



Ten Steps

EXECUTIVE SUMMARY

**A Guide for Health Promotion and Empowerment of People
Affected by Neglected Tropical Diseases**

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american
leprosy missions

Foreword

For centuries, the infectious diseases that are collectively known as neglected tropical diseases (NTDs) have caused immense suffering, disfigurement and lost human potential. A global effort to control these diseases is now underway, led by the World Health Organization and supported by a vast network of public and private partners. The primary focus of this effort has been to reduce the burden of – and in some cases even eliminate – the infectious agents that cause NTDs. Far less attention has been given to alleviating the suffering and improving the condition of those who already have these conditions.

Ten Steps: A guide for health promotion and empowerment of people affected by Neglected Tropical Diseases is a gift of compassion, a guide to compassionate action. It provides clear instruction in the essential practical skills needed to relieve suffering caused by NTDs, especially those that affect the limbs, such as leprosy and lymphatic filariasis. The guide is also highly relevant for people with other NTDs such as Buruli ulcer, as well as for managing skin wounds, the complications of diabetes and many other conditions.

The guide is written primarily for caregivers – health workers, traditional healers, community volunteers and teachers – who can serve as “Health Coaches” to empower affected persons, their families and their communities. It addresses not only physical health issues faced by those with NTDs, but also the crucially important problems of impaired participation, limitations in activity and stigmatizing attitudes that create barriers for people with NTDs. The authors provide both encouragement for self-care practices and instruction on when to seek further help.

Each of the ten steps is meant to be practiced, not merely read. For each step, the basics are presented first, with the possibility of expanding in the future to more advanced interventions for those with the appropriate training, experience or resources. Indeed, the guide is recommended for training people at community, local and even national levels. The spectrum of issues addressed in this volume is impressive, ranging from healthy eating and personal cleanliness to appropriate footwear and care of the skin and nails, wounds and scars.

Recent research shows that providing appropriate care for those with chronic NTD-related diseases actually improves community acceptance of drug-based interventions aimed at reducing transmission of the infectious agents that cause them. Caring for those with NTD-related diseases is not only the right thing to do from a humanitarian and ethical perspective; it also results in substantial societal and economic benefits that extend far beyond the affected individual.

I wish to thank the authors for their unwavering commitment to this project. *Ten Steps* reflects their collective wisdom, acquired through many years of dedicated work and innumerable conversations with colleagues and affected people around the world. I am grateful that they persevered in the face of many challenges. May this guide be a blessing to many.

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Introduction to the Guide and Support Materials

Millions of people live with the physical, psychological and social challenges of Neglected Tropical Diseases and, for many, disability is an everyday reality. Morbidity management and disability interventions can have a clear and often immediate positive impact on the lives of the people affected.

Ten Steps: A guide for health promotion and empowerment of people affected by Neglected Tropical Diseases will enable health workers, communities and the people affected to identify common problems early, take appropriate actions to prevent or minimize complications, know when and where to refer, and understand how to monitor results. Since basic care at the community level is strikingly similar across diseases, this guide facilitates and promotes integrated, cross-cutting approaches. By empowering individuals, health workers and communities to competently and confidently face disease and care challenges, overall health outcomes can be improved.

The participation of people affected by NTDs and their communities is central to planning and implementing the *Ten Steps*. But they cannot do this without the broader support of the health system. The health worker, community volunteer, educator, traditional healer or other can act as a “coach” to develop awareness and capacities

to take action. Thus, in this guide the training facilitator is referred to as the “Health Coach.”

The *Ten Steps* package contains three sets of materials: a training guide, a summary card with key messages and actions, and a manager’s executive summary of each step.

The steps within this guide are best understood and learned when participatory and problem-solving teaching methodologies are used within the local context. All steps can be taught together or individually, and repeated as often as needed until the care can be done adequately. Confidence will develop as skills are practiced and positive results are seen.

Since 2008, the *Ten Steps* model has helped to control disease, preserve mobility, prevent disability and create inclusive communities for people affected by NTDs, disability or other health conditions. It is our hope that the publishing of this updated *Ten Steps* guide will enable many more people and communities to benefit from its approach.

