

# SELF CARE GROUPS In Indonesia

A MANUAL FOR LEPROSY  
CONTROL PROGRAMMES



Directorate General of  
Disease Control and  
Environmental Health



## FOREWORD

The vision for the elimination of leprosy in Indonesia, which seeks to liberate the people from the economical and social burden brought upon by leprosy, includes the mission to heal people affected by the disease, to increase their quality of life by proper treatment, medical and social rehabilitation, and eradicate the stigma in society. Self care for people affected by leprosy with permanent disabilities is an important part of increasing the quality of life. Health workers need to advise that permanent disabilities cannot be cured but further deterioration can be prevented. Sometimes explanations by health workers are felt to be too instructive and theoretical leading to reluctance to follow them.

When explanations are given by people who are also affected by leprosy and who have been successful in managing their disabilities the result may be very different, as patients see directly the improvement, as a consequence of practicing self care in the right way. Such an exchange of experience between people affected by leprosy can be achieved if they are part of a group conducting regular meetings. The establishing of Self Care Groups is therefore of great importance. To guarantee good performance of a group, active participation of its members and of the surrounding community are required. The health worker only facilitates and guides the group. Hence, this manual about the formation and implementation of Self Care Groups is of much value.

I express my thanks to the writers who developed this manual about Self Care Groups for people affected by leprosy. I hope it will be of benefit in the field, in order to assure that the mission to increase the quality of life for people affected by leprosy in Indonesia, as expressed in the program for the elimination of leprosy, is not just a slogan.

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Director for Directly Communicable Diseases

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## INTRODUCTION

In spite of great achievements towards the elimination of leprosy, disabilities and socio-economic problems are still a burden for many people affected by leprosy. One way to approach some of these problems is the formation of **self-care groups**, which has been successfully carried out in different countries.

**A self-care group is a group of leprosy patients and/or former leprosy patients, who come together with the aim of supporting each other primarily in prevention and reduction of disabilities, and in finding solutions for problems they face as a result of leprosy.**

A more positive attitude to life is the outcome reported in many places, like responsibility for managing their own wounds and supplying their own wound healing materials, as well as increased confidence participating in society, restored dignity and self-respect and a sense of belonging within the community.

The concept of self-care groups originates from ALERT, Ethiopia, in 1995. By December 1999, a total of 72 groups had been established in Ethiopia. The first self-care groups in Indonesia started in West Java in 2000.

Man is a social creature, living in groups and depending on each other. In Indonesia, particularly in villages, social life is characterized by strong relationships and mutual help in all social activities, known by the word *gotong royong*. People affected by leprosy are a part of this way of life. Self-care groups are therefore a human and natural approach, bringing people together to discuss their problems according to their usual habits.

To study the process of self-care groups in more depth, two groups were formed in March 2003 in the district of Jeneponto in South Sulawesi. The groups were guided by the provincial and district leprosy and tuberculosis control team and Mrs Kerstin Beise, physiotherapist. At the same time, four self-care groups were established in North Sulawesi by the local team. Based on the observations and experiences with these groups this manual has been developed.

These are **guidelines** for those who want to establish self-care groups in their own area; it gives information and advice. A demonstration film on CD-Rom is added to give a practical example on how a SCG can be conducted.

People are different everywhere, and no two self-care groups will be the same. Some advice might be useful for one group but it may not apply to the conditions in another area. We urge the leprosy control teams to be flexible and creative when establishing self-care groups. Think globally – act locally!



## **1. Concept**

### **I. DEFINITION**

A self-care group is a group of people affected by leprosy trying to solve their problems due to leprosy.

### **II. OBJECTIVES**

**The general objective** of a SCG is to prevent or reduce disabilities in their members.

**Specific objectives** can be:

- To enable members to support each other in finding solutions for their own (physical, psychological, social or economic) problems related to leprosy.
- To encourage group members to use locally available materials for their treatment.
- To monitor the participants efficiently and effectively.
- To refer promptly for special care (e.g. reconstructive surgery, rehabilitation).

**Additional Objectives** can be:

- To increase the self-esteem and the self-confidence of the members in order to be able to participate more actively in society.
- To decrease leprophobia among the participants, their families, and involved staff.



### III. PRINCIPLES

The **main principle** of a SCG is that the members participate in all aspects of the group. They should be encouraged to decide about organisational matters within the group or topics to be discussed. Ideally the facilitator of the group only *guides* the activities during a meeting.

In a SCG it is the members who prevent and reduce disabilities, not the facilitator. The members are supposed to practise self-care daily at home by using local materials. They should use the group meetings to control their improvements and to exchange experiences.

### IV. ADVANTAGES OF SELF-CARE GROUPS

Coming together in a group to approach similar problems brings many **advantages**:

The understanding of the members about self-care will increase, because special time is reserved for explanations, discussions and practice. Better understanding will then contribute to independent and confident management of disabilities by each member at home. The peer pressure within the group helps them to be serious about practising self-care at home.

Difficulties can be solved directly, problems can be discussed together and experiences exchanged. Sharing problems may lessen the burden of the individual member.

In the relaxed atmosphere of a group, asking and talking will be easier than it might be during the limited consultation time with the juru in the HC. For example, further ideas concerning socio-economic issues can be developed.

Helping and supporting each other gives people a good feeling about themselves, and increases self-confidence.

The burden of wound healing for the juru is reduced in terms of work, funds and time.



## 2. Task Descriptions

The following describes the responsibilities of health staff at different levels in the process of establishing SCGs. Other ways are possible, according to the local conditions, and at the end of this chapter two examples are given of groups, which have been formed in their own ways.

The process of establishing and running a SCG normally includes several steps, involving different levels and staff. These may be as follows:

- Initiating / proposing a group by any motivated health staff, either at the HC, district or provincial level
- Approval of the group(s) at provincial level
- Starting up the group by the district wasor and the juru
- Facilitating the group by the juru
- Organising internal matters by the group leader and the members, if necessary with the help of the juru

### I. PROVINCE

#### ➤ Initiative / Approval

The province team may either be the initiator of a SCG, or decides about approval of proposals from others to establish a SCG.

The provincial team should inform the districts about the possibility of establishing SCGs, and encouraging them to take the initiative. (*See below: 'Follow up'*)

If the provincial team selects districts suitable for a SCG, the criteria described under '*Organisation of a SCG – Conditions*' (p.16) should be considered. One of the most important criteria is a **motivated** district wasor, as he/she will have major tasks in supervising and supporting the facilitator.

#### ➤ Advocacy and Start-Up Talks

Advocacy and start-up talks with the officials of the district and the district wasor can be conducted during regular supervision by the provincial team.

➤ Supervision

In the beginning, the provincial wasor (or qualified others) should visit the SCGs, quarterly if possible, maybe more often, depending on the situation.

