Chronic Care for Neglected Infectious Diseases: Leprosy/ Hansen's Disease, Lymphatic Filariasis, Trachoma, and Chagas Disease

A Guide for Morbidity Management and Disability Prevention for Primary Health Care Services

PAHO Pan American Health Organization World Health Organization Americas

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Foreword

Considerable progress has been achieved both globally and in the Region of the Americas towards the control and elimination of the neglected tropical diseases (NTD), known in the Americas as the neglected infectious diseases (NID). In 2016, for the first time in history, according to the World Health Organization (WHO), more than 1 billion people were reached globally with preventive chemotherapy interventions for NID such as lymphatic filariasis, onchocerciasis, soil-transmitted helminthiases, schistosomiasis, and trachoma; this figure was maintained in 2017. Most countries in the world have eliminated leprosy as a public health problem, 17 countries in the Americas have interrupted the domestic transmission of Chagas disease by the main vector species in whole or part of their territory, while there has been progress toward the global elimination of lymphatic filariasis, onchocerciasis, and trachoma. These are indeed very important public health achievements.

However, the NID can also have devastating chronic sequelae for patients, such as disability, visible change or loss in body structure, loss of tissue, and impairment of proper tissue and organ function, among others. All of these can in turn lead to unjustified discrimination, stigmatization, mental health problems, and partial or total incapacity to work, perpetuating the vicious cycle of neglected diseases as both a consequence and a cause of poverty.

Patients with chronic conditions require proper health care in order to prevent further damage and improve their living and social conditions. This should be provided at the primary health care level, as patients suffering from NID are often unable to travel to or afford to pay for specialized care services. Care for patients suffering from chronic morbidity caused by NID should be integrated into care for other chronic conditions caused by non-communicable diseases. For example, services that provide health care for patients with diabetic neuropathy could also offer care for patients with peripheral neuropathy caused by leprosy. Relatively simple measures, including self-care, can help prevent and improve the quality of life of patients living with chronic sequelae of NID.

Comprehensive disease management, care, and rehabilitation services should be integrated within the general health system. Providing morbidity management and disability prevention (MMDP) services for NID will contribute to the achievement of target 3.3 of the Sustainable

Development Goals (SDG), "By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases," and also to the achievement of universal health coverage (UHC), making sure that no one is being left behind.

The manual presented here provides a framework for MMDP of patients affected by NID and gives specific guidance for the proper care of patients suffering from chronic conditions caused by lymphatic filariasis, leprosy, trachoma, and Chagas disease. This manual is intended to be used mainly by health care workers at the primary health care level, but health workers at more complex and specialized levels may also find it useful.

PAHO's Neglected Infectious Diseases Program commissioned this manual to Ms. Linda Lehman, who has a great breadth of knowledge and experience working on MMDP and NID, particularly on leprosy in Brazil. She was able to convene an outstanding group of renowned experts as authors and reviewers for each of the chapters of the manual.

PAHO wishes to thank Linda, the authors, and reviewers for their excellent work and hopes that health care workers working in often remote locations where NID are prevalent will find this manual useful for the benefit of the patients and the communities they serve.

Santiago Nicholls

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Chapter 1 was authored by Linda F. Lehman, American Leprosy Missions, Belo Horizonte, MG, Brazil, and K. H. Martin Kollman, CBM International, Nairobi, Kenya, and reviewed by Paul Saunderson.

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Acronyms

ACE	Angiotensin-converting enzyme
ADL	Adenolymphangitis
ADLA	Acute dermato-lymphangio-adenitis
AFA	Acute filarial attack(s)
ARB	Angiotensin receptor blocker
AT	Assistive technology
BEST	Behavior, environment, social inclusion, and treatment
CCC	Chronic chagasic cardiopathy
CO	Corneal opacity
DEC	Diethylcarbamazine
DG	Disability grade
DMDI	Disease management, disability, and inclusion
ECG	Electrocardiogram
ECHO	Echocardiogram
EF	Ejection fraction
ENL	Erythema nodosum leprosum
GPELF	Global Programme to Eliminate Lymphatic Filariasis
GPS	Global positioning system
HD	Hansen's disease
HF	Heart failure
HIV	Human immunodeficiency virus
ICD	Implantable cardioverter defibrillator
ICF	International Classification of Functioning, Disability and Health
ICTC	International Coalition for Trachoma Control
LF	Lymphatic filariasis
MB	Multibacillary
MDA	Mass drug administration
MDT	Multidrug therapy
MEM	Manual edema mobilization