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Cross-Cutting Issues by Type of NTD

	Leprosy	Buruli Ulcer	Yaws	Leishmaniasis	Lymphatic Filariasis	Podoconiosis	Trachoma	STH
WASH & Nutrition Accessible & Available	X	X	X	X	X	X	X	X
Eye: Vision, Exposure, Trichiasis	X	X					X	
Sensory Loss	X	X						
Muscle Weakness	X	X						
Movement Limitation	X	X	X	X	X	X	X	
Dry Skin	X	X	X	X	X	X		
Wound Present	X	X	X	X	X	X	X	
Wound at or Near a Joint	X	X	X	X				
Scar	X	X	X	X			X	
Edema	X	X			X	X		
Footwear	X	X			X	X		X
Activity Limitation	X	X	X	X	X	X	X	
Participation Restriction	X	X	X	X	X	X	X	

Introduction: Terminology and Reflection on How to Give Help/Care

It is important to have consistent definitions for terms such as prevention, rehabilitation and disability. This module aims to clarify terms based on the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) framework and WHO Community-Based Rehabilitation (CBR) guidelines. They both help us appreciate how diseases and health conditions can affect the whole person. The five components of CBR – health, education, livelihood, social and empowerment – are important in ensuring the inclusion of persons with disability within their communities.

This module will help participants reflect on the causes of disability, the kinds of disability and what can be done to promote health, enablement and inclusion for all. Participants will also have the opportunity to reflect on how help and care is provided and what kind of help/care best enables and empowers.

Goals

1. Use uniform terminology when talking about disability, prevention and rehabilitation.
2. Develop confidence, enable and empower through participation.

Key Messages

1. Prevention is the action taken to stop complications/problems from happening or getting worse.
2. Rehabilitation includes all actions aimed at reducing the impact of disability on the individual, enabling them to achieve independence, social integration, a better quality of life and self-actualization.
3. “Disability” is the term which encompasses:
 - Changes or losses in physical or mental functions and/or structure
 - Activity limitations
 - Social restrictions
 - Environmental situations which impede function
4. CBR is a community development strategy that includes key elements of health, education, livelihood, social and empowerment.
5. Explain what kind of help and/or care best enables or empowers.

Step 1: Suspect, Identify and Treat Disease and/or Health Condition Early



Early detection of disease and completion of disease-specific antibiotic treatment are two of the most important ways to prevent impairments, limitations in function and restrictions in participation. Participants need to become aware that community development and other interventions such as medical/surgical, social, educational, agricultural and advocacy may also be needed to promote health, enablement and inclusion of all, including those with disability. This requires the involvement of people affected, families, health workers and the community.

Goal

Earlier diagnosis and care prevents or minimizes disability.

Key Messages

1. Look and feel for painless skin patches, lumps, swelling or ulcers while performing daily hygiene.
2. If these are noticed, a community health worker should be told immediately and a supervisor called to confirm the diagnosis.
3. If there is a specific disease, then it is important to take all the medicine within the time specified. Usually these medicines are provided by the health service free of charge.
4. In addition to taking specific medicine, there may be other problems to care for like wounds, swelling, movement limitations, scars, difficulty doing daily activities, social isolation, etc.
5. Early discovery and treatment of disease or health conditions can prevent or minimize disability.

Step 2: Eat Healthily



A balanced daily diet with a mixture of different types of foods helps the body to grow normally, fight off diseases, provide energy for daily activities and heal wounds. Eating foods that are rich in protein (eggs, meat, fish, beans, nuts, dairy products), fresh fruit, vegetables and whole grains will help the body grow and heal faster. Eyes will be healthier if foods with vitamin A are eaten. Sources of vitamin A are found in breast milk, milk, yoghurt, cheese, eggs, red palm oil, red pepper, spinach, sweet potato, tomato, pumpkin, papaya, orange, fish, liver, carrots, cantaloupe melon, apricots, broccoli, butternut squash and cabbage.

Water makes up 60% of the body's weight. The body depends on water to cleanse it of waste and toxins, to carry nutrients to the cells and to provide a moist environment for the ears, nose and throat tissues. The amount of water required depends on where you live, how active you are and your state of health. Lack of water leads to dehydration, making it difficult for the body to function and making one feel tired. Water is lost through breath, perspiration, urine and bowel movements. Adequate amounts of foods containing water need to be consumed daily. If enough water is consumed, one will rarely feel thirsty and the urine will be colorless or light yellow. Eight to ten cups of water a day are recommended, but this may have to be adjusted according to individual and local circumstances.

Beliefs and culture influence what people eat as well as food availability and food cost. This module will help participants explore the reasons why people eat what they eat and increase awareness and knowledge on how to eat healthily.

Goal

Promote a healthy diet including water and foods that help the eyes fight off disease, give energy and help the body to grow and heal.

Key Messages

1. Eat as well as you can. Try to include the three food groups in each meal. Include many different colors of food each day.
2. Remember, a balanced daily diet helps the body to heal and grow normally, fights off diseases and gives energy for daily activities.
3. Drink adequate amounts (2 liters or 8-10 cups) of clean water daily.