During supervisions visits, attention should be paid to the participatory way of conducting meetings.

➤ Follow up

The quarterly wasor-meetings should be used for discussion and dissemination of information about the SCGs in the various districts.

## **II. DISTRICT**

The district health department should support the activities of SCGs.

The district wasor is the supervisor of the SCGs. His/her tasks are as follows:

➤ Selection of health centres

The district wasor selects the HC in which a SCG should be established, or a juru proposes this to the wasor.

The criteria a HC should fulfil to establish a SCG are described under '*Organisation of a SCG – Conditions*' (p.16).

It is essential that the juru is motivated, has good communication and facilitation skills.

➤ Advocacy and start-up talks

Advocacy and start-up talks with the juru and the head of the HC can be conducted during regular supervision by the district wasor.

➤ Supervision

The district wasor is responsible for the overall monitoring and should initially supervise the group meetings monthly for at least the first 3 months, then quarterly to give support and 'on the job training' to the facilitator.

The wasor should support the juru in his/her tasks of organising the SCG and teaching self-care measures to the members.

See: '*Monitoring and Evaluation*' (p.35)

### **III. HEALTH CENTRE / FACILITATOR**

The head of the HC should support the activities of a SCG.

The juru of the HC is the facilitator of the SCG. He/she attends every meeting, as long as the group needs this. His/her tasks can be summarized as follows:

He/she

- selects the group members  
(see: 'Selection of Members, p.17')
- prepares the meetings  
(see: 'Preparing a Meeting', p.22)
- introduces the aims of a SCG to the members  
(see: 'Introduction of the Aims of a SCG to the members', p.32)
- leads discussions with the members about organisational issues like meeting place, group leader, frequency of meetings  
(see under 'Organisation of a SCG', p.16)
- teaches / demonstrates / explains about POD / self-care  
(see Annex 3: 'How to Teach the Main Self-Care Activities', p.50)
- motivates, directs or initiates discussion, tries to create group dynamics where all members are actively involved in the activities  
(see: 'How to Facilitate a Group – Some Guidelines', p.33)
- guides the group leader in becoming acquainted with his/her tasks  
(see below: 'Group Leader')
- monitors and evaluates the group  
(see: 'Monitoring and Evaluation', p.35)



#### **IV. GROUP LEADER**

The group leader is one of the members and chosen by them.

He/she should be able to communicate with the other members, and be concerned about the other members.

His/her tasks are normally more spiritual than administrative:

- He/she should maintain the spirit of the group by e.g. asking the group members about difficulties and helping to solve these, supporting them in wound-care and recognizing and praising improvements, encouraging them to participate actively in the group activities.
- The group leader might also take over administrative functions (recording / examination forms), if he/she is willing and able to do so.

Ideally, the group leader will eventually take over the tasks of the facilitator, in order to lead the group independently from the facilitator and HC. Although this is a difficult aim to achieve, the facilitator should always keep it in mind and increase independence by **handing over tasks to the group leader**. (See: *'Training the Group Leader'*, p.43)



#### NGOs

To support the juru in facilitating a SCG, help from local NGOs can sometimes be very useful, especially when their members are trained in facilitating groups.

If a SCG is village-based, the role of the facilitator could be taken over by a NGO member.

## OTHER WAYS TO ESTABLISH A SELF-CARE GROUP: THREE EXAMPLES

### The Associations of East Java

In East Java the provincial leprosy team experienced difficulties when requesting district wasors and jurus to establish SCGs. In spite of motivation and a sufficient budget at provincial level, the selected health staff at district and HC levels was not interested in making the effort to form groups with their (ex) leprosy patients. What finally led to success was the support given to those members of the control team who **were already motivated** and felt responsible for helping their patients in the best possible way. These people established two groups without order or instructions 'from above', but on their own initiative together with the patients.

### The SCG of the Jongaya Settlement

In the large leprosy settlement of Jongaya in the middle of Makassar, some **inhabitants themselves** set up a SCG, after they heard about groups in other places. With only a minimum of guidance from the provincial leprosy team they selected members, organised a meeting place, and started to meet every two weeks. They then asked for professional supervision. As the responsible wasor and juru weren't active in Jongaya, the provincial team decided to follow another way of supervising and facilitating by involving people who were **available and motivated**: an experienced, retired provincial wasor was appointed as supervisor, and the talented group leader became the facilitator of the group.

### The Madura SCG

In Madura a man approached the control team to ask for financial support for his small business. The employees including himself are people affected by leprosy. It was possible to arrange some support for him, but at the same time he was asked whether he would be interested to meet with his employees once a month to learn and practice self-care. In this group, the health staff was only involved at the beginning to teach about self-care and for occasional supervision visits.

These examples show that **flexibility** is needed to successfully establish SCGs.

The above-given task descriptions offer guidelines, which should be adapted to the local situation, whenever appropriate.

**It is always good advice to look for the help of people –both health staff and people affected by leprosy- who are truly motivated!**

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**Notes:**



### **3. Organisation of a Self-Care Group**

#### **I. CONDITIONS**

To make a SCG possible, some **conditions** at provincial, district and HC level are required:

- Province and district should cooperate in matters of general organisation, financing and evaluation.
- The budget to establish and run a SCG should be guaranteed.
- There should be enough people affected by leprosy to form a group. These potential members should live so close together that monthly meetings are no problem.
- It is essential that the district wasor is motivated to establish SGCs in his/her district. The group, as well as the juru as facilitator, will need supervision and support, which is not possible unless the wasor is committed. As an alternative other motivated people might be found to help and supervise. (See: 'Other ways to establish a SCG, p. 14')
- In the same way, the juru as facilitator needs to be motivated and committed for his/her task, and willing to spend some of his/her time and energy on it, with the reward of effectively helping people, preventing disabilities and restoring their self-confidence.
- The selected meeting place needs the necessary facilities to conduct SCG meetings, which is mainly an undisturbed place with water supply. (See 'Meeting place', p. 19)



## II. SELECTION OF MEMBERS

The facilitator normally selects the group members, because he/she knows the people affected by leprosy best. The district wasor should help him/her with this task:

1. The facilitator and the wasor should discuss candidates for the group, according to the criteria for membership (*see below*).
2. The facilitator should speak with the selected people, either during their visit to the HC, or during the facilitator's visit to their homes. He/she should explain the plan to form a SCG and its aims, and invite them to the first meeting to see if they would like to become members.

### Criteria for Membership

- People **on treatment and/or people after treatment**, who have physical problems related to leprosy (disability grade 1 and/or 2).

There is no age limit; children below 10 years should come with a family member.

If there are more candidates than the group size (*see: 'Group Composition, p.18'*) can support, RFT patients may get preference. In this case, the people on MDT should get proper health education and guidance at their monthly visits to the HC.



