

## RECONSTRUCTIVE SURGERY SERVICE AS PART OF NLEP: HOW TO STEER IT FROM STARTUP HICCUP TO A WHOLESOME ACT

Prevention of disability in leprosy has become the dominant passion of leprosy control in India. From prevalence-obsession to patient orientation the transition in the character of the programme has been unmistakable and expeditious. This deep departure from the number focus has also resulted in reawakening of interest in persons with leprosy-related disabilities. Prevention of disability has been reintroduced with new identity- Disability prevention and Medical Rehabilitation (DPMR) - and a wholesome new direction. There are three important elements in DPMR: prevention of the occurrence of disability through early diagnosis and treatment of leprosy with MDT and recognition without delay and prompt management of reactions including neuritis; limitation of disability through special measures that promote self care; and correction of deformity through surgical intervention. With the introduction of MDT and improvement in quality of diagnosis the proportion of disability among the new cases has come down drastically. But one should not lose sight of the fact that there are persons still living with residual disabilities due to the disease contracted earlier. Some of them may need surgical interventions.

Many countries have attained the goal of 'elimination of leprosy as a public health problem'. Even in the few others that have not managed to reach that goal, the huge patient load has come down to such low levels as to make vertical leprosy

programmes untenable. Many voluntary organisations devoted to leprosy are now diversifying into other areas as they do not have enough work to keep them fully occupied in leprosy. Integration of leprosy into general health is a reality in many countries. As the care of leprosy affected persons is getting progressively integrated within the general health care

services, it is obvious that the burden of providing specialized tertiary care service for those with complications will essentially be vested with specialised NGO centres, district and Medical College Hospitals.

There is no valid data on disability to know the magnitude of its problem. Moreover, the general experience is that only 10% of the persons with disability may be willing to undergo surgery. The experience in Bihar

where RCS service has been established in two Medical College hospitals is that it requires meticulous planning, intense training, high levels of motivation, constant guidance, involvement of the District Leprosy Office, and financial support to initiate and maintain quality service. Perhaps, as a first step one could think of identifying/establishing at least one tertiary care centre in every state for managing persons with complications (recurrent reactions, complicated ulcers, reconstructive surgery, etc). This could be an NGO or a Government centre.



*Contd. in page 2*

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**RECONSTRUCTIVE SURGERY SERVICE AS PART OF NLEP: HOW TO STEER IT FROM STARTUP HICCUP TO A WHOLESOME ACT - Contd.**

Of the different types of deformities in leprosy, those resulting from muscle paralysis and many of the deformities that result directly from local damage because of the disease process, are quite amenable to surgical correction. However, many of these corrective procedures require special training and expertise as well as other supportive facilities like physiotherapy and occupational therapy. Even some of the other conditions like scar contractures and recurrent ulceration, can be improved by surgical intervention. Because the underlying predisposing cause (anaesthesia over the region) is permanent, corrective surgery alone is not enough and the person has to take other measures to protect the insensitive part from further damage. Plastic procedures help a lot in dealing with chronic ulceration of the foot by way of island or pedicle grafts. There are several septic conditions of the limbs that would require mandatory surgical interventions, but education of persons is of utmost importance in empowering them to take care of their disabilities themselves. In dealing with persons with peripheral neuropathies one must be careful to consider the person as a whole and not focus strictly on the nerve deficit. The attitude and motivation of the person is important to the success of therapy or any surgical intervention. Equally important is the experience and expertise of the surgeon.

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Management of persons with leprosy-related disability requires a specific plan which takes into consideration the estimated number of those requiring specialised care, the training needs of the general health staff, the distribution of referral centres providing the needed service, and the exact mechanism of referral and follow-up. Collection of baseline data on disabilities from the existing records, site mapping of referral centres and allotment of districts to these centres, training of the peripheral health staff in identifying persons with early recognition of nerve function impairment through a symptom guide tool and those leprosy related disabilities, preliminary screening of these persons and matching service interventions to the needs are some of the essential activities that could go into the development of plan. Tendency to start tertiary referral centres and mandating them to do a certain number of reconstructive surgeries without an estimate of the problem and building the referral system should be avoided.

There should be a simultaneous effort to seek support from other agencies in establishing a suitable mechanism for the socioeconomic rehabilitation of the debilitated few. Since POD, rather DPMR, is a highly specialised field, it would be in the fitness of things to form a committee of experts which could be given the responsibility for guiding the programme. There is definitely a role for Reconstructive surgery in leprosy. But one should be careful in giving it the right importance, neither more nor less. Service should be titred to the felt needs of the affected, not the perceived needs of the provider.