Step 3: Practice Good Personal and Household Cleanliness



Individual and household behaviors are keys to preventing illness and infection. Soap and clean water should be used for daily bathing, for keeping faces clean and for handwashing. Handwashing should be done before food preparation, before eating and after toileting, and at other times when clean hands are needed. It is also important to wash food before eating and to keep clothing clean through regular washing.

Waste needs to be buried or stored/disposed of safely, and households kept free of material that attracts flies. It is important to explore common cleaning practices and discuss which methods are most effective and how they can be accomplished. Water and sanitation should be made safe for all and accessible to those with disabilities.

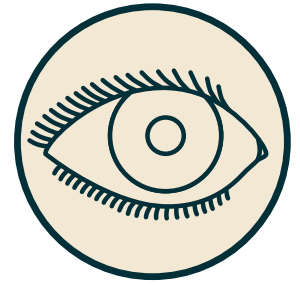
Goal

Practice daily hygiene and safe storage of waste to maintain health and prevent infection.

Key Messages

1. Bathing daily and washing face, hands, food and clothing with soap and water protect you from infections that cause sickness.
2. Wash, rinse and dry the body from top to bottom.
3. Wash and dry gently between the toes and in skin folds.
4. Repeat washing and rinsing of any body part until the water is clean/clear.
5. Ask for help if you cannot wash and dry areas that are difficult for you to reach or see.
6. Do not share the same towels and bed sheets with others.
7. Ensure faces are clean, waste has safe storage/disposal and that households are free of material that attracts flies.

Step 4: Care for Eyes



Good vision is important for performing activities at home, work, school and play. Vision is also needed to identify injuries and health problems early. Vision is even more important for people who have lost the ability to feel in their hands and feet, because they depend even more on their vision to perform self-care and other daily activities.

Fortunately, most blindness is avoidable. Washing the face often with clean water and soap can prevent serious eye infections that may lead to blindness. Other simple ways to preserve eye health include: eating healthy foods high in vitamin A such as sweet potatoes, carrots, dark leafy greens and chilis; taking childhood immunizations (measles); and protecting the eyes from dryness, sun glare and accidental injury.

The community can also promote behavioral and environmental changes to reduce factors contributing to eye infection and/or disease. Such changes include improving individual and household cleanliness, safely storing and/or disposing of human and animal waste, and eliminating the standing water that attracts flies.

It is also important to know the difference between healthy eyes and those with problems. Healthy eyes should be bright with clear corneas, black pupils (centers), and white eyeballs. The eyelids should open and close completely. There should be no eye pain, itching or blurring of vision. Eyes that are not like this should be referred. Sudden change or loss of vision is an emergency and should be referred to an eye specialist immediately.

Goal

Promote eye health and preserve vision.

Key Messages

1. A diet rich in vitamin A is good for eye health.
2. Good personal and environmental hygiene can prevent infection that can cause blindness.
3. Identifying eye problems early and taking action to provide care or referral can preserve vision.
4. Vision is critical to helping protect hands and feet with loss of feeling.

Step 5: Care for Skin and Nails



The skin covers the body, keeps in body fluids and keeps out dirt and germs. The skin has nerves which allow us to feel touch, pressure and pain. It also helps us know the differences between hot and cold and smooth and rough surfaces. Nails are special parts of the skin formed by its hard outer layer to protect the tips of the fingers and toes. Healthy skin and nails can enhance the body's natural beauty, the image we present to the outside world. However, the skin can be damaged by the sun, physical injury (e.g. blisters, cracks, tears or burns) and/or chemical injury (e.g. pesticides or strong soap). Proper skin care keeps the skin clean, soft and flexible. The nails can be frequently damaged by fungal infection. Keeping the nails clean and properly cut prevents injury and infection.

The first signs of health problems/illness often appear in the skin and nails. It is important to develop the daily habit of looking at and caring for the skin and nails. Therefore, good vision and lighting are essential to identify problems early and take action.

Goal

Practice good skin and nail care daily to improve appearance, protect against injury, prevent infection and preserve full joint mobility.

Key Messages

1. Look carefully at the skin and nails daily. If a problem such as a crack or wound is identified, take action to care for it and/or seek help.
2. Practice good skin and nail care, daily.
3. Arms, hands, legs and feet with loss of feeling are at high risk for injury. Take extra care to prevent damage when doing skin and nail care and protect them during the day, at work, at play and when walking.

