# Chapter: 10

## Disability Prevention & Medical Rehabilitation

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**Learning Objectives:** At the end of the session trainees will be able to

- Enlist & Describe the common disabilities and deformities due to leprosy
- Describe consequences of impairments
- Define the criteria for PAL at increased risk of disability
- Describe care of secondary impairments
- Describe & demonstrate self care procedure for prevention of disability in person affected with leprosy without disability & worsening of the existing disability
- List methods for encouraging and monitoring the practices of self care by persons affected with leprosy
- Enlist criteria for reconstructive surgery for PAL with disability
- Describe procedure to establish community based rehabilitation

**Teaching methods** - Lecture discussion, case demonstration, demonstration of articles, Group exercises
10.1 Introduction:

Disabilities/ deformities in persons affected with leprosy can occur as a result of nerve damage. Damage to the nerve results in impairment of its autonomic, sensory and motor functions; leading to loss of sweating, anaesthesia, weakness/ paralysis of muscles of eyes and 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
- Disabilities occur as a result of direct/ indirect effect of damage to peripheral nerves supplying eyes, hands and feet
- Damage to nerves occur due to lepra reactions / insidious process during the course of the disease

10.2 Definitions of Impairment / Disability:

Terms used in relation to POD:

10.2.1 Impairment: Any change in body structure and function is called impairment.

It is classified as:

- **Primary impairment**: Changes in the structure and function of the body tissue directly due to disease process like damage to the nerve e.g.
  - Anaesthesia of area supplied by the affected nerve
  - Impairment of motor function.

- **Secondary impairment**: Changes in the structure and function of the body part due to neglect, excessive use, careless and improper care of organs with primary impairment.
  
  **For example, in case of**
  - Insensitive hand or foot: Development of cracks, ulcer, wounds, septic hand/foot, shortening of fingers / toes, even mutilation of hands or feet and disorganization of the foot or wrist
  - Weak/ paralysed part: Joint stiffness or formation of contractures

10.2.2 Deformity: Loss or abnormality of structure of body part i.e. anatomical changes in form, shape or appearance. It can occur due to infiltration of the tissue by the bacteria or damage to the peripheral nerve trunk by invasion of bacteria. Anaesthesia of sole is not a deformity but presence of ulcer / claw foot is a deformity.

10.2.3 Disability: Inability to perform an activity that is considered normal for a human being, includes any impairment, activity limitation or participation restriction that affects a person.
### 10.3 Disabilities associated with leprosy

#### 10.3.1 Nerves involved in leprosy and associated disabilities

<table>
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<tr>
<th>Site</th>
<th>Nerve</th>
<th>Disabilities</th>
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<tbody>
<tr>
<td><strong>Hand</strong></td>
<td>Ulnar nerve</td>
<td>Clawing of fourth and fifth finger, Loss of sensation and sweat over little finger and over Ulnar half of ring finger</td>
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<td></td>
<td>Median nerve</td>
<td>Inability to abduct thumb and oppose, Loss of sensation and sweating over the thumb, index and middle fingers and radial half of ring finger</td>
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<tr>
<td></td>
<td>Ulnar &amp; median nerves</td>
<td>Clawing of all five fingers, Loss of sensation and sweating over whole palm</td>
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<td></td>
<td>Radial nerve</td>
<td>Wrist drop, Loss of sensation over dorsum of hand</td>
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<td><strong>Foot</strong></td>
<td>Lateral popliteal nerve</td>
<td>Foot drop, Loss of sensation over dorsum of foot and lower leg</td>
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<tr>
<td></td>
<td>Posterior tibial nerve</td>
<td>Claw toes, Loss of sensation and sweating over sole of foot</td>
</tr>
<tr>
<td><strong>Face</strong></td>
<td>Facial nerve</td>
<td>Lagophthalmos</td>
</tr>
<tr>
<td></td>
<td>Trigeminal nerve</td>
<td>Loss of sensation over cornea</td>
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</table>

#### 10.3.2 Consequences of nerve damage

- Nerve damage
  - Loss of sweating (Autonomic function)
  - Loss of sensation (Sensory function)
  - Impairment of motor function
- Dry and brittle skin, develops fissures/cracks/ulcers Crack
- Injury/pressure
- Weakness/paralysis
- Contracture

#### ULCER
10.3.3 Grading of Disability (WHO): Disability is graded as 0, 1 & 2

**Grade 0:** No disability found

**Grade 1:** Loss of sensation in hands and feet due to damage of peripheral nerve(s), must not be confused with loss of sensation in the skin lesions which is due to damage to cutaneous nerves. Eye is not given grade 1.

