

## Consensus Statement on Prevention of Disability

This Statement is the outcome of a Consensus Development Conference on the Prevention of Disability (POD), co-sponsored by American Leprosy Missions (ALM), the World Health Organisation (WHO) and the International Federation of Anti-Leprosy Associations (ILEP), and held at the Waterfront Hotel in Cebu City, Philippines, from Sept. 13<sup>th</sup>-16<sup>th</sup>, 2006.

Participants (from about 30 countries) included WHO staff, national programme managers and a wide range of therapists and practitioners. The contribution of people affected by leprosy enhanced both the content and validity of the resulting consensus. The visible evidence of their empowerment and enthusiasm was an encouragement to all.

### Introduction

Interventions to prevent disability have been undertaken in many leprosy programs for decades. The scientific basis for such interventions can be traced back to the work of Prof Paul Brand in south India in the 1950s, when he realized that hands and feet, rendered insensitive from nerve damage caused by leprosy, were easily damaged by injury incurred while performing everyday activities. He recognized that by modifying the way tasks are performed, the chances of being injured or developing further damage could be reduced. He understood that the role of those affected is vital – they need to understand the principles of prevention and find the motivation to apply them in everyday life.

In the context of the International Classification of Functioning, Disability and Health (ICF), disability is defined as "*an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and the individual's contextual factors (environmental and personal factors)*". While the impact of prevention of disability (POD) could therefore be assessed in terms of impairments, activity and participation, the main focus of interventions has been on preventing impairments, i.e., the physical level. The ICF defines 'impairment' as a "*problem in body function or structure such as a significant deviation or loss.*" POD may therefore be defined as 'a concept comprising all activities at individual, community and programme level aimed at preventing impairments, activity limitations and participation restrictions'. It is widely acknowledged that personal attitudes and circumstances, combined with environmental factors can either precipitate, or help prevent disability. They are often targets for intervention themselves, as in the case of poor self-esteem or negative community attitudes, or may be the subject of preventive education, as with high-risk work conditions.

Disability preventing measures specific for other chronic conditions in leprosy-endemic countries, including lymphatic filariasis, diabetes and Buruli ulcer, have generally been developed more recently. They use very similar strategies and depend in a similar way on the motivation and participation of those affected. Combining strategies and interventions for POD for people affected by a range of related conditions may decrease stigma, be more cost-effective and improve sustainability.

The statements in this document reflect a consensus of the participants based on evidence or best practice. Implementation of recommendations should take into account existing national program policies on POD and also prevailing socio-cultural factors in a given country or area.

The challenge now is to make POD part of routine case management for chronically disabling conditions. The 1990s saw coverage with MDT for leprosy advance from well under 50% to 100%. If POD is to be universally implemented, there must be agreement on the essential strategies and interventions.

### *Objectives of the Conference*

- To discuss POD activities in the context of leprosy and other chronic diseases, such as Buruli ulcer, lymphatic filariasis and diabetes.
- To agree on basic definitions.
- To agree on a basic, evidence-based approach to POD that is part of routine case management.
- To agree on the elements of home-based self-care.
- To agree on methods of monitoring and reporting POD activities.
- To agree on priorities for further clinical and operational research in POD.

### *Questions to be answered*

1. How can we make sure that people with reactions and neuritis are treated as early as possible?
2. What simple approaches can be developed to promote home-based self-care?
3. What are the pre-requisites for an effective footwear program?
4. For effective POD, what are the essential recording and reporting requirements?
5. What are the priorities for research in POD?

### **Consensus Statement**

#### **Q1. How can we make sure that people with reactions and neuritis are treated as early as possible?**

Reactions and neuritis occur in about 10 – 30% of leprosy cases. Steroids are 50 – 70% effective, but are ineffective if more than 6 months have elapsed since the most recent acute episode. For this reason, it is important that treatment is started as soon as possible. Best practice suggests that the starting dose of steroids should be based on body weight. However, the starting dose is less important for efficacy than the length of treatment. Longer regimens give better results. There is insufficient evidence to recommend prophylaxis with steroids at the start of MDT. Although the surgical treatment of neuritis, in addition to the use of steroids, is undertaken in some centres, there is currently no firm evidence of cost-effectiveness, compared with steroids alone.

