reasons leading to non-healing/chronic ulcer are:

1. Mechanical stress: repetitive pressure or shearing stress
2. Physiological: Deficiency of
   • protein, vitamin C & oxygen supply – helps in granulation
   • vitamin A
   • trace elements (zinc & copper)
3. Medical treatment:
   • Antineoplastic drugs, oral steroid
   • Haemostatic drugs
   • NSAID
   • Many systemic antibiotics
   • Toxic antiseptics & unsuitable dressing
4. Psychological factors:
   • Leprosy patients with ulcers rejected by society
• To survive they opt begging using ulcers to their advantage
• Beggar usually avoid seeking treatment for ulcer

Principle of Management of Ulcer:

There are a few major principles that must be remembered while managing ulcers. If these principles are followed, simple ulcers will heal without any medication:

- Rest to injured part
- Maintainence wound Hygiene
- Good wound environment
- Protective foot wear

Rest:

Almost all wounds heal if they are rested and cause of ulceration is removed. Splinting can be used to rest hand and finger wounds and Walking with crutches (or even with a walking stick) can help to rest foot wounds. Whatever the circumstances, the injured part must not be allowed to perform normal functions whilst the tissue is still being repaired.

The best option is for the person to spend as much time as possible, lying down with the foot raised above the level of the heart (bed rest). However, this is rarely possible amongst people who are bread earners for themselves and their families, so other options should be explored.

It is also very important to find out whether the person is able to change his activities so that he doesn’t need to walk so much: for example, can temporarily swap work with another person. Option of using a transport must also be considered for example, riding a bicycle.

Wound Environment:

A good Wound Environment means wound:

- Free of foreign bodies and toxic substances (dead tissue is toxic and dressing material, especially cotton wool is treated like a foreign body)
- Free of pathogenic micro organisms
- Moist but not too wet: discharge from wounds is drained
- Not dry: wounds heal better if they are moist, so care should be taken not to dry the wound too much; many medications commonly used on wounds, such as gentian violet, an antiseptic delays healing by causing the wound to become too dry
- Stable temperature: wound healing is best when the temperature of the wound doesn’t change quickly so wounds should be cleaned or soaked in water near body temperature.
Hygiene:

Many problems can be prevented if good hygiene is observed in the workplace and in the patient’s home (can use one cup of bleaching powder in one bucket of water). Routine cleaning of surrounding, using bleach greatly reduces risk of infection.

When there is raw area in the foot or hand (deep crack, wound/ulcer) add boric acid crystals and calcium hypo chloride (bleaching powder – 2.5 gram i.e. table spoon in one liter in water) this prevents the raw area from getting infected and becoming septic. Mop the wound dry gently. Cover the wound with clean and sterile cloth / gauze.

Protecting the Wound Environment:

The clean, moist wound environment is protected with a cloth or bandage cover. However, if the wound dressing become soaked through, with discharge from the wound (this situation is known as “strike through”), the wound is at the same risk of infection as if the wound was not covered at all. To keep the wound environment protected and to reduce the chances of infection, the wound dressings should be changed if discharge from the wound is seen to have soaked all the way through. Bulky dressings are avoided, as simply to increase the amount of dressing material is not helpful in protecting the wound from strikethrough. Recent foot ulcers give a heavy discharge in the early stages of healing hence, change the dressings every day (at least). As the wound begins to heal, there will be less discharge and dressings can be left in place a little longer (2 to 3 days before changing).

Protection of wound granulation Tissue:

Granulation tissue is treated with great care. Protect it by cleaning granulating wounds very gently with soaked gauze swabs. Do not use cotton wool because strands of fibre may be left in the granulation tissue and act as foreign body and delay healing. Always soak gauze dressings well before trying to remove them to avoid damage to granulation tissue.

Debriding a Wound:

Dead tissues are cut away and the wound be dressed with Savlon (chlorhexide gluconate) for one day, thereafter only saline dressings must be used.

Medication:

No medication is required in the management of cracks and simple ulcers. Many lotions that are commonly used are actually harmful because they delay the healing of wounds. Some medications may be used in certain situations for specific reasons.
Skin Disinfection:

Betadine (povidone iodine) is a good skin disinfectant but it should only be used on intact skin. Soap can also be used to clean the skin, including blistered skin, if it is not broken.

Medications to be Avoided:

There are a number of products that are widely used but which should be avoided for various reasons:

- Gentian violet, a widely used purple dye, is a powerful anti-septic, but it dries the wound too much, damaging the new tissue that is formed in the healing process.
- Salt is an anti-septic which also causes too much drying and damages new tissue.
- Soap is also an anti-septic, causing drying when used on an open wound.

Topical antibiotics should never be used in the treatment of ulcers in leprosy cases. Treating the ulcer is a great opportunity to reduce fear & stigma through demonstrating ulcer care without any discrimination. Family members are also encouraged to learn and practice the dressing of ulcer and nursing care of patient.

Criteria for Referral:

- Ulcer size is more than 2 cms, (need split skin grafts)
- Not healing,
- Recurrent ulcer
- Complicated ulcer (Deeper structures like bone/ tendons is exposed).
- If ulcer is getting bigger in size
- Skin around the wound is inflamed, red and swollen or pus is present (foul smelling wound)

8.8 Care of the limbs with weakness/paralysis of muscles (Physiotherapy)

Involvement of peripheral nerve truck may result in impairment of motor function of the nerve that leads to either weakness or complete paralysis of the muscles.

Deformities of hands (Claw hand/ drop wrist) and feet (drop foot) develop due to paralysis of muscles that can be corrected by surgery but if proper care of deformity is not taken, joints of fingers thumb and ankle may become stiff. Once stiffness starts developing, it is very difficult to prevent stiffness and further worsening of the joints.
Stiffness develops for two reasons:

1. Injury and healing with scarring/fibroses
2. Long-standing untreated deformity

Skin around the joint is loose and when joint moves skin is stretched. Any wound (crack/ulcer/injury) near the joint that heals with scarring result in shortening of the skin and may even involve tendon. Such scars restrict the movement of the joint making it stiff. Once fibrosis develops exercise may not help. When muscles get paralysed, joint gets deformed due to imbalance of muscles power around it. If joint is not moved passively for its full range of movement and kept bent, laxed skin on one side of the joint is not stretched and become shortened (Formation of contracture) resulting in fixed deformity of the joint that restricts the full movement of the joint.