MMDP	Morbidity management and disability prevention
NFI	Nerve function impairment
NID	Neglected infectious disease(s)
NSAID	Nonsteroidal anti-inflammatory drug
NSVT	Non-sustained ventricular tachycardia
NTD	Neglected tropical disease(s)
PAHO	Pan American Health Organization
PB	Paucibacillary
PHC	Primary health care
PNF	Peripheral nerve function
POD	Prevention of disability or prevention of disabilities
PVC	Premature ventricular contractions
RDT	Rapid diagnostic test
SAFE	Surgery, antibiotics, facial cleanliness, and environmental improvements
SEARO	WHO Regional Office for South-East Asia
STEP	Stigma Elimination Programme
TCC	Total contact cast
TF	Trachomatous inflammation – follicular
TI	Trachomatous inflammation – intense
TS	Trachomatous scarring
TT	Trachomatous trichiasis
WASH	Water, sanitation, and hygiene
WHO	World Health Organization

Purpose of This Manual

This manual is a basic guide for primary health care services to identify, prevent, and manage disease consequences (morbidities and disability) in leprosy/Hansen's disease, lymphatic filariasis, trachoma, and Chagas disease.

Goals and Focus

To provide basic information and knowledge needed to:

- Prevent complications and disability;
- Recognize complications that need care;
- Provide basic interventions using a people-centered approach; and
- Seek timely help or refer as needed.

Target Audience

The target audience for this guide is primary health care (PHC) level doctors, nurses, nursing assistants, community health workers, and people affected by neglected infectious diseases (NID).

1 General Overview of Neglected Infectious Diseases

This chapter aims to:

1. Summarize the disease and disability burden of neglected infectious diseases (NID).
2. Describe the continuum of care.
3. Clarify how NID affect function and disability using the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF).
4. Compare the terms *morbidity management and disability prevention* (MMDP) and *disease management, disability, and inclusion* (DMDI).
5. Create an awareness of the importance of addressing stigma and mental health within MMDP.
6. Emphasize the critical role of community-led interventions for sustaining behavior change.
7. Emphasize the critical role of water, sanitation, and hygiene (WASH) in prevention and care activities of NID.
8. Promote a people-centered approach to care and self-care practices.

General Overview of Neglected Infectious Diseases

The Pan American Health Organization (PAHO) includes the neglected tropical diseases (NTD) of Hansen's disease/leprosy, lymphatic filariasis, trachoma, and Chagas disease within a group called neglected infectious diseases (NID).[1] They are called "neglected" because of their association with the social determinants of health and do not receive enough attention, even though most of the diseases are preventable and treatable and can be cured with medication that costs less than one dollar.[1] As of 2017, the World Health Organization includes 20 diseases within the NTD group.[2] NTD are found in 149 countries and affect more than 1.4 billion people, many of whom experience social discrimination and chronic disability as a result.[1,2,3]

NID affect many marginalized communities where there is poor housing and sanitation, unsafe water, and limited access to basic health services.[1,3] Millions of people live temporarily or permanently with the physical, psychological, and social challenges of NID.[2] The challenge is to *ensure healthy lives and well-being* of the people affected by NID by providing a "continuum of care."[4] This includes a comprehensive array of interventions spanning all levels and intensities, from promotional, preventive, treatment, and rehabilitation to palliative care.[4]

Treatment goes beyond efforts to prevent or cure an infection to delivering a comprehensive treatment that responds to the broader needs of individuals and communities. It requires the integration of inclusive disease management, care, and rehabilitation services within the general health system at the primary, secondary, and tertiary levels, as well as within the community. The goal is for services to be acceptable, available, and accessible to people affected, communities, and national programs, with no risk of financial hardship for the people affected.[4] The Neglected Tropical Disease NGO Network (NNN) BEST framework recognizes that the combination of *Behavior, Environment, Social inclusion, and Treatment* determines whether NID disease and disability prevention outcomes are successful or not.[5] Success and sustainability in interventions requiring behavior change are best when communities have ownership and lead interventions in collaboration with health services.[6]