Patient education and awareness are important for early self-reporting of reactions and neuritis. There are examples of good practice in this area from both Brazil and Myanmar. Structured education is needed at both diagnosis and at treatment completion. Regular nerve function assessment is the most effective intervention in the field for the early detection of neuritis, and depends on careful training of the health staff. Where regular nerve function assessment cannot be carried out routinely on all patients, it is helpful to identify high risk patients, for closer surveillance. These include patients with pre-existing nerve function impairment or a current reaction, MB patients and post partum women.

Difficulties commonly experienced in the field include the high work-load of the health worker, limited access to steroid treatment, and poor uptake even when treatment is available. Weak referral systems mean that few eligible patients benefit. The availability of steroids and loose clofazimine is sometimes poor. More stringent supervision will help to identify and address these problems.

Best practice occurs when health workers have appropriate training and are aware of the importance of treating neuritis; a well organized referral system is essential, as many cases cannot be managed in the peripheral health units.

Responses to treatment should be monitored and assessed, including checking for drug side effects.

For further details of managing reactions and neuritis, refer to the WHO Operational Guidelines (2006) and the ILEP Learning Guide Two.

## **Conclusion**

Reasonably effective treatment for reactions and neuritis exists and the current priority is to expand coverage so that all patients have access to this treatment. Patients themselves should be made aware of the problem through structured health education at diagnosis and on treatment completion, to promote self-reporting. During regular follow-up, asking key questions can help to identify patients with symptoms suggestive of reactions or neuritis. Those at higher risk should have monthly nerve function assessments. An effective referral system should be available for patients who have complaints indicative of neuritis or have demonstrable new nerve function impairment.

## **Q2. What simple approaches can be developed to promote home-based self-care?**

Self-care is a major component of the management of any chronic condition (ICCC Reference). In self-care the affected person takes control of the management of their condition. They are supported by a team of health and social care workers, and by community partners including their families. Leprosy is a chronic condition for which this self-care approach has been developed and documented (WHO Operational Guideline Section 6.4 and ILEP Learning Guide Four). However, its implementation so far is limited. In the self-care approach, the person affected is no longer dependent on health professionals; the role of the team of health workers is rather to support the development of self-care. This approach is essential to ensure sustainability.

The community has a supportive function in self-care. The community includes the family, those affected by leprosy and those affected by other chronic diseases, as well as the wider community. The development and implementation of self-care in leprosy can be integrated into self-care approaches for other disabling health problems to promote sustainability and stigma reduction. The development of self-care can be facilitated either by the formation of groups or by the training of counsellors. Both options should be available to meet differing local needs. Groups can also function in other ways, such as by assisting with referrals, footwear, or with self-help activities. Environmental barriers to self-care need to be identified and addressed.

Self-care should be developed within existing local structures and resources to achieve both sustainability and population coverage. Locally identified individuals, who take on responsibility as facilitators, will require both facilitation and counselling skills. Careful consideration should be given to the use of external funding as this may affect long term sustainability. It is important that access to referral services, such as specialized footwear, eye care, counselling or surgery, is available to support self-care, with appropriate follow-up.

Self-care in the prevention of disability in leprosy is one of the main components of the Global Strategy for Leprosy (WHO Operational Guide 2006). For further details see ILEP Learning Guide Four, 2006.

## **Conclusion**

Self-care is a key strategy in the prevention of disabilities and is a vital component of leprosy control, but the extent of its coverage is, in general, very limited. Full participation by those affected is essential in any self-care programme. Development of facilitation and counselling skills within existing local structures is necessary to achieve adequate coverage and sustainability of self-care in the prevention of disability.

### **Q3. What are the pre-requisites for an effective footwear program?**

Bio-mechanical evidence supports the effectiveness of soft insoles in reducing peak pressure, both in specially designed shoes and also in commercially available shoes. Soft insoles (e.g. micro-cellular rubber (MCR) and ethyl vinyl acetate (EVA)) reduce peak pressure in the foot and assist in preventing plantar wounds. The entry point for footwear requirement is loss of sensation on the sole of the foot (Grade 1 disability); it is therefore important that this is measured and recorded. Waiting for the appearance of wounds before recommending footwear is too late. Disability Grades are fully described in the WHO Operational Guidelines and in the ILEP Learning Guide One.

There has been a definite shift from using custom-made protective footwear made in special workshops to commercially available footwear for normally shaped feet with plantar anaesthesia. Developments in modern footwear technology mean that many types of commercially available footwear (e.g. casual sandals and running shoes) incorporate EVA insoles. This footwear is more readily available (in open markets) and more acceptable to people as it complies with the social and cultural norms of each country. People should be assisted in their choice of footwear, so that they choose appropriately (WHO Operational Guidelines p.35).