Site of stiffness in hand

<table>
<thead>
<tr>
<th>Deformity</th>
<th>Site of stiffness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Claw fingers</td>
<td>Middle joint of fingers</td>
</tr>
<tr>
<td>Claw thumb</td>
<td>Tip of thumb</td>
</tr>
<tr>
<td>Drop-wrist</td>
<td>Wrist joint, joints of fingers and thumb</td>
</tr>
</tbody>
</table>

**Treatment of stiffness**

Stiffness is prevented by stretching the unstretched side of the joint daily by moving the joint through full range of movement allowed by the joint. This prevents shortening of the skin around the joint.

Shortened tissue of the stiff joint is stretched daily, gently and firmly by massage and kept in the stretched position for long period with the help of a splint. Thus the range of the movement of the joint is increased gradually over a period of time. Shortened tissue gets lengthened and stiffness improves. Care must be taken to avoid over stretching of the tissue. These exercises are part of self care.

**Care of Paralysed Muscles:**

**Muscles need care:**

- To prevent contracture from setting in/reduce existing contracture /stiffness of joints.
- To strengthen weak muscles.

Both the above aims can be achieved by doing exercises daily for few minutes while the affected part is still oily.

**Note:** avoid exercise or stop exercise if hand has wounds or cracks. Skin must be strong for it to stretch during exercise.
Two types of exercise that can be done are:

**Active** – The patient uses his weak muscles to do the exercise. This prevents contracture and strengthens the weak muscles.

**Passive** – The patient is helped to move the paralyzed part passively to prevent contractures but by passive exercises weak muscles cannot be strengthened.

Exercises for individual nerves are given below: Teach person to:

**Ulnar Nerve Weakness or Paralysis**

**Active: if inter-phalangeal joints are mobile**

- Cup the knuckles joints of the affected hand on the other palm and keep them firmly bent
- Keep the wrist straight
- Stabilize the joint between the hand and the fingers with palm of other hand.
- Extend/straighten the both the inter-phalangeal joints of the fingers as strongly as you can, keeping the same position

**Passive**

- Rest the hand on the thigh or on a table padded with cloth.
- Use the other hand to rub the fingers gently to straighten the clawed fingers of the weak hand repeatedly taking care not to crack weak skin of the fingers. Straighten fingers repeatedly using his other hand.
Increase range of movement gradually if contracture is present

**Median Nerve Weakness or Paralysis**

**Active**
- Rest the little finger side of hand on the thigh
- Use the other hand to support the back of the thumb firmly and hold it straight for a few seconds.
- Straighten the metacaopo-phalangeal joint as strongly as you can

**Passive**
- Pull the thumb gently but firmly at meta-carpo-phalangeal joint using the other hand as though trying to lengthen and Straighten the paralyzed thumb but do not bend backwards
- Holding the thumb at the base with the other hand and pull it away towards the palm.

**Or**
- The person must grip around the week thumb so that the flat part of the thumb lies on the top of the hand
- The gripping hand is drawn over the joint of the paralysed thumb. This action will force it to straighten. The thumb is held straight to account of ten before relaxing.

**Foot-drop/ Common peroneal Nerve weakness/ paralysis**

**Active**
- Practice bending the foot up and holding it in this position for a few seconds.
Passive

- Sit with the leg straight.
- Pull the foot up using a towel.
- Repeat this movement several times

Or

- Hold the outer border of the foot and pull it up to turn the foot out.
  It prevents stiffing of foot in turned in position

Or

- Stand facing a wall with toes at arms length from the wall
- Keeping the feet straight, heels touching the ground and knees straight; lean forward
- Against the wall. This stretches the calf muscles and prevent its shortening

**Exercise must be avoided during active Neuritis**

**8.9 Monitoring of self care:**

**Monitoring the practice of self care:** you and your staff must monitor the self care and support the LAP with disability by:

- Motivating the LAP to practice the preventive measures
- Correct wrong practices
- Discuss problems and find feasible solutions
- Help health functionary & LAP to learn from experience

During the visit to the village, Health care functionaries must visit the house of leprosy disabled person and look for:
The condition of the skin, whether soft and supple or not
Range of movement of the affected joints
Any stiffness being felt in the movement of the joint
During the visit, observe the person performing various activities
Watch working tools, footwear and assess whether precautions are being taken to avoid injury to the affected part; if not explain why it is harmful and how can it be modified according to the person’s need.
Ask persons whether they are facing any problem related to the disease and find a feasible solution with the patient.
Sometimes patients solve their problems through innovation which can be utilized for the benefit of the other LAP in similar situations.
Visit to patient shows your concern for them and motivate people to follow the advice.

8.10  Interventions managed at referral center:

Following conditions need referral and can be managed only at centers with specialized facilities:

Problems with the eyes:
- Any acute eye problem should be managed at an eye clinic
- Corrective surgery may be helpful in severe cases of lagophthalmos
- Cataract is the commonest cause of blindness in elderly people, whether or not they have leprosy; leprosy does not prevent routine cataract surgery

Problems with the hand:
- Modification of tools to avoid injury to insensitive hands
- Removal of thick callous and trimming of ulcers with a scalpel blade
- Need splint to wear at night for weakness muscle or a contracture
- An invasive infection (the hand is hot, red and swollen) is an emergency and is referred for intensive antibiotic treatment and surgery
- Surgery is appropriate in some cases of weakness or claw-hand, as long as the joints remain mobile

Problems with the foot:
- Removal of thick callous and trimming of ulcers with a scalpel blade
- Chronic ulcers requiring orthotics or surgery
• Foot-drop: requires a spring-loaded device to keep the foot in the correct position while walking
• An invasive infection (the foot is hot, red and swollen) is an emergency and must be referred for intensive antibiotic treatment and surgery
• Foot-drop surgery

8.11 Surgical Treatment for Leprosy Disabled Persons:

8.11.1 The conditions that require surgical intervention:

- **Irreversible claw hand** due to paralysis of ulnar / median nerve
- **Foot drop** due to paralysis of posterior tibial nerve
- **Lagophthalmos** due to paralysis of branch of ophthalmic nerve. This is sight threatening condition because of the risk of recurrent conjunctivitis and corneal damage. Patients, irrespective of age, who have a lagophthalmos with lid gap, particularly when there is loss of corneal sensation, should be referred for surgery. Patients with lagophthalmos but not fitting the criteria for reconstructive surgery can be considered for simple procedures such as tarsorrhaphy, which can be performed even on an outpatient basis.
- **Recurrent wounds of hands and feet** Patients who have recurrent wounds of the hand or foot should be referred for surgical advice. Such patients may have sequestra (dead bone) in the hand or foot which require removal. Such procedures can be undertaken in general hospitals and an X-ray of the affected part can help confirm the diagnosis. Sometimes, in
severe cases of recurrent wounds, amputation is the only solution – this should only be considered as a last resort.