**Grade 2:** Visible damage or disability like red eye, corneal ulcer or uveitis in eye, foot drop, claw hand, wounds or ulcers, loss of tissue due to partial absorption of fingers or toes

**For EHF grading:** Please refer section 6.11 in chapter 6: on diagnosis

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Fear of developing disability (inability to perform activities like writing) and its consequences like becoming dependant (inability to carry out certain responsibilities like support family economically), rejected (leaves house) or denied basic needs like food, water & shelter gives rise to stigma against leprosy that is often seen in the society
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10.4 Prevention of Disability & Impairment

10.4.1 Prevention of disability: It means

**People without disability:** Prevention of occurrence of disability

**People with disability:** Prevention of worsening of existing disability (limitation of disability)

**It includes:**

- Timely detection of disease and its effective treatment with MDT
- Identification of high risk people and their frequent monitoring
- Early detection & treatment of reaction and neuritis (acute & silent) with steroids
- Early recognition & treatment of impairments
- Care of insensitive hands, feet and eyes for prevention of secondary impairment (through self care)
- Provision of appropriate footwear, other aids & appliances
- Enabling sensory & motor recovery by medical and surgical means (Refer 18.13.1-viii)
- Minimising disability by use of splint and other physiotherapy measures and surgery
- Prevention of dehabilitation and destitution through community based rehabilitation.
10.4.2 Assessment of disability and Risk status in leprosy

(For assessment of disability refer chapter 6 on Diagnosis)

After complete examination of the PAL, assess the risk status for development of disability and monitor in the following manner:

<table>
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<tr>
<th>Condition</th>
<th>Risk status</th>
<th>Monitor</th>
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| ● PB leprosy, Skin soft & supple, Normal sensibility, No thickening of nerve | No risk                                          | ● Need NFI once in three months  
● Counsel early reporting on development of sign and symptoms of impairment of nerve function |
| ● MB leprosy, Positive skin smear, Multiple patches, Nerve trunk thickened or tender but no sensory loss, Pregnancy, Skin lesion on or near nerve trunk, On hormonal therapy | At risk of developing NFI (Nerve function impairment) | ● Follow up the person frequently every month if taking MDT or 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 with MDT. |
| ● Only impaired sensation, Risk of injuries or burns, blisters and ulcers, Risk of involvement of more nerves | All the above  
● Self care to keep skin of the affected part soft and supple  
● Protection of insensitive part from injury  
● Early detection of any secondary impairment and its treatment |
| ● Blisters, Callosities, Scars, Cracks, Weakness of muscles, Deformity | Risk of progressive damage and disability | All the above including Self care  
● Active and passive exercises to maintain range of movement & improve strength of the muscles |

Those who have already developed some impairment and disabilities are at greater risk of developing new disabilities as well as worsening of existing ones and need urgent specific action. Such persons are identified and monitored more frequently. Risk status for development of disability changes with change in over all condition of PAL affecting management and monitoring of the person. Hence, risk status of a person must be revised frequently during assessment of disability and affected person is counselled and monitored accordingly.
10.4 Protection/Care of body part with nerve function impairment

10.5.1 Aim of self-care activities:
Person with nerve function impairment are trained and encouraged to minimise their disabilities by practicing **self-care**. Health care functionaries at the PHC can support development of self care practices at home or through self care groups.

<table>
<thead>
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<th>Aims of self care activities are:</th>
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<td>To protect anaesthetic hands, foot &amp; eyes from any external injury</td>
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<td>To exercise the affected part to prevent contractures and preserve vision.</td>
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<tr>
<td>To report any impending ulcer &amp; signs of nerve damage and adverse response to treatment without delay.</td>
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10.5.2 Principles of Self care activities
- To keep the skin soft and supple
- To Protect anaesthetic hands feet & eyes from any injury that may be acute/ chronic; Mechanical/ thermal;
- Early detection & management of blisters ulcers/ injuries
- Prevent development of contractures and preserve vision.

10.6 Care of Insensitive Limbs

Loss of sensation is usually accompanied by loss of sweating leading to dryness of the skin. Insensitive portion with dry skin predisposes the affected area to recurrent injury, cracks and ulcer. These in turn lead to chronic infection, stiffness and loss of tissue, leading to worsening of disability. Activities of daily living need modifications to prevent worsening of disability.

10.6.1 Keeping skin soft and supple: (Skin care procedures)
Sebaceous secretions retain the moisture with in the skin. To keep the skin soft, people with loss of sweating must practice soaking the limb in plain water, scraping of any dead tissue and oiling preferably twice daily.

**Procedure: Train the person to:**
- Soak dry hands and feet in a bucket of water for 20 – 30 minutes / more until any hard and dry skin becomes soft. Container should have enough water to cover hands/ feet.
- Rub off the surface layers of keratin by rough cloth / stone with out any sharp edge. In the presence of a crack, thin the edges of the crack by rubbing it along the line of the edge and not across the edge.
• Rub in oil immediately after soaking without wiping. It helps to retain water and keep the skin soft. Use neem oil / liquid paraffin / vaseline. Edible oil may attract rats and insects, which is especially dangerous to insensitive limb.

Caution: Hard and thickened skin should be removed gradually by soaking and scraping over a period of weeks. Trying to remove it in a few days will result in injury to the limb.

10.6.2 Protection of limbs from injury
To protect the insensitive limb, person is made aware about the insensitive part of the body and sensitized regarding possibility of sustaining injury with out knowing about it.

Teach them:

• To inspect insensitive hands & feet daily & frequently after work both at home and at work place, for Signs of impending ulcers like redness (hot spot), swelling, blister and dry hard skin, cracks in the skin.
• To feel for “hot spots” (areas of warmth, redness and tenderness) by holding insensitive hand against sensitive area & press gently to find a sore spot
• To rest the limb if “hot spots” are present.

In case person has sustained injury, train them to think and find:

• Why did the injury occur?
• How can rest be provided to the injured part?
• How can similar injuries be avoided in future?