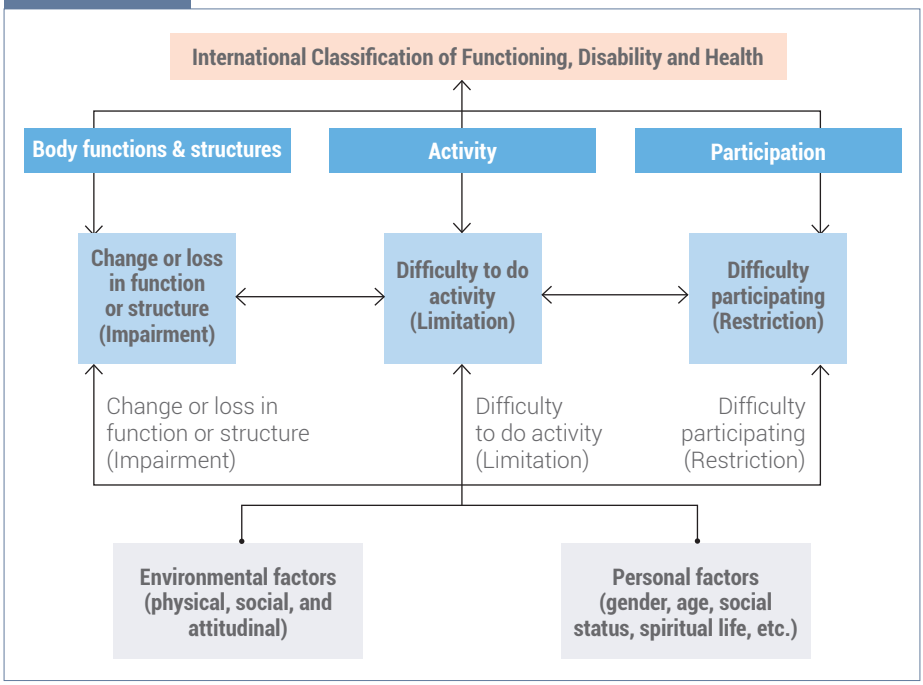
Understanding the NID Care Burden Using the WHO ICF Framework[7]

A more comprehensive understanding of the NID care burden can be gained by using the WHO International Classification of Functioning, Disability and Health (ICF). It is a framework applicable to all health conditions and provides a standard language to understand the effects of disease or health condition on functioning and disability. *Disability* is an umbrella term for impairments,

activity limitations, and participation restrictions caused by the disease or health condition. It indicates the interaction between a person's health condition(s) and the individual's contextual situation (environmental and personal factors).[7] The term *disability* in this manual will be used to describe each of the following:[7]

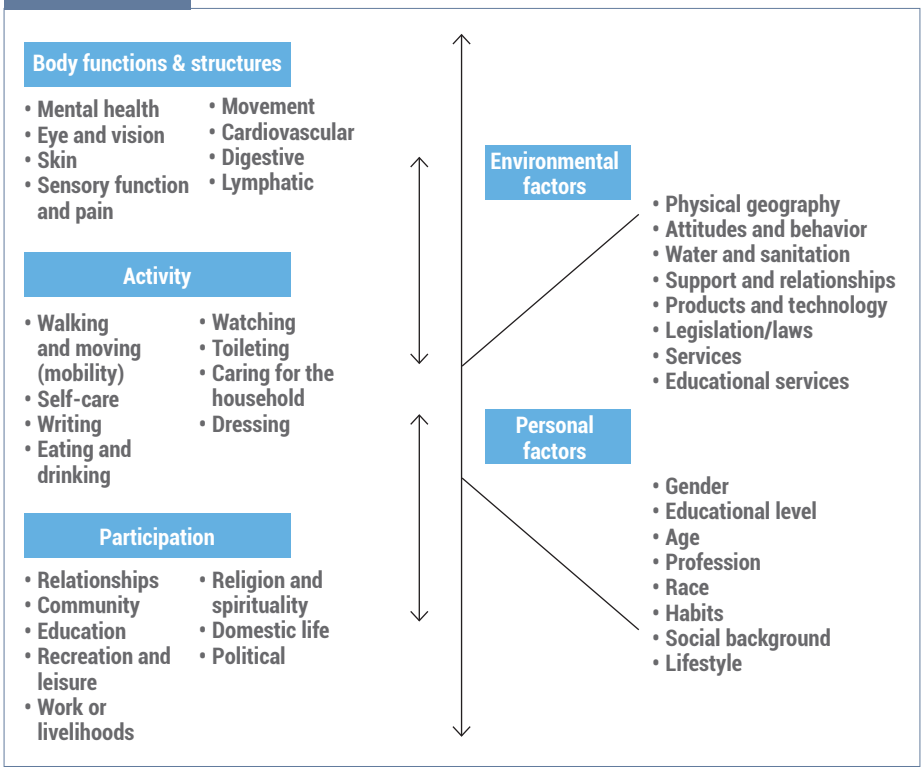
- Changes or losses in body functions and structures (physical or mental), which are referred to as impairments.
- Difficulties experienced by the individual in doing or executing a task or an activity, which will also be called an activity limitation.
- Restrictions to participation in family, school, work, and community life, which will be referred to as a participation restriction.
- Environmental factors refer to the physical (such as climate, terrain, or building design), attitudinal, and/or social factors (attitudes, laws, institutions) that affect functioning and disability. An example is social exclusion as a result of stigma and discrimination.