**Chronic nerve pain and nerve abscesses:** Patients who have chronic pain and swelling in peripheral nerves, which does not respond to analgesics and a course of steroids should be referred for consideration of nerve decompression.

**Cataract** – Cataract due to any cause should be extracted to improve the vision so that LAPs are able to practice self care and protect insensitive parts.

### 8.11.2 Referral of person for Surgery

As a member of health team at PHC, you must be able to identify the LAP who needs surgery and would be benefited from reconstructive surgery or other forms of surgery. It is important that centers doing reconstructive surgery in leprosy, liaise with other staff in developing local criteria and arrangements for the referral of appropriate patients.

The reconstructive procedures considered here are tendon transfer procedures such temporalis transfers for lag-ophthalmos, foot-drop corrections and corrections for paralysed fingers and thumb. Pre and post-operative physiotherapy is essential for a successful outcome of surgery and is arranged in consultation with the surgical centre.

### 8.11.3 Criteria for selection for Reconstructive Surgery

The detailed criteria usually vary between reconstructive surgeons and it is important that surgeons make the members of health team aware of their local policy for referring people. The criteria have been grouped into three categories: **social and motivation, physical, and the leprosy treatment criteria.** Patient must be empowered to take the decision of surgery. The patients and the health workers must be involved in the decision for referral for surgery.

#### Social and motivational criteria

All patients who would be benefited socially, occupationally or economically are considered for surgery. The surgery must have the potential to make a difference to patient’s acceptance in the society, family and improve the socio-economic situation.

Patients must be well motivated and should have demonstrated that they are responsible for their own health and follow instructions on treatment and care of their eyes, hands, and feet before surgery. Patients who are not well motivated in self-care are not likely to be willing to participate in essential pre and postoperative physiotherapy.

Financial support or compensation for loss of income and travel may need to be considered for patients who have dependent families. The surgery involves loss of economic activity for a period of several months and LWD, who are the main breadwinner for the family, may not be able to undergo surgery unless assistance is provided. Contact DHO/DLO for the same.
Physical criteria

The best age for referral for tendon transfer is between 15 - 45 years, but patients younger than 15 years or older than 45 years may be operated on, depending upon the particular circumstance.

The muscle paralysis should be present for at least one year and preferably not longer than 3 years. There may be exceptional cases where there has been muscle paralysis for longer than 3 years and the individual has kept the joints supple through passive exercises. Sometimes, the patient may not remember accurately how long muscle paralysis has been present, so suppleness of the joints is more useful criterion.

Patients with severe contractures or stiff joints are not suitable for tendon transfer, although physiotherapy or surgery can reverse some contractures.

There must not be any infection of the skin such as scabies and any deep cracks, wounds or ulcers at time of referral.

Leprosy treatment criteria

- Patients should have completed the scheduled course of MDT or at least a minimum of 6 months MDT.
- Patients should be free from reactions and symptomatic neuritis for at least 6 months.
- Patients should not have taken steroids during the past 6 months unless the surgery is for neuritis.
- There must not be any tenderness of any major nerve trunk in the limbs.

8.11.4  Facts must be known about surgery:

In addition to the above, patient must be willing for the following before undergoing surgery

Tendon transfer in Hand:
- Person must have 6 month old paralysis of one or more nerve: ulnar, median or radial
- Only mobile deformities without contracture are taken for surgery
- Person needs at least one week of physiotherapy means must be willing to get admitted one week before surgery
- If afebrile, person is discharged after 2-3 days of surgery and asked to return on 21st post operative day for four weeks (for physiotherapy)
- At least four weeks of physiotherapy is needed after surgery commencing from 22nd day of surgery.

Tendon Transfer in Foot:
Person must have at least one year old paralysis of common peroneal or posterior tibial nerve

Person must be willing to spend four weeks in plaster cast after operation and undergo physiotherapy for four weeks post-operatively.

If afebrile, person is discharged after 2-3 days of surgery and asked to return on 28th post-operative day for four weeks (for physiotherapy) or may be admitted for entire period of 8 weeks.

Only mobile deformities are taken for surgery.

**Tendon transfer for Lagophthalmos**

Persons with Lagophthalmos are referred for surgery, irrespective of their age; because of the risk of impairment of vision.

Lagophthalmos can be unilateral / bilateral.

Minimum duration of paralysis must be 12 months.

The patient should not be undergoing steroid therapy and should have completed steroid therapy at least three months prior to being taken up for surgery.

Slit skin smear should be 1+ or less than 1+.

Persons not fitting the criteria of RCS can be considered for simpler procedures like tarsorrhaphy.

Person must be willing to spend three weeks on liquid diet post-operatively and then undergo physiotherapy.

**Guidelines for surgery of the nose:**

The patient may just have a collapsed nose or collapsed tissue defect of the nose.

The patient should not have an ulcer in the nasal lining.

The minimum duration of the collapse should be for 12 months.

The patient should have completed 12 pulses of MB-MDT, to be considered for surgery.

The patient should not be in Type I or Type II reactions.

The patient should not be undergoing steroid therapy and should have completed steroid therapy at least three months prior to being taken up for surgery.

Nasal & Slit skin smear should be negative.

The patient should not have any complicated ulcers of the other limbs or in another part of the body.

**8.11.5 Priorities for reconstructive surgery**

Operations for lagophthalmos are usually considered as a high priority because of the possibility of secondary damage to the eye and impairment of vision. Feet are usually
considered the next priority followed by hands, but this may depend on the needs of individual patients. Priority must be given to younger persons.

For most patients there is a period of a few years during which surgery is most likely to be beneficial. This starts when the disease is stable (free of reactions and neuritis), MDT course is completed and the muscle paralysis is not likely to progress or recover. Motivation is a key factor as patients may need to be in hospital for at least 6 weeks and will have to work at physiotherapy. Patients in whom surgery will make a difference are considered for referral.

The proposed surgical procedure and its positive consequences are balanced against the consequences of not doing surgery. Discuss this with the patient and the decision whether to undergo surgery, must be taken by the patient. Methods of managing to live with the deformities, without causing further damages to the affected parts should be explained to patients who do not want or are not suitable for surgery.

General criteria of fitness for surgery:

- Ideal age group is between 15 and 45 years
- Duration of the deformity should be > 6 months
- New cases on treatment must have completed at least 6 months of MDT course
- Patient should not have had any episodes of lepra-reaction or neuritis and or treated with prednisolone in last 6 months
- Absence of foci of secondary infection
- Patient should be willing, astute enough to be re-educated.