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The logo was designed to represent the structure of the Federation and its objective, to which every member of ILEP has committed itself. The five petals stand for the five continents.

# Meeting of NLEP Core Partners

Organised by GOI at New Delhi on 28.02.08

*Participants:* CLD-GOI, WHO, ILEP, Alert India, IDEA, NOVARTIS, SILF

*Highlights of the minutes:*

Main focus now was on strengthening integration, promoting DPMR through the integrated set up and establish effective mechanism for promoting public education and behavioural change through collaboration with partners. It was suggested that all partners should pool their efforts and resources to formulate strategy and implement the important component of leprosy control.

- Concurrent evaluation of IEC will be implemented from the year 2008-09.
- Four video spots and four radio jingles produced by TLM Media Centre are being used.
- GOI has plans to provide RCS services in 16 Govt. Medical Colleges/PMR centres. It was reported that 5 of them had started functioning. Equipment had been provided to the remaining centres including training of Physio-Technician.

- Total of 1748 RCS were done in 2007.
- Networking with dermatologist has been started in two meetings held at Delhi and Mumbai. These groups suggested training need of dermatologists and private practitioners.
- ILEP had placed state coordinators in 15 states and need to do the same in other states/UT.
- ILEP helped in developing website for NLEP India which would be hosted shortly. [www.nlep.nic.in](http://www.nlep.nic.in)
- GIS mapping facility is being upgraded with ILEP advice.
- Group of experts on DPMR will be formed to develop roadmap for DPMR plan implementation and to get the same executed on a time bound manner with support of all the partners. NOVARTIS India has agreed to provide facilities to organise the meetings.
- Expert group will be formed to work on modified IEC strategy under NLEP.

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## Baba Amte – an end of Saga of Service to Humanity

Baba Amte, a great humanitarian and the legendary social worker in the field of leprosy passed away on 9<sup>th</sup> February 08 at 4.15 a.m. at 'Anandwan' (in Warora, Maharashtra), the 'Forest of Joy', a place created by Baba to replace pain of leprosy affected persons with the joy of living happily.

Muralidhar Devidas Amte, fondly called Baba by his parents, was born on 26<sup>th</sup> December, 1914 at Hinganghat in Wardha district. He completed his Bachelor of Arts in 1934 and Bachelor of Law in 1936 from Nagpur University. The transformation of the son of a wealthy landowner into a missionary aiming to provide relief to leprosy patients came on a rainy evening. While heading home near Warora, Baba saw Tulshiram, an advanced case of leprosy with maggots by the side of a road. A horrified Baba ran home but his agitated mind brought him back to Tulshiram, whom Baba fed and erected a shed to protect him from rain. Tulshiram died but not without arousing the flame of 'Fellowship of Pain' in Baba.

Baba then extensively read about leprosy and also completed a certificate course in leprosy in 1950 from the School of Tropical Medicine, Calcutta. After founding Maharogi Sewa Samiti in 1951 at Warora, Baba started training leprosy patients in nearby villages and formed weekly clinics. His work grew with his zeal and enthusiasm for service and now Anandwan is known the world over.



In 1964, Baba developed Cervical Spondylitis with progressive degeneration of spine and surgeons at Wimbledon performed Laminectomy and Cervical Fusion following which he was advised not to sit. Since then Baba never sat down.

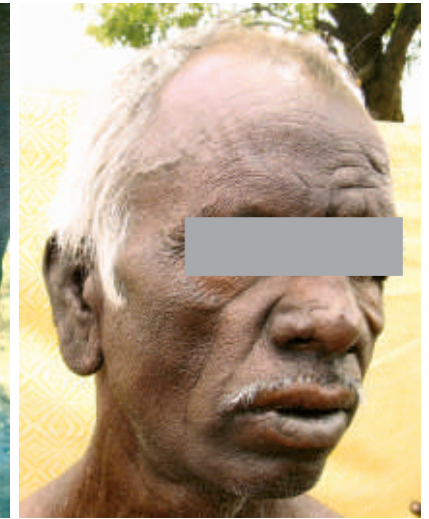
Despite all these physical constraints, Baba continued to work not only for leprosy but also to arouse youth to a meaningful life through Youth Camps at Somnath. To propagate the spirit of National Integration, Baba undertook the Khatu India movement from Kanya Kumari to Kashmir during 24<sup>th</sup> December 1985 to 10<sup>th</sup> April 1986 covering a distance of 5042 Km in 107 days.