Method of protecting insensitive hands: Person is taught to:
Teach and encourage person to use safe methods of handling hot, hard or sharp implements by using simple protective devices like

• Keep away the insensitive hand from fire, use stick / tongs to poke the fire
- Handle hot/sharp objects using gloves/cloth/insulated handles/holders
- Avoid washing in hot water / check temperature of hot water using sensitive part of the body before using it for insensitive part.
- Avoid doing one type of job for a long duration / change job/ give rest/ inspect hands frequently for any red hot spots to avoid blisters

**Methods of protecting insensitive foot: Tell person to:**
- Avoid standing or squatting for a long time. Avoid walking for long distances / for long duration and on rough / uneven surface. Take frequent rest.
- Walk slowly, avoid running / jumping
- Take small steps
- Use bicycle or any other means of transport
- Use appropriate foot wear (soft inside but hard outer sole, never tight but not very loose, no nails) or MCR foot wear for even distribution of body weight
- look for any hot spot / swollen foot / seek advise

**10.6.3 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 foot wear daily/ frequently by piece of a cloth
- Make sure that nails are not used in footwear
10.6.4 Characteristics of appropriate footwear

- Shoe must fit well, neither tight nor loose
- Usually one size bigger than the required size with broad front so that it has plenty of space for clawed toes or any orthosis if needed.
- It may be designed with adjustable strap to allow adjustment for bandage.
- Back strap to be able to retain footwear
- Velcro straps instead of buckles to avoid injury
- 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 moulded to the contours of the weight-bearing sole for badly deformed foot
- Support for foot drop if needed
- Nails or braded thread are not used (may cause injury)

**Note:** Special MCR footwear is not recommended routinely for all the persons affected with leprosy. 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.
10.7 Care of the limbs with weakness/paralysis of muscles (Physiotherapy)

Involvement of peripheral nerve trunks 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. If proper care of deformity is not taken, joints of fingers, thumb and ankle may become stiff.

Stiffness develops for two reasons:
1. Injury and healing with scarring/fibrosis
2. Long-standing untreated deformity

Skin around the joint is loose to permit movement. Any wound (crack/ ulcer/injury) near the joint that heals with scarring result in contracture 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, the limb gets deformed due to imbalance of muscles around the joints. If the joint is not moved passively for its full range of movement, lax skin on one side of the joint is not stretched and becomes shortened (Formation of contracture) resulting in fixed deformity of the joint that restricts the full movement of the joint.

10.7.1 Management 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.

10.7.2 Care of paralysed Muscles

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

Physiotherapy is very important in the management of disabilities and deformities for prevention of worsening and in pre and post operative period. It comprises:
- Exercises,
- Oil massage
- Wax bath
- Hydrotherapy
• Splinting
  • Electrical stimulation of muscles
  • Short wave diathermy
  • Ultrasound therapy

**Physiotherapy helps in**
- Restoring the normal tone of the muscle and preserving the physiological properties of muscles
- Preventing muscle atrophy and the over stretching of paralysed muscles
- Preventing contractures and keeping joints mobile by improving the range of movement
- Maintaining and improving blood circulation
- Making the skin soft and supple

**Massage**: Gentle but firm massage with oil (any locally available oil that does not attract insects and rodents) stimulates muscles, increases local circulation and makes skin soft and supple. It helps in reducing stiffness and prevents contractures. Massage is done for few minutes before exercise or applying splint.

**Splints:**
Most frequent indications for splinting are:
- Flexion contracture of proximal interphalangeal joint of fingers & thumb
- Web contracture of thumb
- Paralysis of short muscles of thumb
- Open wound at finger flexion creases
- Foot ulcers/ foot drop
- Wrist drop

**Splints are of two types:**
- **Static splints**: Static splint does not permit any movement of the joint (active / passive). A well padded splint helps in immobilization of the joint, adjacent to the affected nerve to reduce pain and stimulate healing of the nerve during reaction. It can be used at night to prevent development of contractures or reduce it gradually taking care not to stretch too much to avoid splitting of contracted skin.
- **Dynamic splints**: Dynamic splint has elasticity and works on the principle of recoil. It permits active and passive movement of the joints and needs correct fitting to avoid injury due to friction. They are used for active exercise of the weak muscle to regain strength.

**Exercise:**
Both the above mentioned 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 person uses his weak muscles to do the exercise. This prevents contracture and strengthens the weak muscles.

- **Passive**: The person is helped to move the paralyzed part passively to prevent contractures but by passive exercises, weak muscles cannot be strengthened.

Exercises for individual nerves that can be taught to PAL are given below: Teach them:

**Ulnar Nerve Weakness or Paralysis**

**Active**: If interphalangeal joints are mobile

- Cup the knuckles joints (MP joints) of the affected hand in the cupped palm of the other hand 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 both the interphalangeal joints of the fingers as strongly as one can, keeping the same position till count of ten.

**Passive**

- Rest the hand on the thigh or on a table padded with cloth.
- Using the other hand; 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 the other hand.
- Increase range of movement gradually if contracture is present
Median Nerve Weakness or Paralysis

Active

Rest the little finger side of the affected 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 metacarpo-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, pull it away towards the palm and keep in position till count of ten.