8.12 Support to LAP with disability:

For prevention of occurrence of disability/ its worsening, disabled people need support of the health functionaries, family members and community. Encourage them to practice self-care at home and ensure they understand its importance. Facilitate physical and socio-economic rehabilitation.

Check awareness of lifestyle that can predispose the person to develop ulcers and injuries. Help the person to list all such activities (cooking, cutting grass, etc.) Encourage the patient to look critically at all objects, which can hurt him. Discuss ways to overcome the problem.
Ensure that person understands the concept of self-care by explaining the importance of practicing self care, giving examples of aids that can be used to prevent injury eg. Tongs, cloth etc.

Explain and demonstrate procedure of preventing deformities repeatedly till the patient understands

Ask the patient to demonstrate to you that he has understood. Give the person a feedback on his performance

Ensure the support of family members and friends to persuade the patient, who can influence the patient’s decision making and can be a powerful aid to convince him to accept self-care. At least one of their family members must be taught self care to support and monitor practicing self care by the LDP.

Find the cause: If, in spite of the best efforts the patient does not follow the advice, try to find the cause and help her/him to solve the problem.

Self-care groups may be started in the community. A number of people practicing self-care need support. To provide them support, facilitate them to form self help group and members of self help group can meet together regularly to discuss the practicalities of self-care. These groups are often supportive and can be very motivating for members.

8.13 Community based Rehabilitation:

Rehabilitation includes all the measures used for reducing the impact of disability for an individual, enabling him/her to achieve independence, social integration, a better quality of life and self-actualization”.

The Ministry of Health & Family Welfare and Ministry of social justice & empowerment, GOI are expanding rehabilitation services to the persons with – disabilities. For example Ministry of Health & Family Welfare GOI is establishing physical medicine & rehabilitation department in medical colleges & regional hospitals. An additional support is being provided to institutions conducting reconstructive surgery for polio disabled persons. In addition there are several NGOs / Institution supported by ILEP partners for carrying out rehabilitation services.

Till now rehabilitation has been observed as institution based programme. Institutional rehabilitation provides excellent services to address the problems of individual disabled person and is often available only for a small number at a very high cost. Moreover, the endeavours in an institution are often out of context to the felt needs of the disabled person and thus fall short of their expectations. In an institutional rehabilitation program, the community is not linked with the process. Hence, when the disabled person returns home, it may become difficult for them to integrate into their community.
Disability often requires life-long management, which should become a part of daily life. Therefore, activities aimed at enabling people with disability should be community based as much as possible. Community Based Rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. However, although most basic rehabilitation activities can be carried out in the person’s own community, a multi-sectoral / multi-disciplinary concept of CBR is adopted. This concept emphasizes working with and through the community to create positive attitude towards people with disabilities, to provide assistance to people with disabilities and to make the necessary changes to the environment and service delivery systems. In response to this conceptual change, CBR is now defined as a community development program that has seven different components.

8.13.1 Components of CBR

- Creation of awareness for Prevention of disability
- Provision of care facilities for disabled.
- Creating a positive attitude towards people with disabilities.
- Provision of functional rehabilitation services.
- Empowerment, provision of education and training opportunities to the disabled persons
- Creation of micro & macro income generation opportunities.
- Management / monitoring and evaluation of CBR projects

In this approach governmental and non-governmental institutional and outreach services support community initiatives and organizations.

Comprehensive rehabilitation would include services for prevention of impairments, promotion of self-care, provision of assisting and protective devices (e.g. wheel chairs and prostheses) physiotherapy & occupational therapy, counseling, formation of self-help groups, corrective surgery, vocational training including education, literacy, micro-credit schemes and other developmental activities.

8.13.2 Organisation of CBR

CBR workers are key personnel in the implementation of CBR. They are usually the main person in contact with the family. Multipurpose health worker of sub-center or voluntary workers like ASHA & AWWs can act as CBR worker and:

- Act as local advocates on behalf of people with disabilities and their families with the health services personnel
- Provide liaison and continuity of care in the community on behalf of professionals eg. Continued supervision of home programs
- Act as directors of community initiatives to remove social and physical barriers that affect exclusion
Provide a positive role model for service users if they themselves have a disability.

Professionals such as surgeon, physiotherapist, vocational trainers, counselors, support staff, orthotists / prosthetists and technicians at district hospital or specialized centers are recognized to provide referrals services.

8.13.3 Steps for establishing CBR

Leprosy affected / disabled persons are identified either by referring registration register / survey through health worker. A self help group of 6-8 members is established. Assess disability and identify needs for rehabilitation. Provide basic services like drugs, dressing materials, protective footwear, counseling and training in self care through the health team of Primary Health center covering that area. Group meets at a pre decided place at decided interval, where they can practice self care, discuss problems of the members and based on their experience, find feasible solutions. Group identifies a leader and certain rules, regulations and guideline are formulated for the smooth functioning of the group.

Health worker acts as supervisor and trainer. Liaison is established with Village Health & Sanitation Committee to discuss the issues of disabled people, with referral centers to provide specialized care to those who are in need like physical rehabilitation services, like ulcer care, physiotherapy, surgical treatment, treatment of eye complications, prostheses etc. and so on. Follow up of referral services is also an essential task.

Accessibility to ‘socio-economic rehabilitation services’ is facilitated through social welfare department by a ‘CBR worker’. District Nucleus steers the rehabilitation activities and provides support to CBR workers in facilitating the accessibility to different services.

Self-help Groups work on principles of mutual respect and trust for the members of the group and on understanding that everyone can contribute in the group activity. Each member participates based on their strengths and equal opportunity is provided to all the members irrespective to sex or cast.

8.13.4 Advantages of CBR

Being members of the Self-help Groups people can advocate for themselves and to take responsibility for their own development. In CBR programs, SHGs provides visibility of group members, support for individual group members; Better solving of group problems, enhanced mainstreaming of disability issues into development projects, group identity among the group members and of the group within the community and members act as a resource to the community.

Empowerment of Disabled: People with disabilities and their families are provided updated information and training so that they are able to take responsibility for their development within the context of general community development.
The expected outcome of CBR in NLEP is to change the mindset of the disabled people so that each LAP does not remain a passive recipient and becomes an active contributor and participates in family and community life like in learning, playing, working, and household activities; in politics and cultural activities.

**Empowerment of community:** Community to assume responsibility for ensuring that all its members, including those with disabilities, achieve equal access to all of the resources that are available to that community and that they are enabled to participate fully in the social, economic and political life of the community.

It also helps in:

- **Reducing stigma & discrimination:** Advocacy meetings during village health day and with ‘Rogi Kalyan Samiti’, participatory rural appraisal and demonstration of non discriminatory behavior will reduce the perceived fear of infection & misconceptions related to leprosy.