In recognition of his work, Baba was conferred with several National and International Awards. Notable among them are Padma Shree in 1971, Damien Dutton Award in 1983, Magsaysay Award in 1985, Padma Vibhushan in 1986, UN Human Rights Award in 1988, and International Gandhi Peace Prize in 1999 by Govt. of India

In August 2007, Baba was diagnosed as having blood cancer and the doctors at Nagpur predicted his survival for six months. The prediction came true and in his passing away the Nation lost a true Gandhian and a legendary humanist.

V. Prabhakara Rao  
Director, GMLF, Wardha

## How many is too many?



Mr. Penchillanna (name changed) aged 45 years from a small village in Anantpur district had small swellings over the extremities since 3 to 4 years. He consulted several General Medical Practitioners including RMP doctors at nearby town. He was treated for skin disease for which he had spent Rs.4000.

One of his neighbours directed him to a skin specialist in Anantapur. The dermatologist diagnosed leprosy and referred him to Government Hospital for free MDT. Non Medical Supervisor (NMS) at the PHC during verification process enquired about similar illness among other family members. To his surprise the NMS detected three more members from his family having MB leprosy (Father-65 years, wife-40 years and son-21 years). None of them sought medical advice because they had thought that it was a self limiting disease. All these individuals were counselled and MDT was initiated.

These were illiterate labourers. The Health Worker post was lying vacant for many years. This small village had a population of about 1000. People may not be aware of leprosy and the services available at PHC. General Medical Practitioners were not able to diagnose leprosy.

Cluster effect is observed in leprosy endemic region. Focal epidemic is more likely to occur as observed in this village when incidence of leprosy declines. Also one could expect more new cases of leprosy among contacts. There is no need to panic. At the same time suitable modifications need to be done to the existing strategy to strengthen the health system. Such incidences should be documented and focal health campaigns could be organised to detect other existing leprosy patients at an early stage. Such campaigns would also increase the awareness on leprosy care services among the people and improve the confidence in the health system as a whole.



# Operational guidelines for Leprosy control activities

(World Health Organisation SEA/GLP/2006.2)

Contd. from October 2007 Issue

## 4.3 How and why are leprosy cases classified?

Leprosy is a very variable disease, affecting different people in different ways, according to their immune response. Those at one end of the spectrum, with a high level of immunity harbour a low number of bacilli and are termed paucibacillary or PB patients. Those with many bacilli in the body are referred to as multibacillary or MB cases. MB patients need more intensive treatment than PB patients – they need three rather than two antileprosy drugs, taken for a longer period. Classification in routine programmes is therefore a practical step which divides leprosy patients into two treatment groups.

A simple clinical rule is now used to divide patients into these two groups. The number of individual skin lesions is counted (this means that the whole body must be examined, including more private parts, to make an accurate count):

PB cases have up to five skin lesions in total.

MB cases have six or more skin lesions.

If a skin smear is done and is positive, the patient must be classified as MB, whatever the number of skin lesions. If the smear is negative, the classification is decided by the number of skin lesions. Other factors like nerve involvement may be considered at the referral level for classifying the disease. The risk of nerve damage is greater in MB patients. Therefore, classification is helpful in assessing future risk (section 6.1) and in guiding patient care.

## 4.4 What should be done when leprosy is suspected but the diagnosis is uncertain?

Generally, the most difficult cases to diagnose are people who present with one or two pale patches, without loss of sensation or other signs of leprosy. In these cases, there are three options:

- refer: know where to refer cases that are difficult to diagnose; discuss cases with colleagues who have experience of managing leprosy (section 2)
- consider the possibility of another skin disease and treat appropriately
- wait 3 – 6 months and review the skin lesions again; if it really is leprosy, loss of sensation may now be found and MDT can be started.

If there is no loss of sensation in the skin lesions and no enlarged nerves, but there are suspicious signs, such as nodules or swellings on the face or earlobes, or infiltration of the skin, it is important to try and get a skin smear test done. In these circumstances a positive skin smear confirms the

diagnosis of leprosy, while a negative result (in the absence of other cardinal signs) would, in practice, rule out leprosy. An alternative diagnosis should then be considered.

In PB cases (in whom the skin smear will be negative); loss of sensation is almost always detected. In MB cases, normal sensation may still be present in a proportion of cases, but these patients often have one or more enlarged nerves and a positive skin smear. Signs of nerve involvement (enlarged nerves or signs of nerve damage, such as numbness, tingling or weakness affecting hands or feet) may occasionally occur without any obvious skin lesions. In such cases, known as neural leprosy, the disease can only be diagnosed by someone with experience of assessing nerve involvement in leprosy.

## 4.5 How can the accuracy of leprosy diagnosis be ensured?

The diagnosis of leprosy is straightforward in the majority of cases; these cases should be diagnosed in clinics as near as possible to the patients' homes and treatment with MDT should be started immediately or at least within a few days.