OR

- The person must grip around the weak 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 paralyzed thumb. This action will force it to straighten. The thumb is held straight till a count 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 and keep it in this position for some time.
- Repeat this movement several times

OR
- Hold the outer border of the foot and pull it up to turn the foot out. It prevents stiffening 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 and retain this position for some time. This stretches the calf muscles and prevent its shortening

**Lagophthalmos:**

**Active:** Close eye forcefully using facial muscles and keep them closed for a count of ten.

**Passive:** Keeping finger at the outer canthus of the eye, pull it outwards and upwards and maintain the position till count of ten.

**Exercise must be avoided during active Neuritis**
10.7.3 Monitoring self care

Monitoring the practice of self care: PHC staff must monitor the practice of self care by PAL with disability and support them by:

- Motivating PAL to practice the preventive measures
- Verifying that person has understood what to do, how to do it? knows the reason for doing it
- Correcting wrong practices adopted by the PAL
- Discussing problems and finding feasible solutions
- Identifying needs for aids and appliances
- Helping health functionary & PAL to learn from experience

During the visit to the village, Health care functionaries must visit the house of leprosy affected person with disability and look for:

- Condition of the skin, whether soft and supple or not; presence of cracks, callosities and ulcers
- 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. In case person is not taking the required precautions; explain the person why the current practice 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 PAL in similar situations.

Visit to PAL shows your concern for them and motivate people to follow the advice.

10.8 Prevention and Management of ulcers

To prevent recurrent ulcers and worsening of deformity; detect and manage cracks, callosities, blisters and ulcers of palm and sole during the early stages.

10.8.1 Callosities & cracks:

Skin of insensitive hands and feet are prone to become thickened and hardened in localized areas (callous) due to abnormal pressure and repeated friction. Callous is actually protective but dry and thickened 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, all the calluses around the creases of hand and fingers and those under the feet should be removed.
Prevention of occurrence of callous/crack and its management requires:

- Interposing a soft cloth or pad between the hard surface of handle of tools used by the PAL and insensitive portion of the body to reduce the pressure and friction.
- Keeping hard skin with callosity soft and supple by soaking, scrubbing and oiling (refer self care)
- Covering cracked skin by dry dressing to prevent infection and hasten healing

10.8.2 Ulcers & Blisters:

Reasons of ulcer formation 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 (Meta-tarso-phalangeal) 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, traumatic inflammation & breakdown of subcutaneous fat underneath the MTP joint. If sensation in the foot is normal it is recognized as fatigue and rest provides it time to heal; 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 undergoes necrosis & liquefaction resulting in formation of blister. If neglected, covering skin of the blister may break down resulting in formation of ulcer.

The location of planter ulcers depends on the mechanical factors. Planter ulcers are most frequently located on the fore foot because forefoot bears most of the force exerted to move the body forwards. Ulcers usually occur at pressure points like beneath the heads of the metatarsal bones.

Ulcers usually heal by secondary union i.e. formation of scar tissue and process of healing begins only when causal factor is removed. If factor causing ulcer persists, ulcer does not heal and becomes chronic non healing ulcer. Ulcers recur on continuation of the causal factor.

Stages of ulcer formation:

Formation of ulcer passes through the following stages:

Stage 1 (stage of threatened ulceration): Stage of ischemia and inflammation, which is recognized as fatigue by normal feet. Rest to the injured tissue at this stage, provides time to the injured tissue to repair itself and become normal.

People with insensitive feet are not able to realize this warning and therefore, taught to inspect their hands/feet frequently and regularly. One can identify this stage by presence of the following features:

- Presence of deep oedema recognized by increased gap between toes/fingers
- Deep tenderness at the affected site
- Local warmth
- Possibly puffiness over the corresponding site on the dorsum of foot/ hand

**Appropriate management of the condition at this stage prevents formation of ulcer. It is managed by:**

- Absolute rest to the affected part to allow healing
- Elevation of the affected part for 48-72 hours to prevent further tissue damage & permit resolution of traumatic inflammation
- Educating & demonstrating foot care to the person (refer self care)
- 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 PAL to manage Blister (Concealed ulcer) at home.**

**Manage blister by**

- Gently cleaning the skin over and around the blister with soap &d water.
- Mopping it dry taking care not to damage the overlying skin.
- Padding the lesion well and covering it to avoid injury
- Bandaging it firmly
- Providing rest to the affected part for three weeks to allow healing
- Elevating the affected part

If necessary, blister could be snipped away and the area covered with sterile Vaseline gauze dressing. Blisters of foot may need below knee plaster cast with provision for walking made in it 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 to the affected person & provide protective foot wear
- Find the cause of blister and think of a way to avoid the circumstances/activities causing it

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. If unavoidable, ask the person to use crutches with sling for walking. Blistered foot should not be made to bear weight, instruct patient to keep the foot elevated. Re-examine after 72 hrs. If improves, continue the treatment.
Stage 3 (stage of overt ulcer)

Blister may break open due to external injury or continuous use of the affected part or increased pressure from inside due to oedema leads to breakdown of tissue and formation of ulcer. Formation of ulcer results in exposure of damaged tissue to external environment.

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

- **Rest & Elevation of affected part**: Wounds heal if they are rested by using splint (hands) and/or crutches (foot) and cause of ulceration is removed. What ever may the circumstances, the injured part must not be allowed to perform normal functions whilst the tissue is still being repaired.