### Tips

- ❑ Although registered patients with disabilities in a HC may be few, the facilitator and wasor should not forget to **go through the old patient cards**, which will remind them of many former patients with disability grade 1 or 2, who could benefit from a SCG!
- ❑ A person may not want to join the group because of fears that neighbours might recognize him/her as a person affected by leprosy. In that case intensive consultations are necessary, to show him/her the advantage of caring for him/herself instead of hiding. In the same time, the team should take the responsibility to create awareness in the surrounding community. (*See: 'Attendance', p.24*)
- ❑ In some groups, family member may be asked to join the meetings, to enhance support for the individual member.

### Group Composition

- Preferable size of a SCG is between 8-12 members.
- In case of a large number of potential members and the need to establish more than one group, composition according to profession (e.g. farmers) is advisable, because they will have many problems in common. Alternatively it could be according to the place where they live.
- People with insensitive hands or feet only but no further disabilities might feel uncomfortable in a group with severely disabled people, or may not take seriously their insensitive hands / feet. In this case a separate group for these people may be considered, or individual health education and guidance instead of membership of a SCG.
- Women are sometimes forgotten or neglected as potential group members, because they often play a less visible role in society. This should be avoided when selecting members.

### New Members

People who would like to become members after the group has been started are welcome. The facilitator should keep in mind that the size of a group should not become too large, and if necessary form a new group.

In Jenepono, experience showed that too many new members complicated the process of group-development / group feeling. However, the integration of a few new members was successful.



### III. MEETING PLACE



#### Criteria for a Meeting Place

- The meeting place needs to be central for everybody, and not too far and difficult to reach.
- It should be large enough to sit comfortable in a circle with enough space for everybody to soak his/her feet or hands.
- It needs to have a water supply.
- Members should feel comfortably, relaxed and free to speak.

The **meeting place** can have a lot of influence on the character and the success of a SCG. In general there are two alternatives: the HC or a private place in the village where most of the members live.

The aim of a SCG is to strengthen the ability of its members to care for themselves by supporting each other. The aspect of mutual help, which might also include neighbours, friends and family members, might be achieved best in the normal environment of the people, which is in their villages.

A meeting place in a village could be considered as the better choice compared to a meeting place in the HC.

*Some considerations about the different meeting places are listed in Annex 2. (P.48)*



### Transportation to the Meeting Place

A general problem is that members may need money for **transportation** to the meeting place.

Principally it is not wise to hand out money to the members, especially fixed amounts disregarding the actual transportation costs the members have, because they may get the impression of being paid for joining the group, which is contrary to the aim of a self-care group, i.e. to increase responsibility.

Experience indicates that in the beginning members are often not willing to spend their time and money on something they don't know yet. Later, some members may not be able to continue to attend meetings because they cannot afford the transport.

The optimal solution is to find a meeting place, which is **central** for everybody so that no costs for transport arise.

Alternatively, the facilitator could reimburse transportation costs for members who are very poor, and/or live far away. However, groups which continue to meet longer than a year are strongly advised to look for more sustainable solutions.



## **IV. FREQUENCY OF MEETINGS**

The usual **frequency** of meetings is once a month.

- An alternative is to meet twice a month during the first 3 months, especially if the members are very shy and need more time to get to know each other, or to get used to self-care.

### Fixing Dates

The facilitator and the members should discuss the date and time of the meetings, which should be suitable for all.

**Members who cannot leave their work represent a serious difficulty in finding a proper meeting time.** In open discussions members and the facilitator should try to find solutions.

The dates should be written down and a copy of the meeting schedule distributed to all members to take home!



#### Tips for Meeting Dates

- ❑ Dates like 'every first Thursday of the month' are easy to remember for the members.
- ❑ Meetings on market days, where people can combine their trip with other necessary activities, are useful especially in areas with people living far away.
- ❑ According to the situation, meeting times in the afternoon or on Saturdays might be necessary where the majority of members have to work regularly. The additional burdens for the facilitator might be shared with other volunteers like NGO workers.

#### **V. DURATION OF A SCG**

A SCG should continue for **one year**. After this time an evaluation should show if the group was successful in achieving their aims. (See: '*Monitoring and Evaluation*', '*Indicators for Evaluation*', p.35)

- If the group was successful, and the members are all independently able to care for themselves, the group may be closed if the members see no reason to continue meeting.
- If the group wants to continue, the budget should then come from sources other than the province (e.g. from the district).
- An alternative to completely stopping the group could be to conduct meetings every two or three months only.
- If the group was not successful, and the reasons for the failure cannot be corrected, the group should be closed and other activities to prevent disabilities tried out instead, like individual health education.

A SCG can continue for years, if the members wish it to do so. Such a long-term group should best be community-based, which means based in the village instead of the HC, and led by the group leader as far as possible.

## 4. The Meetings

### I. PREPARING A MEETING

The facilitator should have a list of the meeting dates in the HC, preferably hanging on a wall, to remind him/her and the members of the monthly meetings.

In some cases it may be necessary in the beginning to remind members personally before the meeting. However, this should not become general practice.

A day before the meeting, the facilitator should check if materials are still sufficient and the meeting place is available.

For materials needed during the meetings, see '*Materials*' (p.36).



#### Snack

To relax people, a small snack might be offered.

The members might be trusted with the organisation of the snack, e.g. making cakes at home, to promote friendliness within the group.

Experience showed that members regard transport money much more important than snacks.



## **II. SCHEDULE OF A MEETING**

Although different groups may develop different customs, we advise a **schedule** for the group meetings as follows:

**A. Opening**

**B. Attendance check**

**C. Examinations**

Of each member, with participation of the whole group

**D. Basic self-care program**

Soaking, trimming, oiling

Practised by everybody

**E. Special self-care program**

Individual exercises

Demonstrated by the respective members and discussed jointly

**F. Discussions**

Of problems, questions, special topics

At any proper time

The length of a meeting is usually about two hours.

In the first meetings, the facilitator will have to *teach* basic self-care techniques, which might take some extra time, so that a regular schedule like the above mentioned might only be established later.

*Some teaching examples are listed in Annex 3: 'How to Teach the Main Self-Care Activities' (p.50.)*

Below, the activities of the regular schedule are described in more detail:



### A. Opening

A meeting should be opened officially by the facilitator or, even better, by one of the members to increase group ownership.

**The group members and the facilitator should sit together in a circle.**

### B. Attendance

The attendance of the members should be checked at the beginning of each meeting, and noted in an attendance form like the example below.

Member	May 4 <sup>th</sup>	June 4 <sup>th</sup>	July 4 <sup>th</sup>	Aug 4 <sup>th</sup>	Sept 4 <sup>th</sup>
Bp Sili	x	x	x	x	x
Ibu Tan	x	sick	x	x	x
Ibu Heri	x	x	-?	-?	x
Bp Ula	x	town	x	x	x

If possible, one of the members should be appointed as secretary with the task of checking the attendance, to increase participation.