Illustration 1.1 . **International Classification of Functioning, Disability and Health**



International Classification of Functioning, Disability and Health. WHO.[7]

Illustration 1.2 . Examples of WHO ICF Framework Applied to Neglected Infectious Diseases



General Considerations about Morbidity Management and Disability Prevention (MMDP), Inclusion, and Stigma Reduction

The term MMDP is not easily understood outside the health sector. MMDP promotes health, self-care, surgery, and physical rehabilitation, in addition to addressing a wider range of issues relevant to NID, such as water, sanitation, and hygiene (WASH), community-owned and -led initiatives, empowerment, psychosocial and socioeconomic support, stigma reduction, and inclusion. MMDP needs to go beyond a medical model to

using social and human rights models for interventions. In 2016, the Neglected Tropical Disease NGO Network (NNN) began to substitute the term DMDI (disease management, disability, and inclusion) for MMDP, as the term is more comprehensive and inclusive. The BEST conceptual framework recognizes that NTD programs are comprehensive and inclusive and are fully integrated into strengthened national programs.[5]

The WHO Global Programme to Eliminate Lymphatic Filariasis describes MMDP and says it requires a broad strategy:[8]

> *This includes simple hygiene measures such as basic skin care; surgery; psychological and socioeconomic support for people with disabling conditions to ensure that they have equal access to rehabilitation services and opportunities for health, education and income; promoting positive attitudes towards people with disabilities; preventing the causes of disabilities; providing education and training; supporting local initiatives and supporting micro- and macro-income-generating schemes; and education of families and communities to help patients to fulfill their roles in society. For example, vocational training and appropriate psychological support may be necessary for overcoming the depression and economic loss associated with the disease.*

A person with NID may have temporary or long-term impairments, making access to general and specialized health services and rehabilitation difficult. Health services can be made more "disability" inclusive by doing the following:[7,9]

- Eliminate physical barriers (stairs, limited space for persons using crutches or wheelchairs, poor lighting and ventilation).
- Make examining and procedural areas accessible (door widths, chair and examining table heights, etc.).
- Make water and sanitation facilities accessible at the health service.
- Improve health worker knowledge and skills to effectively communicate and physically handle and position persons with impairments and disability.
- Change beliefs and attitudes of health workers about disability and specific diseases by improving awareness of negative imagery, language, stereotypes, stigma, and discrimination.

- Adapt waiting lists, booking systems for appointments, referral to specialized services, and treatment follow-up.
- Adapt care and frequency of health facility visits based on the individual's and family's ability, availability, and resources.
- Promote person-centered approaches to treatment.

Inclusion:

"a sense of belonging: feeling respected, valued for who you are; feeling a level of supportive energy and commitment from others so that you can do your best" (Miller FA, Katz JM. The Inclusion Breakthrough: Unleashing the Real Power of Diversity. San Francisco: Berret-Koehler Publishers; 2002).

Stigma is considered the "hidden burden" of disease.[10] It impacts people with NID and their families. Stigma appears to be related to the experience, meaning, and behavior associated with the disease by people affected and unaffected in the community. For many, there is a fear of contracting the disease. There are also different reactions to the physically visible impairments or exaggerated concerns about the danger of contagion. Muela Ribera et al. state that "*stigma can produce an often-irrational rejection of its victims by the stigmatizers, and also by the stigmatized themselves (self-stigma) and their allies.*"[11] For this reason, stigmas are often labeled as "social killers" since this rejection can lead to loss of social networks, loss of work, difficulty in finding marriage partners, divorce, loss of reputation, discrimination, isolation, ostracism, etc.