  The best option for the person is to lie down with the foot raised above the level of the heart (bed rest). If rest is not possible, other options like using crutches/ stick, using a transport or swapping the activities must be explored

- **Maintaining good wound Environment**: A good wound environment means that wound is 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. Wound is kept clean, moist and covered with clean / sterile dressing

- **To clean** the 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 litre water) in water near body temperature. This prevents sudden change in the temperature of the wound and prevents raw area from getting infected and becoming septic. **Mop** the wound gently with soaked gauge swabs to avoid any damage to the granulation tissue. Do not use cotton wool for mopping because strands of fibre may be left in the granulation tissue and act as a foreign body.

- **Wounds heal better if they are kept moist** and the temperature of the wound doesn’t change quickly. Wounds should be covered with dressing soaked in normal saline to keep it moist and changed after 2-3 days to keep the temperature stable; but it should neither become dry nor too wet. Discharge from wounds must be drained and dressing changed whenever it becomes wet to avoid infection. Recent foot ulcers give a heavy discharge in the early stages of healing. Hence, change the dressings at least once in a day. As the wound begins to heal, discharge becomes less and dressings can be left in place a little longer (2 to 3 days before changing). While changing dressing, always soak gauze stuck to the wound, using normal saline or clean warm water to avoid damage to granulation tissue.

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**Available options for resting foot for healing of blister or simple ulcer caused by walking:**

- Resting the 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 (limping)
- No local application: 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. 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 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.

- Examination of Ulcer:

While treating the ulcer determine whether ulcer is simple or complicated

Observation:

- Size of the ulcer: Person having ulcer with maximum diameter more than 2 cm must a referred.
- Edges of the ulcer: Undermined (ulcer expanding in active stage)/ sloping (ulcer is healing). Slight bluish hue of the edges merging with surrounding skin means ulcer is healing well and epithelization is taking place.
- Discharge: Copious or scanty; clear straw coloured (transudate), creamy discoloured thick sticky but not foul smelling (exudate – does not need antibiotics), thick pale foul smelling (infected - antibiotics needed)
- Look at the base: Look for granulation tissue whether healthy or not and its amount. Gel like bright red not bulging above the edge is healthy. Bright red but bulging above the edge (Called hyper-granulation, it occurs due to some foreign body or sequestrum irritating inside the wound) needs referral. PALE with necrotic tissue – infected and unhealthy must also be referred. If bone tendon or muscle is visible at the base of the ulcer (complicated ulcer) refer the person to tertiary care.
Palpation:
- **Palpate the surrounding tissue:** whether normal and elastic (normal ulcer treatment)/inflamed and oedematous. Surrounding tissue is still elastic / firm and fixed to underlying tissue in chronic ulcer (non healing) needs referral
- Press the surrounding area firmly while looking at the ulcer for any increase in **discharge through any sinus connected** with deeper structure.
- **Palpate the edges of the ulcer:** If hard with callous formation means non healing ulcer and needs referral.

All the wounds and ulcers are categorized as grade II disability and must be referred to district hospital after initial treatment (first aid). These people are referred back after initial management for follow up management at primary health centre.

- **A simple ulcer** is an ulcer that is
  - Not infected
  - Has non infected discharge
  - No involvement of underlying structure
  - Absence of slough
  - Has sloping /healing edge

**Rest** is the only way to heal a simple ulcer. But usually patients cannot afford such rest. They need to work to earn their daily wages. For option of rest refer management of blister

Healing while walking can occur if the patient is provided with Below Knee Total Contact Cast with or without a Bohler Iron. These casts rest the tissues of the foot by immobilizing them while permitting the patient to ambulate.

Refer, a simple ulcer if does not heal within 6 weeks with appropriate management

- **A complicated ulcer** is an ulcer with presence of one or more of the following features:
  - Infected discharge (foul smelling)
  - Not healing within 2 weeks
  - Involvement of underlying structures
  - Ulcer fixed to surrounding deeper structure
  - Hyperkeratotic edge, hard fibrosed base
  - Pale unhealthy granulation tissue
  - Presence of slough
  - Malignant change

**Management of the complicated ulcer consists of treating the complication by:**
  - Surgical Debridement
  - Immobilisation in a splint
  - Appropriate footwear

It is the complicated ulcer, which requires surgical management.

**Principles of Debridement of wound include:**
  - Removal of all the septic foci.
  - Provision of adequate drainage
  - Not to leave behind any
    - Sharp spiky bony ends and / or
    - Bony prominences over scarred weight bearing areas

Presence of these features causes recurrence of ulcers or sinuses.
Recurrent ulcer:
Most plantar ulcers recur on return of the cause for ulcer or may recur despite adequate care, even on walking for 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:
- Preventive care of the foot & reducing stress on foot by limiting walking & using protective footwear
- Eradication of infection through debridement if needed.
- Improve the quality of scar by excising scar & closing gap by re-suturing / skin grafting, use of flaps including myo-cutaneous flaps and free flaps
- Surgical procedures to modify architecture of foot for distribution of body weight
- Reduce the load on the scar by modifications in footwear (metatarsal bar, arch support, moulded insole)

Family members are also encouraged to learn and practice dressing of ulcer and nursing care of patient.