Especially in the beginning, **irregular attendance** of members may be a real problem. The main reasons, according to our experience, are lack of free time, embarrassment about their own problems, and not yet understanding the benefits of self-care.

It is therefore important to:

- explain and discuss repeatedly the advantages of spending 2 hours a month for their own health (e.g. by asking people with experience in self-care to tell the others),
- discuss the reasons for not attending and try to find solutions (e.g. different time),
- give the members a feeling of belonging to the group, by involving them in all group activities, and showing them that they are needed to support their fellow members,
- pay attention to every member and his or her actual problems.

We have found that a facilitator who is close to his/her patients (e.g. comes from the same area) finds it easier to convince them to join a SCG.



Above left: Soaking feet at the SCG Bonto Ramba, Jeneponto, South Sulawesi

Above right: A member explains about his foot. SCG Bonto Ramba



Left: Soaking hands at the SCG Bonto Nampo II, Gowa, South Sulawesi

Below: Group leader explains, at the SCG Malaka, Soppeng, South Sulawesi





Above left: Self modified sandals

Above right: Wasor explains at the first meeting of the SCG Lauleng, Pare-Pare, South Sulawesi

Left: Meeting at the SCG Jongaya, Makassar, South Sulawesi

Below left: Two members discussing. SCG Malaka

Below right: A member cleans his wound. SCG Pacongkan, Soppeng, South Sulawesi



Right: Trimming callosities at SCG Bonto Ramba

Middle left: Hand exercises at SCG Bonto Nompo II

Middle right: Straightening clawed fingers at SCG Bonto Nompo II



Left: SCG Blora, Central Java, held in the house of the group leader



Above: Relaxed atmosphere at SCG  
Lauleng

Right: A member of the SCG Bonto  
Ramba shows his hands without wounds  
as the result of self-care



Below left: Self care and demonstration  
material at the SCG Sengkol, Central  
Lombok



Below right: Social -economic help for a  
man in the East Java



### **C. Examinations**

All members should be **examined regularly** at each meeting, because only then is it possible to monitor the *development* of disabilities.



Monitoring the development of disabilities is important for

- motivating** the members by pointing out and **praising** improvements
- correcting self-care practices in case of worsening
- evaluating the results of the group in order to decide about continuing

Examinations can mean:

- Inspection of feet and hands for **wounds**, the presence of any skin abnormality, and inspection of eyes for infection is the standard examination.
- In groups facilitated by a medical person (juru), more detailed examinations may be conducted (VMT/ST, detection of reactions), but **not necessarily** as the standard examination.

When deciding about examination, remember that:

- People on MDT undergo detailed monthly examinations by the juru, which need not be repeated during the group meeting.
- People with long-standing disabilities (RFT patients) will not show much change in muscle strength and sensitivity.
- To detect reaction in people during surveillance, the facilitators should thoroughly inform the members about the signs of reactions, and during the meetings **ask** them about any problems like pain, fever etc.
- In order to keep motivation high, it is advisable to concentrate on disabilities with a prospect of improvement, instead of disabilities with a small or no chance of improving.

#### Example:

For a member with long-standing paralysed and clawed fingers it is not necessary to make a VMT at every meeting, but it is important to keep the fingers mobile and to check if no wounds or cracks have developed, and that the skin is smooth.

### Let the group members examine!

The first principle of examination should always be that the whole group **participates** in the examination of each member, and results and problems are discussed **jointly**.

To achieve this, the facilitator/group leader should ask the members, one after the other, to tell the group about his/her progress (e.g. a wound or claw fingers), and to show their hand or foot to the others. The other members should be asked to give comments, particularly their own experiences.

This part of a meeting demands the **skill of a facilitator** to guide the members in understanding self-care:

- Identifying a problem
- Thinking about the reason
- Finding a solution

#### Example:

A member shows a new wound. Together with the other members he/she discusses the reason for this wound. Together, they try to find a way to avoid this kind of wound the next time.



#### Recording:

Recording of examination results should be kept short: the members benefit much more from **discussions about the findings**, than from extensive recording.

An **example of an 'examination booklet'** is added to this manual: It contains examination forms for one year of monthly meetings. The first page is used for basic data of the member, taken at the beginning of his/her membership. The next pages correspond with the next meetings, **concentrating on the inspection of wounds**. At the end, an evaluation can be done.



### **D. Basic Self-Care Program**

The very effective method of soaking hands / feet for about 20 minutes in soap or salt water, rubbing off thick parts of the skin, and then oiling the wet skin, we call the '**basic self-care program**' because it should be daily practised by *everyone* with a disability grade 1 or 2 of hands / feet.

The basic self-care program should be a part of the regular schedule of each meeting, although the members also do it daily at home. Practising together provides an opportunity to check if all members perform correctly, and increases the group feeling.

The time of soaking can be used e.g.

- to discuss various problems
- to exchange experiences
- to teach and discuss special knowledge like signs of reaction
- to inspect the footwear of the members



### **E. Special Self-Care Program**

Apart from the basic self-care program, some members will need to do **exercises** for their hands, feet or eyes. These are not the same for everyone, but depend on their individual disability (e.g. a weak drop foot needs different exercises than a paralysed drop foot).

The individual exercises can be taught during examination, during soaking, or at any other time, e.g. after the basic self-care program.

The skills of the members in performing their individual exercises should be checked at every meeting, and discussed together with all members.





### **F. Discussions**

Discussions about problems, questions or special topics are always welcome and should be encouraged at any time.

It is also possible to keep a special time during the meetings reserved for discussions.

If members are too shy or are not used to open discussion, it is the task of the facilitator to **ask leading questions which might provoke discussion**.

See also '*Additional Activities*' (p.37)

### **III. INTRODUCTION OF THE AIMS OF A SCG TO THE MEMBERS**

To avoid misunderstandings, the facilitator should explain clearly to the members at the first meeting(s), why they have been invited to join a SCG.

Examples of the contents could be as follows:

Regarding **self-care**, the members need to know that:

- Some of them might always have insensitive feet and hands, but they can manage to avoid further problems with regular self-care.
- They are much better caretakers for their hands, feet and eyes than the HC staff, because they can care for themselves every day at home.
- They are the only ones who can *prevent* (worsening of) disabilities on hands, feet and eyes. A HC worker can help to heal, but not to prevent.
- They don't need medicine and white bandages to care for most of their wounds. Everything they need, they have got at home.

Regarding the **group**, the members need to know that:

- They come together to learn and practise how to prevent and cure wounds and other disabilities, as well as to discuss whatever problems they might face.
- They will have to apply this knowledge at home, while at the meetings the progress of healing will be assessed and discussed.
- Every member is asked to help and support the others with his/her own ideas and experiences.
- The facilitator will not care for their wounds, but will show them how to do self-care.
- It is important that they attend regularly.