In some cases, the diagnosis of leprosy is more difficult. As stated above (section 4.4), the most difficult cases are early PB cases with one or two pale patches on the skin; another difficult group (especially if skin smears are not available) are early MB cases with very vague skin patches and no loss of sensation.

The following steps will help to ensure the accuracy of leprosy diagnosis:

- (1) adherence to the criteria for case definition (section 4.2)
- (2) good training about leprosy diagnosis for health workers (section 9.4)
- (3) regular and effective supervision, with on-the-job training (section 9.1)
- (4) clear lines of referral for suspect cases, when the diagnosis is uncertain (section 2)
- (5) availability of appropriate training and reference materials (section 10.1).

The quality of diagnosis should be monitored as part of regular technical supervision. If there are indications of substantial over-diagnosis, a validation exercise on a representative sample of cases can be conducted (section 8.3), in order to understand the magnitude of the problem.

Contd. in page 6

## 4.6 How is disability assessed and recorded in leprosy?

Disability is a broad term covering any impairment, activity limitation or participation restriction affecting a person.

### Disability Grading in leprosy

Every new case of leprosy must be assigned a Disability Grade, which shows the condition of the patient at diagnosis. The grade is either 0, 1 or 2. Each eye, each hand and each foot is given its own grade, so the person actually has six grades, but the highest grade given is used as the Disability Grade for that patient.

Grade 0 means no disability found.

Grade 1 means that loss of sensation has been noted in the hand or foot (the eyes are not given a grade of 1). Loss of sensation in the hand or foot means that one of the main peripheral nerve trunks has been damaged by leprosy and this is more common later in the disease than at diagnosis. It should not be confused with the loss of sensation in a skin patch, which is caused by local damage to the small nerves in the skin, and not to the main peripheral nerve trunks.

People with loss of sensation (grade 1 disability) on the soles of their feet, but no other abnormality, are at significant risk for developing plantar ulcers. People with grade 1 disability who routinely use appropriate shoes are protected from ulceration and have far fewer long-term problems with their feet. Therefore, measuring and recording grade 1 disability is an essential step in preventing damage to the feet of people affected by leprosy – it is therefore a key component of quality leprosy services.

Grade 2 means that visible damage or disability is noted.

For the eyes, this includes the inability to close the eye fully or obvious redness of the eye (in leprosy, this is typically caused by either a corneal ulcer or by uveitis); visual impairment or blindness also gives a disability grade of 2.

For the hands and feet, visible damage includes wounds and ulcers, as well as deformity due to muscle weakness, such as a foot drop, or a claw hand. Loss of tissue, such as the loss or partial reabsorption of fingers or toes is a late sign in leprosy, but it also gives a disability grade of 2 for that hand or foot.

### Peripheral level

- (1) Check for grade 1 disability by asking the patient for the presence of loss of sensation in the hands and the feet
- (2) Look for the signs of visible disability (grade 2):
  - Wounds or ulcers on the hands or feet
  - Marked redness of the eye
  - Muscle weakness – causing:
    - Incomplete eye closure
    - A claw hand
    - A drop foot
- (3) Loss of tissue, such as fingers or toes shortened or missing

Any patient showing the above signs should be referred to a referral unit where POD services are being provided. Visible disability should be recorded before referral.

### Referral level

Examine carefully for any disability, recording the full results of the examination in the Patient Record Card for future reference:

#### Eyes

- check the Visual Acuity of each eye separately, using a Snellen chart; if no chart is available, ask the person to count fingers at 6 metres; if the person cannot read the top line of the chart, or count fingers at 6 metres, they are visually impaired and have grade 2 disability in that eye.
- look for an inability to close one or both eyes (lagophthalmos) and check for normal strength of eye closure
- look for any redness of the eye

#### Sensation in hands and feet

Check the sensation in the palms of the hands and the soles of the feet, using a ballpoint pen:

- Explain the test to the patient
- Ask them to close or cover their eyes
- Touch the skin very lightly with the ballpoint
- Ask the patient to point to the place you touched
- Test a minimum of four points on each hand and foot
- Note any areas where the pen is not felt

NB: In the palm of the hand, the side with the little finger is supplied by the ulnar nerve. The part with the thumb, index and middle fingers is supplied by the median nerve. The sole of the foot is supplied by the posterior tibial nerve.

To be Contd.

# Different Presentations of Leprosy



Plaques ▶

## Different Presentations of Leprosy



Plaque in reaction



Ulnar abscess



Superficial Peroneal Nerve



Ulnar abscess

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