Step 6: Care for Wounds



A wound is an injury or break in the skin or nail, including cracks and blisters. It is important to heal a wound as quickly as possible because it is an entry point for dirt and germs. When the wound is at or near a joint, special actions may be needed to preserve movement. Good wound care helps wounds heal quickly and prevents complications such as infection, pain and movement limitations. Moisture-retentive dressings speed healing and reduce pain and incidence of infection in chronic and acute wounds. This helps to preserve limbs and mobility, leading to improved participation and quality of life.

The purpose of this step is to provide basic training for the management of simple, uncomplicated wounds at the community level. Large or complicated wounds require advanced wound management and should be referred.

Goal

Practice wound care that aids in healing, prevents complications and improves quality of life.

Key Messages

1. Wounds will heal more quickly and with fewer problems if the six basic principles of wound management are applied during daily wound care.
2. Moisture-retentive dressings speed healing, reduce pain and reduce incidence of infection in chronic and acute wounds.
3. Keep dressing as clean and as dry as possible during bathing and other daily activities; change if wet.
4. Exercises and movement can be done when there is a wound, but movement is restricted for approximately 7-10 days after skin grafting.
5. Contact your community health worker if you notice these situations: excessive fluid soaking through wound dressing; or increased bad odor, pain, swelling, wound size, warmth or fever.
6. Handle and dispose of contaminated material safely.

Step 7: Care for Scars



A scar forms when a wound or burn heals. It results if the skin's injury is deeper than its outer layer (epidermis). The scar is never as strong, flexible or protective as the original skin and is at higher risk for injury. Therefore, the scar requires lifelong protection from moisture loss, trauma and sun damage. Good scar care decreases pain, minimizes itching and improves flexibility and appearance. It also decreases adhesions and soft tissue contractures that can limit movement. The scar's strong contracting forces can restrict movement and/or cause a visible impairment sometimes called "deformity." Early, careful positioning and exercise to oppose these forces can help preserve joint mobility. If caregivers, health workers and affected persons neglect scar care, it can lead to unnecessary complications.

Goal

Practice scar care that improves appearance, preserves movement and prevents complications that may lead to disability.

Key Messages

1. Scars at or near a joint are at higher risk of restricting movement.
2. Complete healing of a scar takes 1-2 years, and the scar is never as strong, flexible or protective as the original skin. Therefore, scars require lifelong protection from moisture loss, trauma and sun damage.
3. Keep the scar soft and flexible by soaking or applying wet compresses, applying moisturizers, and gently mobilizing the scar.
4. Early, careful positioning and exercise stretches the scar's strong pulling forces in the opposite direction to prevent movement limitation or to regain movement.
5. Sun-damaged scars and those that repeatedly break down and re-heal over time have a higher risk of developing cancer.

Step 8: Care for Swelling (Edema)



Swelling from any cause requires attention. In all types of swelling, early detection and action to reduce swelling can prevent complications and produce the best outcomes. Complications that may occur include: severely enlarged limbs and body parts, frequent infections and wounds that are hard to heal. Swollen limbs are heavy, painful and difficult to move. This limits the ability to do daily activities and can restrict participation in family, school, work, leisure and community activities. In addition, it is difficult to find footwear and clothes that fit.

If swelling does not go down, or lasts longer than three months, it may become a permanent condition called *lymphedema*. Lymphedema needs to be referred. The high protein content of lymphedema attracts bacteria and increases the risk of infection. These infections are called “acute attacks” and may be life threatening. When lymphedema affects the genital area, referral for surgical treatment may be necessary.

Lymphedema requires lifelong self-care management to control the swelling and infections. Without treatment, the condition worsens and may progress to *elephantiasis*. It is called elephantiasis because the skin becomes hard, thick, knobby and severely enlarged, resembling an elephant’s leg.

Early treatment and self-management produce the best results and can prevent progression. Teaching the affected person and their family/caregiver to practice daily skin and nail care, elevation and frequent movement of the swollen body part is essential. Additional reduction can be experienced when Manual Edema Mobilization (MEM) is added to self-care practices. MEM includes deep “belly breathing,” light lymphatic self-massage, exercise and light compression with foam, bandages or Lycra® undergarments or clothing.

Note: If the swelling is caused by infection, massage should not be used as it can spread the infection by moving fluid through the nodes (specific filter points which remove germs from the body) faster, before all germs can be destroyed. If it is unclear whether or not there is an infection, massage only one set of nodes that is closest to the swollen area. If there are no increased signs of infection, then massage can include additional nodes.

Goal

Swelling is detected early and action is taken to prevent complications and progression to lymphedema.