#### IV. HOW TO FACILITATE A GROUP – SOME GUIDELINES

It is not always easy to **facilitate** a group. People who come together have different expectations and needs, different characters and backgrounds. A facilitator should try to unite and direct these to achieve a common goal.

Some **guidelines** might help the facilitator to fulfil this task:

- Especially in the beginning the members might have different personal reasons to join the group. It is necessary to come to an agreement on the objectives and tasks for the group.
- A relaxed and trusting atmosphere should be cultivated during the meetings, but also a level of discipline maintained (e.g. members are encouraged to talk to each other, but should stop this during group discussion).
- Everybody should be involved in the group activities and discussions. While the quieter or shyer members might need special encouragement, the domination by more vocal members should be carefully controlled.
- All questions, ideas and problems should be taken seriously, since these are what actually concern the members at home.
- The juru should try not to instruct like a teacher, but be a facilitator, asking questions and initiating discussions. The exchange of experience should be encouraged, as advice is often more acceptable when coming from someone else who has (had) a similar problem than from the health worker. It may sometimes be a challenge for the facilitator to step back from an authoritarian role and trust in the ability of the members to organise themselves.
- In the beginning, the members might *wish* to be lead by the facilitator, because they are used to authority. The facilitator should try to encourage them to think and behave on their own.
- As much as possible should be **practised** directly (e.g. soaking, trimming and oiling), because this is the most effective way to learn. *See the drawings on the next page!*



#### Tips

- ❑ Facilitators who have already gained experience in organising and facilitating a SCG can be **valuable instructors for other facilitators** who have just started a group and feel insecure!
- ❑ **Talented group members** can also be asked to join a new group as group leader or as a helping hand during the first meetings!

DIFFERENT WAYS TO TEACH

EXPLAINING  
IS GOOD



DEMONSTRATING  
IS BETTER



PRACTICE  
IS BEST



## **5. Monitoring and Evaluation**

### **Monitoring**

The main indicator for the performance of a SCG are the results of the group concerning **POD**. The facilitator should monitor the members by means of examinations, which are performed at every meeting and the results noted in the examination forms (see: '*Examinations*', p.29, 26). He/she should also note the **attitude** of the members towards self-care.

Psychological or social developments can be assessed as well.

### **Evaluation**

After 6 and 12 months, the facilitator and the wasor should **evaluate** the success of the group with the help of indicators, and report the results to the district and province.

After 12 months the facilitator, the wasor and the group members should discuss about continuing, reducing or ending the group meetings, according to success, need and wish of the members (see: '*Duration of a SCG*', p.21).

**Examples of Indicators**, which can be used for the evaluation of a SCG, are:

- Proportion of group members who observed progress of their wound healing
- Proportion of group members who observed improvements of disabilities like increase of muscle strength or more mobile claw hands
- Proportion of group members who show a positive change of behaviour towards self-care (e.g. proper use of shoes, motivation to practise self-care at home)
- Other observations (like interest and participation in the group, individual psychological or social developments, change of social status, etc)
- The proportion of people who are still group members

The facilitator / the wasor should also remember the following targets:

- There should be a 0% dropout rate amongst the members who are still on MDT
- Delay of detection of leprosy reaction should be no longer than 1 month
- The number of group members who get leprosy reaction to be adequately treated with anti-reaction drugs (*prednisone* or others) should be 100%
- Appropriate referral should be provided to all members who are in need of it

## 6. Materials

**Materials** needed during the group meetings are:

- Basins and rubbing stones according to the number of members; soap or salt and oil for the basic self-care program

These items are normally stored in the meeting place to make sure that they are not lost and nobody forgets to bring them.

Sometimes, members might take the basins home to use them daily, and bring them with them to each meeting. This applies mainly to SCGs in leprosy settlements.

An alternative to basins is to dig holes into the earth of an outdoor meeting place. A plastic sheet or bag lining the hole will keep the water in.

- Self-care kit for presentation purpose

This might include a cooking pot with wooden handles, clothes for wrapping hot or rough handles, cloths usable as dressing, a cigarette holder made from bamboo, a walking stick, examples of protective footwear, etc.

- Information material should always be available for distribution (leaflets etc)

- Sunglasses for members with lagophthalmos may be distributed depending on the budget. For footwear for people with insensitive feet see: *'Footwear', p.34*

Other devices like crutches, splints for claw fingers, rubber bands for training weak drop feet, etc can be very helpful to prevent and reduce disabilities. A stock of these should be ready at least at the provincial head quarter. Otherwise the members can be encouraged to make devices themselves.



- Antiseptics and antibiotics do **not** belong to the standard equipment of a self-care group. See: *'Special Topics: Medication'* on the next page.

In general, no handouts are given to the members of a **self-care** group. It is important to make this clear from the beginning to avoid wrong expectations.

## 7. Special Topics

### I. MEDICATION

Members of a SCG often expect to get antiseptic liquids and dressings for their wounds from the facilitator, because they have no experience yet with self-care. They may not yet appreciate that self-care is much more effective for prevention and reduction of wounds than the limited medication they could get from the HC. Experience shows that repeated explanations and discussions are necessary.

Antiseptics or dressings should *not* be used to treat simple wounds! The members should be encouraged to use locally available materials for their treatment, which is water and salt or soap for soaking hands and feet, clean pieces of cloth to cover wounds, or natural ointments they would normally use to treat other wounds. After understanding this principle and seeing early results, they will be **proud** of curing their wounds without any help from the HC!

During meetings, wounds should be treated in the same way the members would do it at home: by **soaking, rubbing, oiling and dressing with clean cloth**. It should be remembered that the group members are supposed to learn to care for themselves. By treating them with antiseptics during the meetings, they will not believe they can also do without it!

In certain cases special treatment is indeed necessary and the member has to see one of the health personal:

- A member with an infected (swollen, hot) foot or hand should be given antibiotics, or in severe cases be referred to a hospital

It should always be explained to all members why the one wound needs to be treated with medication and the other not.




Remember:

- A facilitator should always note other abnormal conditions or diseases affecting the members, and take the necessary steps.
- Reactions must be noticed and the necessary steps taken immediately!**

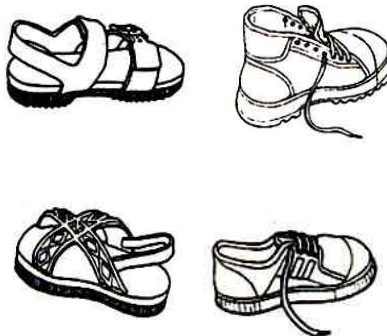
## II. FOOTWEAR

An essential part of self-care is the protection of insensitive hands and feet to avoid wounds in the first place!