- **Socio-economic rehabilitation:** Increased accessibility to SE rehabilitation services for LAP also will be tried through developing links with social welfare departments. Meeting with MOSJE at national level and with social welfare dept. at district level will facilitate these provisions. Local NGOs & CBOs will be supported for this purpose.

- **Legislative measures:** Advocate repealing of some acts that are not relevant now and changes that would facilitate further boosting the process of rehabilitation and in regaining self-esteem by LAP.

### 8.13.5 Monitoring & Evaluation of CBR

Monitor & evaluate disability prevention & rehabilitation activities of the group by some process indicators & outcome indicators such as early case detection cure rates by cohort, number of new disabilities, changes in EHF score, proportion of cases operated, treated for neuritis and rehabilitated economically. It will guide in planning other required interventions.
9. IEC & Counseling

Structure:
IEC
9.1 Introduction
9.2 Block Leprosy Awareness Campaign
9.3 Key message for the community
9.4 Planning IEC activities through Strategic Framework

Counseling
9.5 Introduction
9.6 Counseling Skills
  9.6.1 General guidelines for effective counseling
  9.6.2 When to provide counseling
  9.6.3 Place of counseling
  9.6.4 Characteristics of a good counselor
  9.6.5 Barriers of good counseling
  9.6.6 Process of counseling
9.7 Counseling Leprosy affected person
  9.7.1 At the start of MDT
  9.7.2 Patient on Completion of Treatment (RFT)
9.8 Counseling of family members of the LAP

Objectives:

- Enlist local channels of communication to transmit information regarding disease
- Enlist wrong notions about leprosy, prevalent in their community
- Describe information to be given to family members and community members to encourage them to support LAP

Teaching method/Activity: Role-play and group discussions

Case One: Treated case of MB leprosy visited PHC Medical Officers with complaint of that hypo pigments patches are not disappearing and he is unable to feel hot or cold by his hand, unable to hold things with the same hand. Medical Officer tried to convince him that hypo-pigmented patch would persist but the person was anxious about the cure of the disease. How will he convince the patient that disease has been cured? Discuss from counseling aspect of the case.
Case Two:  (Role Play)
Counseling a case for better patient compliance and self-care
Script of structured role play-

Hello hariramji, how is life? Is every thing all right?
No Sir, nothing is all right. I am tired of it.

Hey, why such hopelessness, tell me what has happened?
Sir, with great difficulties ulcer on right sole had healed, now it has appeared in left sole. I think the disease is not cured fully as yet. I had requested you not to stop my treatment.

Let me examine. How is your business (after looking at the left sole)? Are you using same old sewing machine?
Yes sir, problem is that the business is doing very well. I am supposed to deliver six pairs of trousers by day after tomorrow. I am getting plenty of orders, but I am not sure how to manage it?

Are you operating machine with left foot?
Yes Sir, you advised so, as it would give rest to the right sole. I continue to put on shoes, I am doing soaking my feet in water and oil massaging it twice daily. And now again the same ulcer…..

Hari ram have you marked that even stone gives way to stream of water and even the rope leaves it’s mark on the stone slab while passing over it repeatedly to fetch water from well. Now tell me how this ulcer occurred on your sole?

First the skin hardened than a callosity formed and it broke open in to an ulcer. You overexerted your left foot and sole to give rest to right foot. Skin of your left sole was getting continuous pressure from the paddle and became hard. Later it cracked open in to an ulcer. Had it been due to the disease not getting cured, the ulcer could have occurred anywhere but on pressure spot.
Yes sir, I think I am getting your point and can understand how this ulcer appeared. But what I am supposed to do now?

Continue using the machine avoid pressure on the sole for long duration. Can you think of a way out?
After thinking for some time Hari said. If I put a pillow under the sole would it work?

Exactly, this is what we should do. Clean and dress the ulcer so that it doesn’t get infected. Have you got dressing material with you? I would visit your house next week to see the healing of ulcer.
Right sir, good by.
Discussion points after role play-
- What is the problem of Hariram?
- Since how long the problem existed?
- Why did this problem occur?
- What possible alternatives or options can be made available

Conclude the session by summarizing – what is counseling and how it is done
Communication is a process of sharing ideas, feeling and information. Purpose of communication is to transmit right information / message to right person at the right time.

IEC is delivery of correct information by the source (Health department / functionaries) to the recipient (Community) using various channels (paper media, electronic media, loud speakers, pamphlets etc) in such a manner that recipient able to understand the massage correctly. It can be either a one way process like mass media or print media or two way process. In one way communication message is sent from sender to receiver with out any feed back and main disadvantage of one way communication is that sender is never sure that receiver understands the message.

Under the national leprosy Eradication programme, since long the responsibility for identifying case of leprosy was held solely by health services, particularly, specialized (vertical) leprosy services. The role of the individual, the family and the community in suspecting leprosy and reporting was not given due importance and the community was a mere recipient of services through specialized staff. While this approach had certain advantages, the major disadvantage was relatively poor coverage of population resulting in large number of patients remaining undetected. Another important aspect of the disease is that lesions related to disease are visible on the skin as insensitive patches and people in leprosy endemic areas often know that these patches could be due to leprosy. Still, a large proportion of them do not report to health services in time. Reason may be many like lack of information regarding availability of services free of cost in the nearest health center or lack of faith on government system or fear of discrimination due to prevalent stigma in the community.

Hence, the major focus has now shifted to generating community awareness by providing accurate information about the disease; its curability and the availability of MDT services free of cost to encourage self reporting for treatment by the affected person. Long term effect would be reduction of stigma for the disease in the community.

Messages delivered, through various channels like media, including electronic media create awareness in the community that gives basis of discussion in the community through local institutions like in mahila mandals, youth clubs, panchyat meetings and village health & sanitation committee.

**Features of a good message:** Message should be simple, correct, specific, clear, short and need based. Too much of information may confuse the receiver. It should be designed keeping in view the age, sex, literacy level and social aspects of the target population. Frequent repetition is essential as people have a short memory.
Local channel of communication like folk media, community radio etc are more effective because that is part of their social system and must be selected to communicate the message.

9.2 Block Leprosy Awareness Campaign:

Though the case load of leprosy is declining, many districts and blocks have prevalence rate much higher than the national level. In the year 2004-05, Government of India decided to extend focus of attention under National Leprosy Eradication Programme from endemic states to these high priority district and blocks under special situational plan called Block leprosy awareness plan. Under BLAC high priority districts and blocks are identified as per the fixed criteria. Special measures are taken in identified priority areas on a campaign mode every year during the months of September to November to increase awareness of the community for self reporting, detect hidden cases, improve case management and reduce stigma and discrimination to bring down the prevalence rate in these high endemic areas.