Interventions for enacted stigma may include promotion of public awareness to explain or correct exaggerated or inaccurate concerns about the dangers and risks of NID. In addition, legal protection and codes of conduct may protect people from enacted stigma in public places or provide compensation for discrimination. People with self-stigma may benefit from self-care groups, advocacy groups, and/or counseling.

STIGMA: *"a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group identified with a particular health problem."*[10]

Addressing Mental Health Care as an Important Part of MMDP

WHO states that mental health is an integral part of health and is determined by a range of socioeconomic, biological, and environmental factors.[12] Furthermore, recognizes that cost-effective public health and intersectoral strategies and interventions exist to promote, protect, and restore mental health.[12]

There is strong evidence of high rates of mental health problems among people living with NID.[13] The most common are depression and anxiety, as well as other mental disorders. In leprosy/Hansen's disease, the prevalence rates of depression are over 25% and for lymphatic filariasis more than 40%. The combination of the direct physical consequences (pain, physical disfigurement, and limitations), social attitudes, and stigma (enacted or self-stigma) often results in the person not participating fully in society. When treatment and care do not address these issues, more profound depression, anxiety, or other mental health conditions can result.[13] Mental health can improve if health workers are aware that depression, anxiety, and stigma are common, and they are trained to recognize problems and provide basic counseling and/or referrals when needed. Campaigns and peer support groups can help fight the damaging effects of social exclusion. Persons participating in self-care groups develop self-efficacy and frequently state that the psychosocial support of the groups contributes to their improved sense of well-being (physically, socially, and psychologically).[12,13,14,15]

"No health without mental health."[12]

Critical Role of Water, Sanitation, and Hygiene (WASH) in NID Prevention and Care[6,16]

The vicious cycle of poverty and diseases is linked with poor access to water, sanitation, and hygiene (WASH). Poor access and availability of WASH contributes to disease and makes treatment and care difficult at health service locations and at home. The WHO WASH Strategy 2015-2020 summarizes this critical role in preventing and caring for NID.[16] Communities and primary health services working together can assure WASH is safe, of good quality, available, and accessible for all, including those with disabilities. WASH can help prevent disease transmission, reduce complications, and improve quality of life. Community-owned and -led interventions play a crucial role in the sustained behavior change needed for WASH adoption. It is important to remember that WASH is a cross-cutting issue in the treatment and care discussed in all chapters of this manual.

Table 1.1. Critical Role of WASH in Preventing and Caring for Neglected Infectious Disease

NID prevention	NID treatment and care
• Access and use of sanitation to reduce environmental contamination in household and other community settings • Safe water supply for consumption, enabling hygiene practices, and reducing contact with surface water • Water resource and waste management for vector control and contact prevention • Hygiene practices such as handwashing with soap, face washing, overall personal hygiene, and safe food preparation.	• Availability of water for treatment and care at health care facilities and for self-care practices at home • Accessible WASH services for individuals with physical impairments • Prevention of stigma-based exclusion from WASH services enables personal hygiene and dignity.

Table 1.2. WASH Role in Leprosy/Hansen's Disease, Lymphatic Filariasis, Trachoma, and Chagas Disease

(Adapted from WHO WASH Strategy 2015-2020[16])

Disease	Role of WASH	
	Infection prevention	**Care**
Leprosy/ Hansen's disease	• There is no established WASH-related primary prevention strategy. • WASH contributes to more hygienic conditions and better health, and therefore a better immune status that may make communities and individuals less susceptible to the disease.	• Permanent nerve damage requires daily skin care with water to prevent skin fissures (cracks) and infection. • Wounds need water for wound management to prevent infection and furthering of disability. • Stigma can result in the person's being excluded from water and sanitation facilities. Limited access can lead to poor cleanliness and care, contributing to isolation and exclusion.
Lymphatic filariasis	• Improved sanitation and water management can reduce breeding sites of vectors which transmit the microscopic disease-causing worm.	• Chronic lymphedema from lymphatic filariasis requires daily personal hygiene using water and soap to prevent secondary infection. • Stigma can result in the person's being excluded from water and sanitation facilities. Limited access can lead to poor cleanliness and care, contributing to isolation and exclusion.