Consequently, all members with **insensitive feet** have to wear proper, protective footwear.

 Criteria for Protective Footwear

- A soft insole
- A hard outer sole
- A heel strap / cup
- No sharp objects used
- Fitting the foot well (not too tight and not too big)
- In good condition and not too worn out



It is a general problem that people affected by leprosy often don't have the means to provide themselves with good quality footwear, or that they don't see it as a priority, compared to other daily life requirements.

It is advised that a group spends some time at each meeting to talk about this problem and inspect the footwear of each member, so that the members become accustomed to this issue:

- It is important for the group members to understand that they might have insensitive feet for the rest of their lives, and will always need proper footwear to avoid wounds. If a foot is destroyed due to continued wounds and has to be amputated, then the person will face many more difficult problems, for example in earning money.
- The members with insensitive feet have to learn to regard proper footwear as 'medicine', and as a necessity of daily life, just like soap or toothpaste. It must become routine to always wear protective shoes, like putting on a shirt.  
This means changing one's habits, which is only possible when the person understands the reason and gets used to this new habit, through repeated discussions.
- As the members will not receive footwear from a health facility for ever, they have to take care of these themselves. They have to see that spending money on sandals means spending money on one's future. Ways of saving money for footwear should be a topic of discussion within the group. With a small amount of money saved

every week, a person will have enough for a new pair of sandals in some months. Ideally, this should be practiced directly at the meetings.

It is recommended to provide members with insensitive feet with **one pair of protective sandals** at the start of the meetings. This is not only to help poor members, but also to show the members that the advice to wear proper sandals is meant seriously, and to give them an example of a proper protective sandal.

**Remember: The provision of one pair of footwear does not change the habit of a person. It is essential to discuss the above mentioned points at every meeting!**

If a budget is available, providing rubber boots for farmers / canvas shoes for fishermen or workers is worthwhile, in order to avoid early damage to the sandals.

To prolong the life of sandals, the members should:

- double-sew the soles and straps when they are still new
- not use the sandals in the bathroom / at the well / in wet rice fields
- use rubber boots in wet rice fields, and canvas shoes for work in plantations / rough stony areas / construction sites (also for safety!). According to experience from East Java, canvas shoes are also suitable for fishing in the sea.

Both canvas shoes and rubber boots should have an additional softer insole to guarantee the very important cushion effect! The sole of a rubber slipper, slipped into the shoe, can substitute a soft insole.



### Special Footwear

The facilitator should note those members in need of **special footwear**:

- For people with a drop foot, special drop-foot sandals should be ordered from leprosy hospitals. Alternatively, a local shoemaker could be asked to make a drop-foot sandal, if an example is available. High boots are another possibility.
- For feet with ulcers, special sandals with pressure reducing holes at the place of the ulcer are available from leprosy hospitals, or a local shoemaker can be asked. Alternatively, normal footwear can be modified with holes in the backside of an additional soft insole.
- The orthopaedic workshops in some leprosy hospitals may produce good quality prostheses, as well as shoes which are moulded to the form of a severely deformed foot.



Information about obtaining special footwear should be available at provincial level.

See also 'Referral' (p.40)



### **III. REFERRAL**

#### **Emergencies**

Members with special problems, which need treatment others than self-care or treatment in the HC, need to be referred. These problems are primarily:

- An ulcer not improving within 3 months of treatment, or which reoccurs within 3 months
- A swollen, hot (septic) foot / hand
- Ulcers with signs of malign changes
- A sudden loss of vision, or other eye problems not responding to treatment
- Severe reaction not responding to treatment in the field

The **district hospital** should be the place of referral for all cases they are able to handle. Further cases should be referred to a specialized leprosy hospital.

#### **Reconstructive Surgery**

Especially for young group members reconstructive surgery may be considered in some cases. In a SCG they could get moral support and in some cases instructions for physical preparation (in coordination with the hospital).

Disabilities possible to improve by surgery are mainly:

- paralysed fingers, thumbs or drop feet (without contractures and wounds)
- Lagophthalmos with a eyelid gap of > 6mm
- Deformities at feet which lead to reoccurring ulcers (like prolonging claw toes)

All disabilities have to be permanent since at least 1 year.

#### **Special Footwear** (See: 'Footwear', p.38)

For special moulded shoes, the member needs to be referred to the hospital producing this shoe. For other special footwear like drop foot shoes it is possible to make a footprint of the feet by experienced staff, and send it to the workshop.

*Detailed information about conditions and procedures of referral can be obtained in the National Guidelines (Buku Panduan and Buku Pedoman, see Annex 5: 'References').*

#### IV. ADDITIONAL ACTIVITIES

##### Extra Education

The facilitator could give or organise extra education to the group members e.g. on nutrition (especially childhood nutrition) or other health topics. He/she could invite speakers from other departments, who might give helpful talks to the group members (e.g. about chicken breeding etc).

##### Social-Economical Rehabilitation

Very often, good results in wound healing are spoiled because people have to do hard physical labour, for example as farmers. The only way out of this dilemma is by changing their work. In other cases, a person may have lost his or her previous job, due to stigma.

It is a logical step that members of a SCG, having increased awareness about wound healing and protection, and often increased their self-esteem, have the wish to improve their working and socio-economic conditions.

A SCG provides a good opportunity for various activities in socio-economical rehabilitation.

A good start may be the running of an *Arisan* (a traditional saving system). If the members are interested in this, income generating projects may be discussed together.

A person may receive an interest-free micro credit, repayable after an agreed period. It is also possible to provide capital to start a business activity: for example a sewing machine, which could be paid back gradually every month, or a goat that can be refunded with one of the new-born goats. The decision of whether to have all loans repaid can be decided according to the situation. Repayment would encourage seriousness on the recipient's side, and sustainability of the program because the refunded money can be given to other people.

For an income generating project the recipient has to propose a feasible and profitable project. On the donor side, funds have to be made available (financial assistance for income generating projects is not covered by the SCG budget) from local government, private or other organisations. It is also necessary to provide technical assistance and supervision.

During SCG meetings, the projects can be discussed, advice and assistance can be given also from other members, and repayments be encouraged.



## **8. Common Problems**

In spite of clear ideas and good intentions, establishing a functioning SCG has its traps and difficulties.

Here we mention the most **common problems**, taken from experiences in Sulawesi, in order to avoid or reduce these problems elsewhere.

- Members **attend irregularly** because of their daily work, embarrassment, not understanding the aims and benefits of a SCG, and/or negligence with their wounds. (See: 'Attendance', p.24)
- The facilitator (juru) doesn't know enough about **POD**.
- The facilitator (juru) has difficulties in changing from health instructor to **facilitator** of a group.
- Members cannot afford transportation **costs** to the meeting place and the costs of protective footwear, so this puts a burden on the provincial / district budget.
- Members are **shy** and are not used to discuss their problems with other people.
- Wound healing is delayed because of **hard physical labour**.