Key Messages

1. All swelling requires immediate attention.
2. Early detection and action to reduce swelling can prevent complications and produce the best outcomes.
3. Early care for swelling and good self-care practices can prevent progression of the swelling to lymphedema and/or decrease frequency of “acute attacks” in lymphatic filariasis.
4. It is essential to teach the affected person and their family/caregiver the signs of infection and to practice daily skin and nail care, elevation and frequent movement of the swollen body part.
5. Additional reduction can be experienced when Manual Edema Mobilization (MEM) is added to self-care practices. MEM includes deep “belly breathing,” light lymphatic self-massage, exercise and light compression with foam, bandages or Lycra® undergarments or clothing.
6. Decreasing the swelling usually lessens the pain and improves movement/mobility.
7. If care does not improve the condition, confirm that care practices are being done and being done correctly.
8. If swelling gets worse, seek help from the community health worker and/or referral center.

Step 9: Care for Movement Limitations



Higher risk for movement limitations is observed when wounds, burns and/or scars are at or near a joint. Some limitation of movement may also occur when a lesion is not near a joint or is a result of muscle weakness or paralysis. Identifying limitations in movement early and taking immediate action to restore full movement is important, and prevents joint stiffness and contractures. Preserving mobility is key to doing daily activities and participating fully in family, school, work and community life. Teaching the affected person and their family how to do daily movement/exercise helps prevent or restore lost movements. Movement and exercise start at the time of diagnosis, continue during disease-specific treatment and may need to continue for one to two years after the lesion is healed or continue for a lifetime, if there is muscle weakness or paralysis. The participation of the affected person in their self-care and other daily activities is critical for improving movement and strength.

Goal

Identify body structures (eyes, limbs, etc.) at risk for movement limitation early and take action to prevent or improve loss of movement.

Key Messages

1. The goal is to have the movement on the affected side be the same as the unaffected side.
2. Best results come from doing a few exercises many times a day.
3. Frequent movement/exercise is needed even when a wound is present and may need to be continued after the wound is healed.
4. Movement/exercises should be learned and practiced by the affected person or done with assistance from the family/friend/caregiver.
5. Movement/exercise may cause discomfort, but should not cause intense pain.
6. Movement causing severe pain is a sign that movement/exercise is excessive and the exercise needs to be modified.
7. If a limitation in movement increases, the community health worker or nurse should be contacted immediately.

Step 10: Use Protective Footwear



Basic footwear keeps the feet clean, comfortable, cushioned and protected. Wearing footwear prevents contact with dirt, germs, hot/cold and rough surfaces, and foreign debris (chemicals, sand, rocks, glass, nails, etc.). Footwear also protects the feet from injuries. Pain and areas of pressure can be reduced when appropriate footwear and accommodative insoles are used. Footwear should be comfortable and adjust for swelling, loss of motion and unusual shapes of the toes and feet.

People without feeling in their feet are often unaware of objects inside the footwear or foot injuries because they can't feel pain. Therefore, people without feeling in their feet need to check daily their feet and the inside of the footwear. Good foot care combines the wearing of appropriate footwear with the practice of good skin and nail care of the feet. Identifying early signs of skin damage (redness, warmth, callus, crack, blister, small wounds) and taking immediate action to rest, relieve pressure and/or go for help will help injured areas or wounds heal faster without complications.

It is important to learn how to select footwear. Footwear needs to be periodically cleaned, repaired and replaced. The following are considerations when selecting footwear:

- Match the footwear to the specific foot needs
- Fit the footwear to the foot
- Know what footwear to avoid
- Identify local footwear that is appropriate, affordable and, as much as possible, esthetically pleasing to the person using the footwear

Sometimes the person will need to be referred for custom footwear, assistive technology to facilitate walking or surgery. People who have or have had a history of a wound on the sole of the foot and/or have unusually shaped toes or feet may need to be referred for custom-made shoes and insoles or orthotics. Persons with a drop foot can use an assistive device to help them lift the toes during walking and protect their foot from injury. Referral for surgical correction of the foot may also be needed. Remember that using properly fitting footwear is a key element of good foot care and is effective in preventing disease, injury and infection.

Goals

Select and wear footwear that protects the feet and meets specific foot needs.

Repair and replace worn footwear and special footwear when needed.

Key Messages

1. Using footwear can reduce infections and injuries.
2. At-risk feet with sensory loss need good daily self-care practices along with adequate protective footwear.
3. Unusual foot shapes may require custom-made and fit footwear.



The complete *Ten Steps Guide* and *Executive Summary* are available for download at www.leprosy.org/ten-steps.

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