Prevention of ulcers: it is essential to prevent the occurrence of the first ulcer because after the formation of ulcer in the foot, recurrence is common and difficult to prevent. To prevent the occurrence of ulcer it is essential that person is made aware about loss of sensation, inspect feet frequently, press deeply on the pressure bearing part of the sole to find warm & sore spots, rest on appearance of first sign of injury to avoid ulcer formation, practice SSO (Soaking, Scraping, and Oiling) to keep the skin soft. Use appropriate footwear, take care of the foot wear and walk slowly taking small steps and short distances. Never run or jump.

Criteria for Referral:
- Not healing (with in a period of 6-8 weeks)
- Recurrent ulcer
- Complicated ulcer (Deeper structures like bone/ tendons is exposed).
10.9 Disintegration of the anaesthetic foot (without associated ulceration)

It is also known as ‘Charcot’s foot’, ‘Hot foot’ or simply ‘neuropathic disintegrated foot’. Charcot’s foot is progressive degeneration of the bones and joints of an insensitive foot due to repeated and sustained trauma. It involves ligaments, cartilages and bones of fore foot and mid foot.

**Reasons:** It occurs due to
1. Torn ligaments (sprain / strain)
2. Fracture of cartilages or bone (tarsals or meta-tarsals)

It can occur in a normal appearing insensitive foot or in an already deformed foot. Where previous acute disintegration was not noticed or diagnosed or was inadequately managed or even after being well managed.

**Clinical presentation:**
**Person usually presents with the following features**
- Swollen foot without any ulcer or pain
- Warm but non tender foot on palpation

Person with Charcot’s foot may keep walking normally with swollen foot and if it remains undiagnosed or untreated it progresses to total disintegration of foot.

**Management of hot foot includes**
- Elevation of foot
- Non-weight bearing plaster cast for one month (till oedema settles and cast becomes loose)
- Re-apply plaster cast (weight bearing) for 5 months
- Follow up with fixed ankle brace for 1 ½ years

Such patients must be referred to tertiary care unit for management.

10.10 Conditions managed at referral centre

Persons with conditions that cannot be managed at a particular health centre due to lack of training or necessary resources are referred to appropriate centre for management and staff at the centre must know where a person should be referred.

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

10.10.1 Conditions of the eyes:
- Any acute eye problem must 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
10.10.2 Conditions of the hand:
- Modification of tools to avoid injury to insensitive hands
- Removal of thick callous and trimming of ulcers
- Need splint to wear at night for weak 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

10.10.3 Conditions of the foot:
- Removal of thick callous by trimming
- Chronic ulcers requiring orthosis or surgery
- An infection (the foot is hot, red and swollen) is an emergency and must be referred for intensive antibiotic treatment and surgery
- “Hot foot”
- Foot-drop requiring surgery

10.11 Surgical treatment for Persons Disabled by Leprosy

Leprosy leads to physical, functional, social and/or economical problems. Physical rehabilitation includes physiotherapy and occupational therapy, orthotics and prosthetics services, assistive and protective devices and sometimes corrective surgery. PAL with residual disability and deformity can be referred to specialist for surgical correction of disability. At present such facilities are available at three Central Govt. Institutions, some Physical Medicine and Rehabilitation (PMR) Institutions, PMR departments of selected medical colleges and referral centres managed by NGOs as per the list enclosed in the annexure X. Facilities for reconstructive surgery are also being created in selected District Hospitals in phased manner.

Reconstructive surgery (RCS) aims to restore function and form of the affected part as far as possible and to prevent further disability. It also plays an important role in the prevention of disability and rehabilitation process. All the people with disability due to leprosy are not suitable for RCS. It is important to know the criteria to select suitable people for surgery.

10.11.1 Conditions requiring surgical interventions:
(i) **Irreversible claw hand** due to paralysis of ulnar / median/ both nerves
(ii) **Foot drop** due to paralysis of lateral popliteal nerve
(iii) **Claw toes** due to paralysis of posterior tibial nerve
(iv) **Lagophthalmos / facial palsy** due to paralysis of branch of facial nerve.
(v) **Wrist drop**: Due to paralysis of radial nerve
(vi) **Triple nerve paralysis**: Paralysis of ulnar-median-radial nerves in the same hand
(vii) **Recurrent wounds of hands and feet**
(viii) **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.

(ix) **Deteriorating nerve function** despite steroid therapy

(x) **Facial deformities requiring plastic surgery**:

- **Madrosis**: Graft from scalp or temporal artery island flap
- **Sagging of face/ mega lobule**: Rapid disappearance of lepromatous infiltrate after treatment with MDT and destruction of elastic and collagen fibres in the dermis produces wrinkling of skin and appearance like an ageing skin. Pre-auricular or naso-labial face lift can help selected cases
- **Nasal deformity**: Due to invasion and destruction of nasal tissue esp nasal septum
- **Gynaecomastia (enlarged breast) in males**: Occurs due to hormonal imbalance produced by destruction of seminiferous tubules of the testes

### 10.11.2 Referral of PAL for Surgery

Health care functionaries can motivate suitable persons (those who need surgery and would be benefited from reconstructive surgery or other forms of surgery), refer them for RCS at the right time and encourage them to practice pre and post operative physiotherapy.