Nevertheless we would like to emphasise that nearly all members of the various groups in Sulawesi, once they understood the benefits of a SCG, were extremely serious in practising self-care daily at home, and as a result **experienced great improvements** in their disabilities. Groups that were stiff in the beginning became lively after a while, with their members discussing and supporting each other, showing a changed attitude towards their problems!



## 9. Training

### I. TRAINING THE FACILITATOR

The facilitator of a SCG needs knowledge about **POD / self-care** and skills to **facilitate** and manage a SCG.

#### POD / Self-Care

A juru should have received training about POD / self-care as part of the regular training and on-the job training. However, a juru who is about to become the facilitator of a SCG should get special attention by the district wasor during a supervision visit beforehand. During these visits his/her knowledge and skills concerning POD / self-care should be assessed, and if necessary be improved by on-the job training.

*Some important points to look at during supervision are listed in Annex 4: 'POD Checklist for Supervision' (p.52).*

If several SCGs in a district are planned, it may be useful to conduct POD training collectively. As much as possible **practical training** should be included.

#### Training for Facilitating a SCG

A juru who becomes the facilitator of a SCG needs to be trained for this new task. There should be a meeting of the facilitator(s) with previously experienced staff, during which the aims and functioning of a SCG are discussed, and special attention is given on how to facilitate. This manual and the demonstration film on CD-Rom can serve as material.

For practice, the first SCG meetings should be used for 'on the job training'.

It is very important to pay sufficient attention to communication skills. See: '*How to Facilitate a Group*' (p.29).

### II. TRAINING THE GROUP LEADER

A group leader can contribute greatly to making the group more independent and confident. He/she therefore needs guidance on how to carry out the various tasks. This can be done by 'on-the job training'. The facilitator should always be ready to **hand over tasks** to the group leader (e.g. explaining to a member how to rub off callosities), in order to give him/her the opportunity to learn.

Group leaders who are able and willing to become the **facilitator** of a group should receive the same training as described above.

## 10. Costs

The items, which may have to be included, are as follows:

### Training:

- Training for the facilitator in POD / self-care & facilitating skills

### Preparation of the group:

- Information and advocacy in the district (during regular supervision)
- Self-care kit (basins, oil, rubbing stones, demonstration material)

### Organising and conducting 12-15 meetings a year:

- Incentive for the facilitator
- Incentive for supervision by the district wasor
- Examination forms

Depending on need and availability:

- Snack
- Transportation money for all / some members

### Footwear: (depending on needs)

- 1 pair of protective sandals for each member with insensitive feet
- 1 pair of rubber boots / canvas shoes for members with professions requiring it

The budget for a SCG is normally given for **1 year**. This period should be sufficient time for the members to get used to regular self-care (see: '*Duration of a SCG*', p.21).

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**Notes:**



**Annex****ANNEX 1      LIST OF ABBREVIATIONS**

ALERT	All Africa Leprosy, Tuberculosis and Rehabilitation Training Centre
Dharma Wanita	Indonesian Governmental Woman Organisation
HC	Health Centre
Juru	( <i>ind.</i> ) Skilled worker; Juru Kusta = Leprosy field worker
MDT	Multi Drug Therapy
NGO	Non Governmental Organisation
PLKN	( <i>ind.</i> ) Pusat Latihan Kusta National = National Leprosy Training Centre
POD	Prevention of Disabilities
RFT	Released From Treatment
SCG	Self-Care Group
ST	Sensory Test
VMT	Voluntary Muscle Test
Wasor	( <i>ind.</i> ) Wakil Supervisor = Assistant Supervisor (of the head of leprosy control) in province or district



## **ANNEX 2      CONSIDERATIONS ABOUT THE MEETING PLACE**

### **A. The health centre**

#### **Advantages:**

- The members can meet without being exposed to other villagers who sometimes recognize them as having (had) leprosy only through this activity. In areas with high stigma this is a strong argument for the members.
- According to experience in North Sulawesi, members are more convinced about practising self-care regularly at home if the HC doctor, as a respected figure, shows up from time to time and explains to them again the benefits of self-care, or takes care of complicated cases in need of special treatment.
- Meeting in a HC contributes to a lessening of the stigma since leprosy patients mingle with other patients.
- The HC will normally be convenient for the juru as facilitator.

#### **Disadvantages:**

- Group members might be shy and feel afraid of the authorities in a HC, and therefore may not speak and discuss openly.
- Members often expect to get medicine in a HC, and are disappointed not getting any as a SCG member.
- Members might get the impression that the HC is essential for healing their wounds.
- A SCG based in a HC is unlikely to become completely independent from it.
- The HC is not always a central place for everybody and transportation costs may be high.

### **B. A meeting place in the village**

This can be a member's house, the village head's house, an official place like the local Dharma Wanita building, or a place in a garden / under a tree.

#### **Advantages:**

- Places outside the HC help to increase the courage of the members to help each other in spite of stigma and shame. The community gets the opportunity to learn about leprosy and overcome their fear.
- Dependency on the HC and its medications and dressing materials can be discontinued more easily.

- Members might feel more comfortable and open in their normal environment, so that discussions become more fruitful.
- No transportation costs arise if all members come from the same village.
- Meeting times are not depending on opening hours of the HC.

**Disadvantages:**

- Members might be ashamed to meet in a “leprosy group” visible to the whole community. They might be reluctant to offer their house as a meeting place because they fear suspicious neighbours.
- Official places need to be organised and might be refused out of general prevailing stigma.
- Places outdoor must be checked for water supply, comfort, and alternatives during the rainy season.

The type of SCG can also influence the choice of the meeting place: Experience shows that SCGs in leprosy settlements have no difficulties at all meeting in a public place or under the house of a member.

Groups in rural areas might have fewer difficulties meeting outside the HC than groups in small towns, where stigma is often higher.



### **ANNEX 3      HOW TO TEACH THE MAIN SELF-CARE ACTIVITIES**

At the beginning, the members have to learn about self-care activities.

Some teaching **examples** are listed here. For detailed information, see '*Essential Action to Minimise Disability in Leprosy Patients*' by Jean M. Watson!

What to teach first will depend on the prevailing disabilities. Wounds should have priority because proper care has to start immediately.

Teaching should always be accompanied **by practice and discussion of problems!**

#### **Wounds**

1. Everybody is asked to look for wounds on hands and feet and to show them.
2. Discussion about which wounds need special treatment (e.g. infected or complicated ulcers).
3. Discussion & practice about self-care activities to treat all other wounds:
  - a. Caring for the wound by daily soaking / rubbing / oiling
  - b. Protecting the wound by covering / elevating / resting it
4. Discussion about the reason for each wound and how to avoid it next time.