As well as encouraging the use of appropriate commercially available footwear whenever possible, the development of specialized services, including the provision of modified insoles, is encouraged for people unable to find the right footwear in the marketplace. People with anaesthesia who have bought their own shoes can then be given orthotic insoles by the footwear programme, as is increasingly happening in Brazil. For this to work in practice there is need for a strong referral link with the footwear programme, with clear referral criteria. These specialized services are opportunities for stronger links with other disabilities.

Small footwear projects can be successful within communities, by utilizing local skills, such as cobblers and shoemakers, who have received appropriate training. However, it is of note that in several countries, the National Programmes have moved the emphasis onto footwear provision. This is a positive development and has increased coverage of protective footwear, improving accessibility to appropriate footwear and orthoses. Social and cultural norms should be considered by the programmes when they are choosing footwear.

Footwear is an integral part of self care and rehabilitation programmes. Empowering people to take care of themselves, including taking responsibility for their own footwear is important.

Sustainability is an important issue and must be considered in footwear programmes. Different funding models are appropriate in different contexts. Information systems need to be developed for the planning, implementation and monitoring of footwear programmes.

### **Conclusion**

The routine use of appropriate footwear is one of the most important POD interventions in leprosy, as loss of sensation in the sole of the foot and plantar ulceration are so common. Anyone with Grade 1 disability should be helped to obtain such footwear, whether this is by purchasing appropriate shoes in the market or through an organized programme.

#### **Q4. For effective POD, what are the essential recording and reporting requirements?**

The assessment of a new patient, or someone who has already started or even completed treatment, aims to identify potential problems as quickly and as easily as possible. Some of the measurements or findings of this assessment must be recorded for two reasons: firstly, by referring to previous records, any change or deterioration in the clinical condition can be identified and appropriate treatment can be started; secondly, certain measurements that have been recorded can be compiled into various indicators, which will be reported and used to manage and evaluate the programme, and secure the necessary ongoing resources.

The amount of information that can be gathered varies greatly. In some places, enough data is collected to complete the Impairment Summary Form (ISF), which allows a high level of clinical monitoring and reporting. In many places at present, however, very little is recorded – often just the presence of visible deformity (Grade 2 disability) in new cases, which is inadequate, as it does not identify those with loss of sensation and therefore at risk of further disability. Loss of sensation in the sole of the foot (Grade 1 disability) has already been mentioned as an essential measurement for proper case management, namely, a decision about footwear. Grade 2 disability alone is a very poor indicator of change or deterioration, so cannot serve as a tool to monitor POD activities.

The POD programme is planned with an emphasis on home based and community based self care. Self care practices are primarily about wound avoidance, prevention of contractures and preservation of vision. Visual acuity and the absence of wounds/ulcers are therefore essential indicators to assess the efficacy of self care practices, and to monitor the programme at community level.

Recording and reporting forms should be prepared in consultation with field staff, who are responsible for their maintenance. Participation of local field staff is vital in making the reporting system more context specific. The reporting system should also include referral for complicated cases. The forms should be simple and facilitate decision making at different levels; they should also facilitate referral to general rehabilitation services. The system should also include mechanisms for giving feed back about the patient to the peripheral health worker or care giver, to facilitate follow-up.

The recording and reporting system should serve the purpose of the immediate user apart from being a source of information on POD activities in the field. Caution should be exercised while defining the formats of records. They should be able to generate periodic reports to monitor the POD programme. Ideally, recording of patient clinical status should be done on a monthly basis, while reporting should be on a quarterly or half-yearly basis.

#### **Conclusion**

A simple recording and reporting system is vital for the management of prevention of disability. Data collection should be dictated by its use for both clinical and managerial purposes. Measuring and recording Grade 1 disability is necessary for defining the need for protective footwear. Visual acuity and the absence of wounds/ulcers are key indicators for evaluating the efficacy of POD activities.

#### **Q5. What are the priorities for research in POD?**

The priority research questions for POD emerged from the presentations and discussions during the process of the Consensus Development Conference. The fundamental research theme was how to achieve 100% coverage globally of self-care and footwear in order to prevent disabilities due to leprosy. MDT for leprosy was first recommended in 1982 but it took more than a decade to achieve 100% coverage through adaptations and simplifications, and engagement with the basic health services in each country.