Table 1.2. (Continued)

Disease	Role of WASH	
	Infection prevention	Care
Trachoma	• Facial cleanliness (F) and environmental improvements (E) are primary prevention components of the Trachoma SAFE strategy.	• Trichiasis (a turning inward of eyelashes) requires surgical correction that needs clean water and hygienic conditions. • Visually impaired people require access to inclusive water and sanitation infrastructure.
Chagas disease	• Vector control is the key preventive method; however, good hygiene practices in food preparation, transportation, storage, and consumption are also recommended to reduce risk of parasite infection.	• Management of chronic heart disease • Management of digestive symptoms • Physical therapy

People-Centered and Community-Led Approach to Care[6,16,17,18,19]

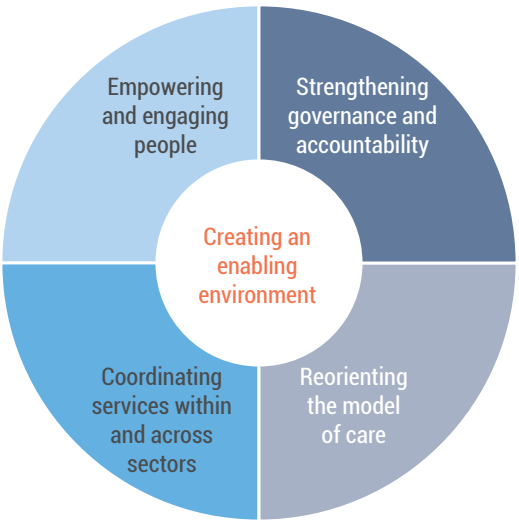
The concept of people-centered and community-led care is important throughout this manual.[6,16,17] Shared decision-making is central to both. It includes listening to, informing, and involving the person and their family, caregiver, friends, and community in planning, implementation, and evaluation of interventions. The care provided is respectful and responsive to individual preferences, needs, and values, and ensures the person and family values guide all clinical decisions. The Picker Institute's eight principles of patient-centered care are summarized below:[9]

1. Respect for the person's values, preferences, and expressed needs
2. Coordination and integration of care
3. Information, communication, and education
4. Physical comfort

5. Emotional support and alleviation of fear and anxiety
6. Involvement of family and friends
7. Continuity and transition
8. Access to care

People-centered health services means putting people and communities, not disease, at the center of health systems and empowering people to take charge of their own health rather than being passive recipients of services (Figure 1.1). The health service aims to maximize the person's, the family's, and the community's capabilities.

Figure 1.1. People-centered health services.



"All people have equal access to quality health services that are coproduced in a way that meets their life course needs and respects social preferences, are coordinated across the continuum of care and are comprehensive, safe, effective, timely, efficient and acceptable and all carers are motivated, skilled and operate in a supportive environment."[17]

Table 1.3. Framework on Integrated People-Centered Health Services: An Overview (WHO 2017)

VISION				
Strategy 1 Engaging and empowering people and community	**Strategy 2** Strengthening governance and accountability	**Strategy 3** Reorienting the model of care	**Strategy 4** Coordinating services within and across sectors	**Strategy 5** Creating an enabling environment
1.1.1.1.1 Strategic approaches				
1. Engaging and empowering individuals and families 2. Engaging and empowering communities 3. Engaging and empowering informal carers 4. Reaching the underserved and marginalized	1. Bolstering participatory governance 2. Enhancing mutual accountability	1. Defining service priorities based on life-course needs, respecting social preferences 2. Revaluing promotion, prevention, and public health 3. Building strong primary care-based systems 4. Shifting towards more outpatient and ambulatory care 5. Innovating and incorporating new technologies	1. Coordinating care for individuals 2. Coordinating health programs and providers 3. Coordinating across sectors	1. Strengthening leadership and management for change 2. Strengthening information systems and knowledge 3. Striving for quality improvement and safety 4. Reorienting the health workforce 5. Aligning regulatory frameworks 6. Improving funding and reforming payment systems
Potential policy options and interventions Partial list: Health education, self-management, social participation in health, training for informal carers, peer support, national health plans promoting integrated people-centered health services, patient satisfaction surveys, performance evaluation, shared electronic medical records, eHealth, case management, merging of health sector and social services, integration of traditional medicine into health services, change management strategies, information systems, multidisciplinary teams, provider support groups, bundled payments, and other				
Implementation principles Country-led, Equity-focused, Participatory, Evidence-based, Results-oriented, Ethics-based, Sustainable, Systems strengthening				