#### **Exercises for the hand**

1. Everybody is asked to show their hands and to describe any difficulties with them.
2. Discussion about the reason for difficulties (e.g. difficult to grip because of weak thumb and fingers; stiffness of fingers because they have never been straightened).
3. Discussion & practice about how to straighten claw fingers.
4. Discussion & practice about how to strengthen muscles.

### **Exercises for the feet**

1. Everybody is asked to show their feet and to describe any difficulties with them / while walking.
2. Discussion about the reason for difficulties (e.g. loosing a sandal because of drop foot; wounds at the tips of the toes because of claw toes).
3. Discussion & practice about how to straighten claw toes.
4. Discussion & practice about how to avoid stiffness of a drop foot.
5. Discussion & practice about how to strengthen a weak drop foot.

### **Protection and exercises for the eyes**

1. Everybody is asked to close their eyes and to describe any difficulties with them.
2. Discussion about the reason for difficulties (e.g. red eye because of dirt).
3. Discussion & practice about how to protect the eyes (frequent blinking, wearing glasses, etc).
4. Discussion & practice about how to strengthen an eye with lagophthalmos.

### **Signs of reaction**

1. Discussion about the dangers of reactions and the need to report directly if a member notices signs of reaction.
2. Discussion about nerve pain as a sign of reaction.  
Practice: checking on themselves if there is any pain at the elbows, knees and ankles.
3. Discussion about increasing insensitivity as a sign of reaction.  
Practice: checking on themselves if hands / feet can feel.
4. Discussion about increasing muscle weakness as a sign of reaction.  
Practice: checking on themselves how strong small fingers, thumbs and feet are.
5. Discussion about other signs of reaction (active patches, fever etc).

## ANNEX 4      POD CHECKLIST FOR SUPERVISION

**Example** of a checklist, which can be used during regular supervision to assess the knowledge and skills of a juru in **POD** before starting a SCG.

	Good	Not confident	Wrong	Not done
<b>1. <u>Examinations:</u></b>				
<b>Palpation of nerves</b>	N. Ulnaris			
	N. Peroneus communis			
	N. Tibialis posterior			
<b>VMT</b>	For eyes			
	For small finger			
	For thumb			
	For wrist			
	For foot			
	Can differentiate between 'strong', 'weak', 'paralyzed'			
<b>ST</b>	Hand			
	Foot			
<b>Examination of wounds</b>				
<b>Examination of claw fingers (stiff, mobile)</b>				
<b>2. <u>Recording in POD form:</u></b>				
	Quality			
	Regularity			
	Correct disability grading			
<b>3. <u>Handling Reactions</u></b>				
	Correct regime of medication			
	Complete explanations to the patient			
	Regular control (every 2 weeks, inclusive POD)			
<b>4. <u>Health Education about Self-Care</u></b>				
	For inflamed nerves (immobilisation)			
	For insensitive hands / feet			
	Ulcer care			
	Exercises of weak muscles (strengthening) and of paralysed muscles (prevention of contractures)			
	Communication skills			
<b>5. <u>Knowledge about referral</u></b>				
<b>6. <u>Organisation of footwear</u></b>				

## ANNEX 5      REFERENCES

- ❑ *The Experience of Self-Care Groups with People affected by Leprosy*: ALERT, Ethiopia; Catherine Benbow, Teferra Tamiru, in 'Leprosy Review', 72, 311-321, 2001  
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Also available as **translation** by Dr Yamin Hasibuan, P2M Kusta, 1998: *Tindakan Penting untuk Mengurangi Resiko Cacat pada Penderita Kusta*
- ❑ *Buku Panduan Pelaksanaan Program P2 Kusta bagi Petugas Unit Pelayanan Kesehatan*, Direktorat Jenderal PPM dan PL, 2002
- ❑ *Buku Pedoman Pemberantasan Penyakit Kusta*, Direktorat Jenderal PPM dan PL, 2002
- ❑ *Modul Pelatihan Program P2 Kusta Bagi UPK*, PLKN, 2004
- ❑ *Income Generating Activities, A Guideline for Rehabilitation Workers Assisting Persons Affected by Leprosy Through Loan Scheme*, GLRA-Ethiopia, 1997

## ANNEX 6      LIST OF BOOKS AND ARTICLES

- ❑ *The Effectiveness of Self-Care Support Groups in the Prevention and Management of Ulcers: An Evaluation Study in Ethiopia*; Motbainor Abera, Girma Lemma; in 'Asia Pacific Disability Rehabilitation Journal', Vol.14 No 1, 2003
- ❑ *The Role of Support Groups in Raising the Self-Concept of People affected by Leprosy: An Evaluation Study in Ethiopia*; Motbainor Abera, Girma Lemma; in 'Asia Pacific Disability Rehabilitation Journal', Vol.14
- ❑ *Prevention of Disabilities in Patients with Leprosy – A Practical Guide*; H. Srinivasan, WHO, 1993
- ❑ *Wound Care for People Affected by Leprosy – A Guide for Low Resource Situations*; Hugh Cross, American Leprosy Mission
- ❑ *Lesson plans and Handouts for Training TBLS in Information, Education and Communication (IEC)*; NLR Nigeria, 1999

Photos by Kerstin Beise

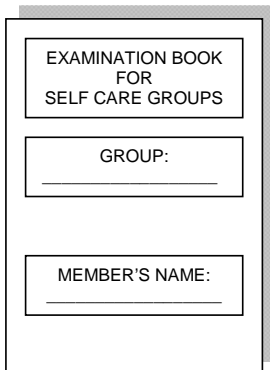
Title photo: Members of the SCG Malaka, Soppeng, South Sulawesi

Drawings with thanks taken from:

- *'Preventing Disability in Leprosy Patients'*, by Jean M. Watson with Illustrations by Judith Cole, TLMI 1986
- *'Tindakan penting untuk mengurangi resiko cacat pada penderita kusta'*, by Jean M. Watson (translation) with illustrations by Judith Cole and Syis Paindow
- *'Footbook'*, by Jan Robijn, Vietnam (Draft)
- *'Buku Pedoman POD'*, by PLKN 1995 (Draft)
- *'A Footwear Manual for Leprosy Control Programmes'*, Part 1, by P. Jane Neville, 4<sup>th</sup> edition, 1990
- *'Prevention of Disabilities – Guidelines for Leprosy Control Programmes'*, ILEP, 1993, with illustrations by Judith Cole

This manual is provided together with

- the example of an Examination Book, containing simple examination forms for 12 meetings,
- a CD Rom containing a 15 minute film about a SCG meeting, focusing on the way to facilitate a group, several forms that may be useful to manage a SCG, and some general information about POD / Self care.



EXAMINATION BOOK  
FOR  
SELF CARE GROUPS

GROUP:  
\_\_\_\_\_

MEMBER'S NAME:  
\_\_\_\_\_