A detailed situational analysis of the selected districts, considering general status of programme implementation, block/Urban area wise analysis of data, quality of diagnosis and case management, cohort analysis for treatment completion rate for PB and MB, child proportion, MDT availability status in last two years, IEC coverage vis-à-vis district IEC plan in last two years, record keeping and reporting, programme supervision at different levels; is carried out to make an action plan including the following activities.

- Capacity Building of all the service providers in the Health centres including those working in urban areas, through 1 day orientation
- Need based IEC and teams to visit all villages to spread awareness about Leprosy.
- To generate awareness and detect hidden cases; house to house visit in the identified endemic villages (villages reporting cases since last two years); by the team of paramedical and voluntary workers
- Availability of trained health functionaries in all the Health Centers
- Work out Logistic details to make adequate MDT stock available in these endemic blocks.
- Identify and list out names of persons to carry out different activities.
- Operational factors hindering progress of NLEP implementation should be discussed and action to be decided.
- Specific plan for supervision
- Budget allocation.
### 9.3 Key message for the community

Following four key messages have been identified to generate awareness in the community.

- **Disease is Curable:** Leprosy is an infectious disease but the risk of developing the disease is low. It can be cured with drugs that are widely available free of charges in all the health centers.

- **Early signs of leprosy:** Early signs of leprosy are pale or reddish, skin patches with loss of sensation. Early detection with appropriate treatment helps to prevent disability from leprosy.

- **No need to be feared:** The disease can be managed just like any other disease, affected people should not suffer any discrimination and treated patients are no longer infectious and can stay in the community while taking MDT and can lead completely normal lives during and after their treatment. The patient and his family should not be stigmatized.

- **Provide Support:** Affected people need support and encouragement of their family and community, firstly to take MDT and any other treatment as prescribed and secondly, to be able to live as normal a life as possible. Encourage person to complete the treatment and avail facility of A-MDT if needed. The patient should not be subjected to any taunt or neglect but should be helped by the community with love and compassion. This will help him/her in completing the treatment and getting cured in time.

**Other massages that must be delivered to the community are:**

- Disability due to leprosy is preventable through early diagnosis and treatment of the disease and its complications by practicing self care

- Residual deformity after treatment does not mean that the patient is still having the disease. Such deformity may be loss of sensation or function of limbs due to nerve damage. Special care is needed to prevent further damage to such parts like MCR footwear

- Residual deformities due to leprosy are correctable through reconstructive surgery and facilities for reconstructive surgery are available in many centers

- Treated Leprosy affected person may become economically independent and lead a normal life.

If any other person in the village has leprosy related symptoms then he/she must be encouraged to go to the primary Health Center immediately for examination by the Medical Officer.
To plan IEC activities to generate awareness and for reduction of stigma as per the specific needs of the community, assess the status of awareness and dimensions of stigma considering the following points:

- Concept of people regarding cause of disease
- Knowledge regarding presentation of disease
- Knowledge about its curability and availability of treatment
- Usual Health seeking Behaviour
- Reluctance to disclose the problem
- Exclusion or rejection from school, work, social groups and activities
- Blame and devaluation
- Diminished self-esteem
- Social impact on family
- Ability to marry and impact on existing marriage
- Compare stigma for different health problems and in different settings

Analysis of these points would facilitate in developing strategy for IEC related to leprosy. Interventions are planned depending on the area requiring focus. Following focus areas and interventions have been identified, though innovations may also be considered.

Focus areas and approach to Interventions to Mitigate Stigma

<table>
<thead>
<tr>
<th>Focus areas</th>
<th>Approach</th>
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<tbody>
<tr>
<td>Health problem</td>
<td>• Public health to control the disease</td>
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<td></td>
<td>• Early recognition and treatment for cure or prevention of disability</td>
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<tr>
<td>Stigmatizes</td>
<td>• IEC and social marketing to enhance compassion and reduce blame</td>
</tr>
<tr>
<td></td>
<td>• Correct misapprehensions of risk</td>
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<tr>
<td>Emotional impact</td>
<td>• Counselling</td>
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<td></td>
<td>• Support of Peer groups and therapeutic communities</td>
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<tr>
<td>Social policy</td>
<td>• Advocacy, lobbying and legislation</td>
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<td></td>
<td>• Research support</td>
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</tbody>
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After deciding the activity, select the channel of communication, person responsible, appropriate time and expected results. Interventions for reduction of stigma are needed at five levels; the intrapersonal, interpersonal, organizational/institutional, community and governmental/structural level. Stigma reduction programs should use a combination of approaches. Promising interventions are empowerment, counseling, contact with affected persons and education.

9.5 Counseling: Introduction

“Counseling is a helping process where one person, explicitly and purposefully, gives his/her time, attention and skills to assist a client to explore their situation, identify and act upon solutions within the limitations of their given environment.”

Counseling is the means by which one person helps another through purposeful conversation and provision of correct information to enable client/patient to express her/his feelings, understands their needs, facilitate the counselee to find a feasible solution to the problem by providing correct scientific knowledge and own their decisions. Counseling is a method of identifying practical solutions to life or work-related problems. Therefore it is also said that counseling is a process of therapeutic communication.

Under the National Leprosy Eradication Program, Counseling is an important component and used by health functionaries to advise the patient in the clinic and the family members and the community members during their field visits. Counseling to the patients, family members and community is essential to dispel wrong notions regarding the disease so as to dispel stigma from the society which will encourage self reporting and help LAP lead normal life in the society

9.6 Counseling Skills

9.5.1 General guidelines for effective counseling Individual counseling is the process of helping a person overcome problems through a professional relationship based on trust. To be an effective counselor you must know the details about the client, significant family members who can influence the decisions of the client, their cultural and social background. Counselor must also possess good communication skills. While counseling take care of the following aspects:

- **Treat person respectfully:** Accept patient the way they are and do not be judge-mental. Determine why the client has come. Be patient; Give adequate time to allow client to express their feelings and emotions.

- **Avoid arguments or confrontation:** Use a language this is not stigmatizing (avoid terms like leper / leprosy – say this disease) acknowledge clients thoughts, feelings, fears and concerns give a positive message.

- **Listen attentively with patience and Be supportive:** Allow the client to express concern and anxieties, help the client to identify the problem, prioritize the problem to
find solution. Facilitate client to find the possible solution, select the best possible solution, encourage/ motivate person to own the decision and work over it.