Member of health team at PHC must be able to identify LAP. It is important that centres doing reconstructive surgery in leprosy, liaise with other staff in developing local criteria and arrangements for the referral of appropriate patient

A disability register must be maintained by collecting information from case cards, old and current registers. Help of other members of the team may be taken to update the list of disabled persons. Persons who can be benefited by surgery and are willing to undergo surgery are referred to District Nucleus team at district headquarter on the designated day for assessment and facilitation of reconstructive surgery.

Pre and post-operative physiotherapy is essential for a successful outcome of surgery and is arranged in consultation with the surgical centre. Those referred back after the reconstructive surgery need:

- Post operative exercise
- Monitoring of nerve function to check recurrence of reaction and neuritis
- Prevention of reoccurrence of ulcers by adopting self care procedures
- Care of orthoses / prostheses

Instructions given by surgeon / physiotherapist at the time of discharge must be followed.

### 10.11.3 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 general 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 especially people 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.
10.11.4 Facts must be known about surgery

In addition to the above, person 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 with stiff hands and feet who are willing to undergo correction of deformity are referred to surgeon to let the surgeon decide for the surgery.
- Person needs at least one week of pre-operative 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 post-operative 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:
- May just have a collapsed nose or collapsed tissue defect of the nose.
- Should not have an ulcer in the nasal lining.
- Minimum duration of the collapse should be for 12 months.
- Should have completed 12 pulses of MB-MDT, to be considered for surgery
- Should not be in Type 1 or Type 2 reactions.
- 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.

10.11.5 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.
10.12 Support to PAL 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. (Please refer annexure X for rehabilitative services available for persons with disability including leprosy)

- **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 PAL with disability.

- Visit the person at home to monitor the self care practices during visit to the village.

- **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.

10.13 Community based Rehabilitation (CBR)

Disability arises due to deliberate/unconscious denial/limitation of equal access to opportunities for disabled people in their families and community. It may be because of cultural social institutional, environmental and attitudinal barriers.

**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”. (For rehabilitative services for persons with disability, please refer Annexure X)

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 to start surgery for PAL. In addition there are several NGOs / Institution supported by ILEP partners for carrying out rehabilitation services.

Till now rehabilitation has been observed as an institution based programme. Institutional rehabilitation addresses the problems of individual disabled person and is often available only for a small number at a high cost. Moreover, the efforts and activities 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 persons return home, it becomes 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, poverty alleviation and social inclusion of all the people with disabilities. It is implemented with combined efforts of people with disability, their families, community, social and government organisation.

The basic physical and social needs of an individual like food, health, education, shelter, social participation etc are same for all the people, including people with disability and people affected by leprosy. CBR facilitates access to basic needs, and promotes equal opportunities and equal rights for the disabled. It is therefore a multisectoral strategy with some key principles to enable people with disabilities to participate in the whole range of human activities.

10.13.1 Basic Principles of CBR

The principles outlined below are overlapping, complementary and inter-dependent.

- **Participation:** It means active involvement of people with disabilities in the various activities of the community as well as development of CBR programme. Disabled people are better aware of their needs, have abilities (not disability) hence, they should be involved in policy-making, implementation and evaluation of the programme.

- **Empowerment:** Local people, specifically people with disabilities and their families are adequately trained so that they are active in decision making, take leadership roles and control resources for their welfare. Service providers, CBR workers, and facilitators are trained to ensure that people with disabilities are included in all the stages of the CBR. This results in people with disability being valued, respected which improves their self-confidence.

- **Raising awareness:** CBR also addresses attitudes and behaviour of the people within the community. Community is told about the disease awareness by making them aware about their abilities as well as problems and support required by people with disabilities. Some of the sustainable benefits of CBR are reduction in stigma, employment opportunities, marriagability, active involvement in family and social welfare. It also promotes the need for and benefit of inclusion of disabled in all developmental initiatives.
**Self-advocacy:** Advocacy means promoting or speaking for a cause. It involves speaking out for in-justice and working for equality of rights. CBR consistently involves people with disabilities in all issues related to their well-being. People with disability organize themselves to represent their needs, get support from other organizations, local community, community leaders, administrators, policy makers to create space for interactions and demands. They also coordinate with other organisations to utilize available resources for their rehabilitation.

**Gender sensitivity and special needs:** CBR addresses needs of individuals as well as groups within the community with special needs like women, children, elderly and socio-economically disadvantaged groups.

**Partnerships:** CBR depends on effective partnership which means all the organizations (community-based organizations, government organizations and other organized groups) working for people with disabilities, agree and work together for the common goal. It includes regular meetings, interactions, planning and monitoring on the progress made/achieved.

**Sustainability:** CBR activities and benefits must continue with minimal external support (trained manpower, money and material) after the initial interventions of the programme. It means locally available resources are used, local people are trained; benefits continue and become long lasting and help generation of its own resources for continuation of the programme.

In CBR, people with disabilities are able to work together to organise their own lives and their development, through active involvement and the support of their families and local communities. It helps in reducing poverty by increasing access to livelihood opportunities and empowerment.

**10.13.2 Potential of the community**

Community is the primary resource available for rehabilitation. It has access to resource, can provide long term support for effective rehabilitation and can understand problems that may arise. Even the poorest community has resources that can facilitate inclusion and participation. Therefore, community workers must have good understanding of the community and its potential.