A multidisciplinary and collaborative approach will be needed to address this research challenge and to develop innovative approaches to identify and overcome the barriers that prevent individuals adopting self-care in different settings and contexts. Research will also be needed to identify individual, community and system barriers as well as to test novel and cost-effective methods to promote self-care and the use of appropriate footwear. Research should also assess the effectiveness of individual components of POD interventions. The multidisciplinary programme will include research disciplines such as psychology, sociology, operational research, health systems research, behavioural science, economics as well as biomedical and biomechanical methods to achieve the aims of the research. Active participation of field staff, the community and those affected by leprosy must be ensured in the research processes and development of the solutions.

Collaboration with academic experts from the generic field of self-care will be required. The findings will have application to the development and implementation of self-care in the increasing burden of chronic diseases in developing countries such as lymphatic filariasis, diabetes, and other disabling chronic diseases. The number of beneficiaries of this research within the leprosy field will exceed 3 million across Asia, Africa and the Americas, and the benefits will include improved quality of life, economic productivity and poverty alleviation.

The second research theme to emerge from the Conference was the need to develop systems to achieve 100% treatment of reactions and nerve damage in leprosy. This will require developments in methods of detection of reactions, effective referral systems and effective therapeutic interventions to reduce the nerve function impairments that result from reactions. A re-focusing of current research in reactions will be required to achieve this research goal.

#### **Conclusion**

Research to address issues of coverage and access should now be the priority, firstly in the area of self-care and footwear provision, and secondly in the area of treatment for reactions and neuritis. Research aimed at improving the efficacy of specific POD interventions is still needed, but it should be seen as a lower priority.

## **Executive Summary**

The Consensus Development Conference brought together 100 individuals from 30 countries with an interest in the prevention of disability (POD) in chronic disabling disorders, in particular leprosy, lymphatic filariasis, Buruli ulcer and diabetes. Participants included people affected by leprosy, WHO and ILEP staff, national programme managers, experts and practitioners.

Five questions were discussed, with the following conclusions:

### **How can we make sure that people with reactions and neuritis are treated as early as possible?**

Reasonably effective treatment for reactions and neuritis exists and the current priority is to expand coverage so that all patients have access to this treatment. Patients themselves should be made aware of the problem through structured health education at diagnosis and on treatment completion, to promote self-reporting. During regular follow-up, asking key questions can help to identify patients with symptoms suggestive of reactions or neuritis. Those at higher risk should have monthly nerve function assessments. An effective referral system should be available for patients who have complaints indicative of neuritis or have demonstrable new nerve function impairment.

### **What simple approaches can be developed to promote home-based self-care?**

Self-care is a key strategy in the prevention of disabilities and is a vital component of leprosy control, but the extent of its coverage is, in general, very limited. Full participation by those affected is essential in any self-care programme. Development of facilitation and counselling skills within existing local structures is necessary to achieve adequate coverage and sustainability of self-care in the prevention of disability.

### **What are the pre-requisites for an effective footwear program?**

The routine use of appropriate footwear is one of the most important POD interventions in leprosy, as loss of sensation in the sole of the foot and plantar ulceration are so common. Anyone with Grade 1 disability should be helped to obtain such footwear, whether this is by purchasing appropriate shoes in the market or through an organized programme.

### **For effective POD, what are the essential recording and reporting requirements?**

A simple recording and reporting system is vital for the management of prevention of disability. Data collection should be dictated by its use for both clinical and managerial purposes. Measuring and recording Grade 1 disability is necessary for defining the need for protective footwear. Visual acuity and the absence of wounds/ulcers are key indicators for evaluating the efficacy of POD activities.

### **What are the priorities for research in POD?**

Research to address issues of coverage and access should now be the priority, firstly in the area of self-care and footwear provision, and secondly in the area of treatment for reactions and neuritis. Research aimed at improving the efficacy of specific POD interventions is still needed, but it should be seen as a lower priority.

*Panel Members:*

Valsa Augustine, Pierre Brantus, Hugh Cross, Jannine Ebenso, Zhang Goucheng, Ernst Hisch, Ranganadh Rao, Paul Saunderson (secretary), Cairns Smith (chair), Doug Soutar, Wim van Brakel

*State-of-the-art lecturers:*

Valsa Augustine, Hugh Cross, Jannine Ebenso, Diana Lockwood, Gift Norman, Wim van Brakel

*Planning Committee:*

Hugh Cross, Jannine Ebenso, Ernst Hisch, Vijay Pannikar, Paul Saunderson (chair), Doug Soutar

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