**Keep the information confidential:** Keep the information provided by patient / family members confidential

**Provide correct scientific information:** Always try to provide dated scientific information to the client

**Do not advice or make decisions for patient:** let person recognize their needs and assist them to take their own decision, according to their circumstances and social needs. Help client to identify focus areas of the problem but never decide or make choices for the client.

**Demonstrate good communication skills:** Good communication skills means active / attentive listening and responding by nodding head, asking questions for more details etc. and paraphrasing.

**Never project your feeling:** Be carefully not to project/ transfer your feelings onto a client like irritable behaviour or speaking loudly with client due to earlier anger/ argument with another person.

**Use client-centered approach for counseling:** means client is the centre of the helping process. Client centered approach provides a safe, non-threatening and warm environment to encourage the client to self-disclose. In this approach we use the client’s own self-healing process through empathy, congruence and unconditional positive regards for the client.

- **Empathy** is trying to understand the client’s world, their meanings, and their life through their eyes by listening actively using reflecting, paraphrasing and clarification skills.

- **Congruence means** being open, honest and genuine. Congruence is present when what is said matches what is felt.

- **Unconditional positive regards for the client i.e.** respecting client without being judgmental towards client. When we show a client that we respect them and accept them as a worthwhile human being, we are showing that they have value and worth and this helps to built trust of the person.

**9.6.2 When to provide counseling**

You may need to counsel the individual at frequent interval. Most important time for counseling is at the time of registration for treatment, during treatment regarding expressed concerns, at the time of completion of treatment, on noticing changes in risk status or disability.
status of the person and for non compliance for treatment. Counseling is done to facilitate client to

- Accept the disease and know about it
- Continue treatment esp defaulters
- Reduce stigma
- Practice self care
- Undergo Reconstructive surgery

Counseling can be for individual to enable person to make decision; family members to motivate the person to support them and help them in decision making.

9.6.3 **Place of counseling:** For counseling choose a quite, pleasant place with comfortable sitting arrangement for you and your client and minimum distraction. Ensure privacy to the client and tell your staff not to disturb you during the process.

9.6.4 **Characteristics of a good counselor:** Good Counsellor is warm, genuine, understanding and with caring attitude, has respect for the client, thinks objectively and has good communication skills

<table>
<thead>
<tr>
<th>Golden rules for counsellors</th>
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<tbody>
<tr>
<td><strong>Don’t</strong></td>
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<tr>
<td>Interrupt</td>
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<td>Generalize</td>
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<tr>
<td>Be distracted</td>
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<td></td>
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<tr>
<td>Summarize</td>
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<tr>
<td>Be be critical/judge-mental</td>
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<tr>
<td>Offer solution</td>
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<tr>
<td>give advice</td>
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<tr>
<td>jump to conclusion</td>
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<tr>
<td>show emotion</td>
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9.6.5 **Barriers of good counseling are given below and must be avoided:**

- Too much noise in the surroundings
- Not looking at the person
- Sitting too close
9.6.6 Process of counseling:

Beginning of counseling session (introduction): As the patient enters the room, greet the person, call the person by name, welcome the client and make him comfortable. Introduce yourself if meeting for the first time and tell the person the purpose of the meeting (to understand the health problem and its best management)

I. Active Attending or Listening: it is most important step in counseling because the details provided by the client is based on it. Active listening is listening carefully and pay attention to verbal as well as non verbal signals. Non-verbal signals of client and counselor like

- Voice quality: Soft, hard, confident, timid, strong, weak
- Breathing: deep, shallow, sobbing, relaxed
- Eyes: looking down, looking away, making eye contact, tears
- Facial expression: relaxed, tense, afraid, happy, shocked
- Hand movements: waving about, tapping fingers
- Leg movements: swinging, tapping foot
- Body posture: relaxed, stiff, upright, and slumped over

Provide in depth information about the fears and worries of the client. Similarly, counselor’s words, expression and posture/gesture (verbal/non verbal communication) indicate that attention is being paid to what is being said. By demonstrating an attending behaviour we enhance the client’s self-respect, establish a safe atmosphere and facilitate free expression of thought by the client. Active listening includes reflection of feelings, questioning, paraphrasing and clarification.

Reflection of content and Feelings: People respond differently to their illness they may express their feelings as fear, anger, anxiety or sadness about disease. E.g. depression may be expressed as short temper, Irritable behaviour, less interest in daily routine, inability to sleep, loss of weight and feeling of worth lessness, and anxiety. Do not try to stop, let the person express their feelings, do not stop patient/ family members from crying. Do not take anger personally and try to stay calm.

The counselor must recognize such feelings in a direct, unemotional way. The focus is kept on the emotions of the client and his/her subjective experiences in coping with the situation.

Counsellor reflects the contents and feeling of the other persons by responding back to the client by communicating a message though empathy, questioning or paraphrasing that you are listening and trying to understand their circumstances.
**Questioning:** Always try to use questions to make communications so that both the problem and the solutions are clear. Asks questions in order to clarify the situation and make client aware of all the dimensions of the problem and help the clients to understand the core issue underlying his/her fears or concerns. Do not ask too many closed questions (closed questions are those questions that can be). Ask Open questions to make communication easier, encourage further discussion and facilitate building of trust and warmth in the relationships.

Use questions containing why with caution as it may easily sound judgmental. If you need to use ‘why’, use it in the middle of a sentence and not in the beginning of a sentence.

**Paraphrasing and clarification:** Paraphrasing is repetition of the jest of client’s feelings by the counselor in their own words. For example, “You seem to be saying that you are afraid that your family is not going to take care of you”. The clients might then agree with the interpretation. If not, the counsellor can seek clarification by saying “will you please explain it with more details?” Utilizing this technique, the counsellor attempts give feedback to the client, the essence or content of what the client has just said and clarifies understanding of the client’s world. Clarification helps the client to come to understand themselves better. When you ask the client to explain something to you in more details or in a different way, the clients not only explore their own feelings further, but will also feel that you are trying hard to understand their situation. In the process, counselors also tell the client about the scientific facts not known to them.

**II Interpretation:** Often people avoid focusing on the real problem and talk around the issue. Interpretation goes beyond what is explicitly expressed by the feelings and implied meanings of the client’s statements. Even client is unaware of this. Counsellor redefines the problem from a different point of view to bring out more clarity to the problem and make client aware to the core problem. The counsellor also helps client to establish what is relevant, emphasising the important points – for example, “Of all the things you talked about today, it seems to me you are most concerned about....”