**10.13.3 Implementation of CBR**

Implementation of CBR varies with local situations (geographical, culture, socio-economic-political etc.) and existing organisations (Governmental, Non-governmental, Community-based organisations etc.). 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, counselling, formation of self-help groups, corrective surgery, vocational training including education, literacy, micro-credit schemes and other developmental activities. Community based interventions must be aimed at changing the attitude of the community towards disabled people from exclusion to inclusion; and mind set of disabled people from passive receivers to active contributors in the development of the community. It also includes making necessary changes
in the environment and service delivery systems to encourage participation of disabled in the development of the community and aims at improving quality of life for them.

**It includes the following activities:**

- Generation of awareness in the community for prevention of disability
- Provision of health care facilities for early detection & management of disabilities
- Creating a positive attitude towards people with disabilities.
- Advocacy for inclusion and equal opportunities for disabled
- Networking between community and other organisations
- Provision of functional rehabilitation services.
- Supplying information to clients or communities about resources and opportunities available in and around them;

- Provide counselling to address psychological or social problems;
- Identify interventions that are appropriate to the specific needs of the client
- Provision of educational and training opportunities for Empowerment of the disabled persons
- Facilitate in initiating small projects that provide income without the risk of aggravating disabilities
- Creation of micro & macro income – generation opportunities.
- Refer client to other organizations providing specific services
- Negotiate access to local government services, schools, pensions or benefits;
- Promote participation of people with disabilities in community development activities
- Management / monitoring and evaluation of CBR projects

Members of health team at PHC can identify Leprosy affected / disabled persons either by referring registration register / through survey. For survey, help may be sought from other functionaries working for the development of the community like Teachers, ASHAs AWWs etc. Assess the disability and needs for rehabilitation by discussing the issue with health workers and disabled people about their experiences, interests, expectations, frustrations and ideas to improve the situation. Provide basic services like drugs, dressing materials, protective footwear, counselling and training in self care. Assist in procuring protective devices. Encourage them to practice self care, discuss their problems, find feasible solutions and refer them to other organisations providing services. Encourage them to become member of an existing self help group or organise themselves in to a self help group

Health worker can act as supervisor and trainer for health related aspects. Health functionaries can establish liaison with Village Health & Sanitation Committee to discuss the issues of disabled people, with referral centres to provide specialized care to those who are in need like physical rehabilitation services, ulcer care, physiotherapy, surgical treatment, treatment of eye complications, prostheses etc. and follow up services. Recognize professionals such as surgeon, physiotherapist, vocational trainers, counsellors, support staff, orthotists / prosthetists and technicians at district hospital or specialized centres to provide referrals services.
Medical officer can advocate on behalf of the people with disability and sensitize local leaders, community, members of health and sanitation committee regarding their needs. Medical officer along with the help of other community leader can communicate with district authorities regarding various facilities available for the benefit of the disabled, coordinate with various agencies/ organisation, and help in dissemination of information to potential beneficiaries / users

Facilitate accessibility to ‘socio-economic rehabilitation services’ through social welfare department. District Nucleus team can steer the rehabilitation activities and provides support in facilitating the accessibility to different services

Officials from other departments/ ministries like educational department, ministry of social justice and empowerment, corporate sector, ministry of labour can address the agreed needs or problems related to individuals or communities such as aids & appliances, grants & aid, occupational training & employment etc.

10.13.4 Advantages of CBR

Organising SHGs provides visibility to the group members, support for individual group members; solve group problems, enhance mainstreaming of disability issues into development projects. It provides identity to the individuals among the group members and to the group within the community so that the members of the group 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.

Change in Behaviour: The expected outcome of CBR in NLEP is to change the mindset of the disabled people so that PAL do not remain a passive recipient and becomes an active contributor and participates in family and community life like learning, playing, working, household activities, politics and cultural activities.

Empowerment of community: Community must 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: Organizing advocacy meetings, participatory rural appraisal and demonstration of non discriminatory behaviour during village health day, with ‘Rogi Kalyan Samiti’ect; reduces perceived fear of infection & misconceptions related to leprosy.

Socio-economic rehabilitation: Increasing accessibility to socio-economic rehabilitation services for PAL by developing links with social welfare departments. Meeting with MOSJ&E at national level and with social welfare dept. at district level will facilitate these provisions.
**Legislative measures:** Advocate repealing of some acts that are not relevant now and can be changed to facilitate the process of rehabilitation and help in regaining self-esteem by PAL.

**10.13.5 Monitoring & Evaluation of CBR**

Monitoring helps in assessing the impact of the CBR activities, identify problems faced by the disabled, unaddressed needs, problems hindering the progress of the programme & assess impact of the programme. Monitoring is done by analysing the reports, field visits, discussion during monthly/quarterly meeting with the stake holders.

Monitor & evaluate disability prevention activities as per Gannt chart (log frame) of DPMR programme. Some of the indicators used are: early case detection, cure rates by cohort, number of new disabilities developed during treatment, changes in EHF score, proportion of cases treated for neuritis / operated etc.

There are other indicators that are qualitative (words) and/or quantitative (numbers) which can indicate the success of the programme at different stages like number of people with disability participating in CBR programme, participating in planning other required interventions for people with disability, number of people utilizing various services, participating in community activities, number of people employed/ economically benefited or by statements like “I drink tea/coffee with my neighbour,” “We walk to the market together,” “Our children play together.”