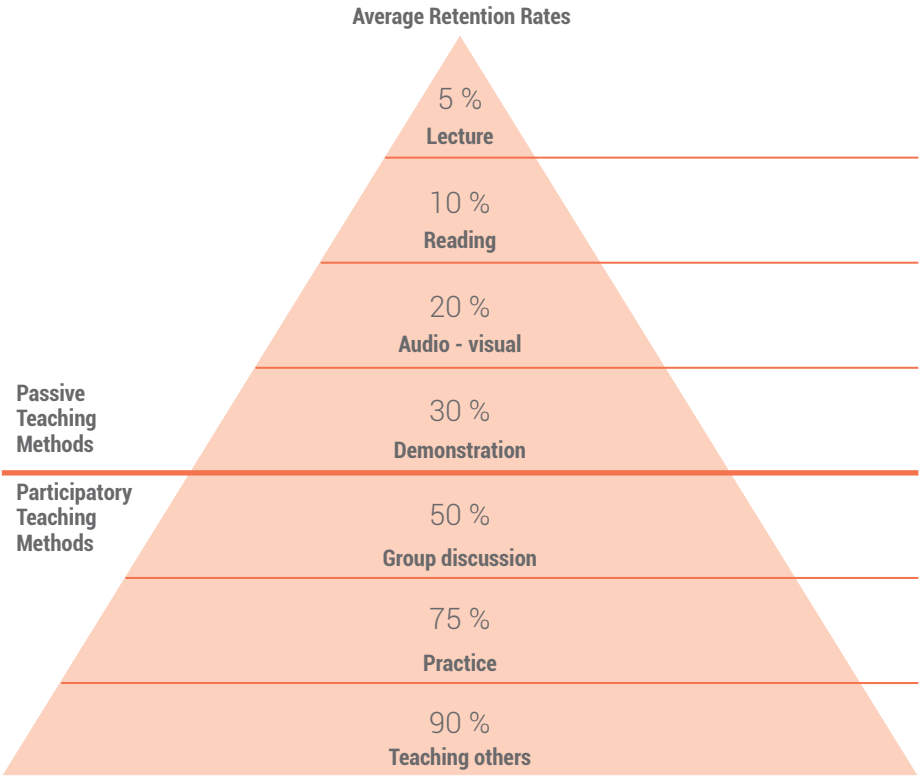
Self-Care

Learning self-care, individually or in a group, can improve persons' perceived beliefs about their capacity to take care of themselves. Developing a strong sense of *self-efficacy* (Bandura 1977, 1994) improves their compliance in practicing daily self-care and improves their sense of well-being. As a result, individuals feel they have the capability to exercise control over their disease, health condition, and disability. Self-efficacy is developed by:

1. Developing the ability to successfully do a task and solve problems.
2. Seeing similar people to oneself successfully do a task and solve problems.
3. Verbal encouragement and support by others and seeing self-improvement.
4. Optimistic self-belief in the worth of doing self-care.

Learning and retaining the information about self-care improves with group discussion, practice, and teaching others. Self-care groups can facilitate this learning process as well as providing important psychosocial support. Lower rates of learning retention and less sense of believing in abilities to do self-care may result if only verbal information, audio-visuals, and demonstration are used to teach self-care, without practical participation.

Figure 1.2. The Learning Pyramid



*Adapted from NTL Institute for Applied Behavioral Science. The learning pyramid. Maine: The National Training Laboratories; [circa 1960s].

KEY MESSAGES

1. NID treatment goes beyond efforts to prevent or cure the infectious disease, to delivering a continuum of care to *ensure healthy lives and well-being.*
2. *Disability* is an umbrella term that encompasses: impairments, activity limitations, participation restrictions, and environmental factors (physical or social) that can impede function and/or restrict participation.
3. MMDP promotes health and physical rehabilitation in addition to addressing a wider range of issues relevant to NID, such as empowerment, psychosocial and socioeconomic support, stigma reduction, and inclusion.
4. *Behavior, environment, social inclusion, and treatment* (BEST) determine whether disease and disability prevention outcomes are successful or not.
5. Available and accessible water, sanitation, and hygiene (WASH) are critical to NID prevention and care interventions.
6. People-centered care means putting people and communities, not the disease, at the center of health systems, and empowering people to take charge of their own health rather than being passive recipients of services.
7. Learning self-care can improve individuals' perceived beliefs about their capacity to take care of themselves and improve their sense of well-being and control over their disease, health condition, and disability.