**III Repeating:** At times of stress and crisis, clients are in a state of denial or feeling overwhelmed. They may not always understand everything they are told. As a counsellor you must not hesitate and repeat salient points of the discussion, statements of support or fact as often as necessary to ensure that the clients clearly understand the problem and requisite action. Client would usually convey that they understand and accept the information.

**IV Summarizing:** Many people who are stunned by news of the disease may respond by talking quickly and trying to provide more details or ask more questions; than counsellor can absorb or comprehend. It is then helpful for the counsellor to interrupt at times and summarize what has been said. This is like paraphrasing and helps to ensure that each understands the other correctly. Summarizing towards the end of the counselling provides guidance and direction.
to both counsellor and counselee; to deal with practical matters of the problem and decide plan of action. A summary resembles a combination of reflection of feeling and paraphrasing over a longer period of time. At the end of each session, the counsellor should summarize the salient points of the discussion, highlight decisions which have been made and need to be acted on.

V **Confrontation:** Many a times client is so much preoccupied with their fears that cannot see the connection between their behaviour and the responses of the others. Confrontation involves a direct examination of incongruities and discrepancies in the client’s thinking, feeling and/or behaviour. The counsellor tells the client that how their thoughts affect their action and behaviour, which in turn affect the behaviour of others towards you. E.g. Because of fear of discrimination, people withdraw themselves and do not speak to friends and relatives. Friends and relatives in turn also respond by not talking to them. Establishment of strong relationship and rapport is essential before commenting on such issues. It is a highly intrusive skill hence timing is very important and advice on confrontation must be delivered in an atmosphere of warmth, caring and concern.

VI **Respecting:** As a counsellor must appreciate that people see their problems in unique personal ways determined by culture, social class and personality. Respect client’s views and beliefs and build on them. Show respect, for instance, by asking a client to explain different aspects of the culture or personal beliefs that are strange to you; for example, “you feel strongly about this. I don’t know about it. Tell me more about it”.

VII **Structuring or Prioritization:** Structuring means helping the client to see relationship between facts and feelings. It helps clients to determine the important aspects of their concern that needs immediate attention and other less important aspects that can be put off until later. It is essential part of planning and probably one of the most critical skills in counselling.

VIII **Deciding Plan of action:** Based on the scientific knowledge, cultural and socio-economic aspect of the client, help the client to explore all the possible solution for the prioritised aspect and choose the most relevant option for action. Encourage client to take their own decision and act accordingly.

IX **Concluding a counselling session:** While ending the session summarize the salient points and decision taken, congratulate client for their efforts, wish them luck and fix next visit.
9.7 Counseling Leprosy affected person:

Conveying the diagnosis of leprosy to a person may be a very traumatic experience because a Leprosy affected person faces tremendous stigma and discrimination in the society due to prevalence of Myths and misconceptions about the disease.

Leprosy affected person needs support of the family members and community. Hence, it is essential to counsel the family members of the leprosy affected person and disseminate correct information about the disease in the community and also encourage the leprosy affected person to take the treatment regularly, complete it and practice self care for prevention of disability and deformity.

Counseling to patients

9.7.1 At the start of MDT

- You have been diagnosed as a case of leprosy. It is caused by Bacteria.
- There is nothing to worry as MDT can kill the bacteria. If you take the Medicine regularly every day for 6 months (PB) and 12 months (MB) as being told you can lead completely normal life during and after your treatment.
- You will be cured after the prescribed doses are taken. However anesthesia and hypopigmented skin patches may persist even after treatment.
- If you cannot come for Medicine in any month, please collect MDT for that month in advance. Always collect the MDT, 3-4 days before the last dose of BCP is taken.
- MDT is safe to be taken during pregnancy and should be continued.
- You may find red colored urine initially with use of every new MDT pack for 1-2 days. This is due to medicine taken on 1st day of each BCP. For this you need not be worried, as the same will pass off quickly.
- For MB patient- Don’t worry about the change in skin colour which is due to the Medicine. This will go away after stopping the MDT.
- Report immediately, if during treatment you develop skin rash that itches or jaundice or any other kind of problem
- Sometimes during treatment or afterwards you may get Reactions, which need prompt treatment to prevent deformity. You should report to the Health Center immediately in case of inflammation of existing skin lesions, nerve pain, loss of sensation, weakness, and tingling sensation in the hands, feet or face.
- New disabilities can occur any time during or after the treatment and must be reported immediately. New disability of recent origin can be treated but existing disability may or may not improve with treatment.
One must practice self-care regularly to prevent disability and worsening of the existing disability.

9.7.2 Patient on Completion of Treatment (RFT)

You have completed the MDT BCP treatment schedules very nicely and therefore you are now fully cured of the disease and need no further MDT. Do not go anywhere else and take the medicine again as the same is not needed at all.

Do not worry about the skin patches that are still lingering on your body. These will take time to regress, which is a very gradual process. Some patches may remain forever, but these are harmless.

If you see any changes in any of these patches showing reactivation of the disease, please come to the Health Center immediately.

Loss of sensation, muscle weakness and other nerve damage will also remain and you must take all the precautions to save these from injury.

Come to health center immediately for treatment if any of the previous symptoms come back again or signs of new nerve involvement, worsening of nerve impairment, reaction, eye involvement appear.

Deformity on your hand and feet already developed can be corrected with surgery and can be arranged in (specify) hospital free of cost. If you are willing for the same, please let us know.

You should continue to follow self-care practices as before to prevent further deformity of your insensitive hand/foot.

If you find anybody in the village having similar problem like you, please send him to the PHC immediately.

9.8 Counseling of family members of the LAP

Family members must be counseled by health worker during the visit to the village/home visit

The disease is caused by bacteria and should not be considered as due to some old sin or curse of god.

The disease is not contagious and if a person has immunity he is not likely to suffer from Leprosy.

Leprosy now a days is completely curable with MDT. The patient after taking MDT becomes non-infective and not a source of infection to the other member.

The LAP can stay with the family members, perform day to day work and lead a normal life during and after their treatment.
The patient should not be subjected to any taunt or neglect but should be supported by the family members through love and compassion. This will help him in completing the treatment and get cured in time.

Please encourage the patient to take medicines regularly daily for 6 months (PB) and 12 months (MB). In case of any problem, bring it to the notice of the medical Officer of the PHC.

In any case of problem encourage him to report to the health facility for help.

Ensure that the patient follows the principle of self care.

If any other member of the family has similar problem, please don’t delay in bringing him/her to the PHC for examination by the Medical Officer.

**Note:** The points given above are about issues on which counseling should be centered. However, presentation of these may vary from person to person in different situation. One must be polite and speak leisurely, so that the person being counseled can understand and react to clarify his/her doubts on the spot or at any time later on.