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2

Care in Hansen's Disease (Leprosy)

This chapter aims to:

1. Clarify stigmatizing terms for the disease and promote the use of the term *Hansen's disease* for leprosy.
2. Summarize the disease and disability burden of Hansen's disease (HD) and define the WHO disability grades 0, 1, and 2.
3. Illustrate peripheral nerve function (PNF) and show how peripheral nerve impairment affects the skin, eyes, hands, and feet in HD.
4. Summarize disabling effects and management of reactions, neuritis, and nerve pain.
5. Describe the importance of preserving vision and how it is critical to people living with sensory loss.
6. Identify common issues needing treatment at the primary health service level and those that need to be referred.
7. Promote a people-centered approach to care and self-care practices.

Care in Hansen's Disease (Leprosy)

This chapter will focus on *care procedures* used by primary health care services, referral services, and self-care practices for people affected by HD or leprosy. Disability is prevented or minimized by a combination of actions:

- Early disease detection and treatment;
- Early management of HD reactions and nerve function impairment;
- Daily practice of self-care for eyes, hands, and feet;
- Psychosocial support; and
- Available, accessible, and inclusive health care services (primary, secondary, and tertiary) as well as inclusive communities.

Stigmatizing Terms of the Disease

People affected by leprosy have requested that the labeling words *leper* or *hansenite* not be used. These labels are offensive and are frequently associated with historical references to a disease that is highly contagious without "cure." As a result of stigma, the person and even family members can experience restrictions in participating in family and community life. To end the stigma and discrimination associated with the name leprosy, some countries in the Americas have adopted and promoted using the term Hansen's disease.[1] In this chapter, the disease will be referred to as Hansen's disease (HD), named after the Norwegian scientist who first viewed the bacillus under a microscope in 1873. Today the disease is treatable and "cured" usually within 6 to 12 months.[1,2,3,4,5,6]

General Overview of Hansen's Disease (HD) and Disease Burden[1,2,3,4,5,6]

Hansen's disease (HD) is a chronic infectious disease caused by *Mycobacterium leprae.* The disease mainly affects the peripheral nerves, the skin, the upper respiratory tract mucosa, and the eyes.

One or more of the following cardinal signs confirms the disease and the need to treat for 6 or 12 months with multidrug therapy (MDT):

- Skin lesions or areas with a loss of sensation to temperature, pain, and/or touch;
- Enlarged peripheral nerves associated with a decrease in sensory, motor, and autonomic functions;
- Presence of *M. leprae* on slit skin smears or skin biopsy.

Table 2.1. WHO Hansen's Disease Disability Grade

Grade	Eyes	Hands	Feet
DG0	No severe visual impairment (can count fingers at 6 meters; visual acuity >6:60) No visible impairments Normal blink (15-20 blinks per minute)	Touch is felt on the palm of the hand No muscle weakness or visible impairment	Touch is felt on the soles of feet No muscle weakness or visible impairment
DG1 Needs self-care	Decrease or loss of blink reflex and/or inability to hold the eyelids closed against moderate force to open them No severe visual impairment (can count fingers at 6 meters; visual acuity >6:60)	Does not feel touch of the 2g monofilament or light touch with the ball point pen on one or more points tested on the palmar surface of the hands* and/or Muscle weakness is present on testing, but there is no visible impairment	Does not feel touch of the 2g monofilament or light touch with the ball point pen on one or more points tested on the plantar surface of the feet* and/or Muscle weakness is present (on testing) but there is no high-stepping gait when the patient walks, and there is no other visible impairment
DG2 Late detection of disease Needs self-care	Visible impairments to eye due to leprosy For example: iridocyclitis, lagophthalmos, corneal ulcer or scars, corneal opacity, ectropion, entropion, trichiasis, nodules on the sclera, irregular shaped or pinpoint pupil Severe visual impairment (cannot count fingers at 6 meters, visual acuity <6:60, regardless of cause)	Visible impairment to the hand if it has occurred since the onset or loss of sensation and/or loss of muscle function due to leprosy For example: any bone loss, claw finger(s), muscle wasting, wrist drop, wound(s), deep cracks	Visible impairment to the foot if it has occurred since the onset or loss of sensation and/or loss of muscle function due to leprosy For example: any bone loss, claw toe(s), high-stepping gait (obvious foot drop), wound(s), deep cracks

* The Brazilian national program has adopted the criteria of 1-point loss on palm of hand or sole of foot using a 2g filament on both hands and feet, adopting earlier identification for earlier self-care practices. Other countries use 10g filament or ballpoint pen to determine DG1.
Disability grading adapted based on Delphi Study by Cross et et al.[8]

Early detection and treatment of the disease are essential for preventing impairments and disability in HD.[1,2] In addition, the early identification and treatment of HD reactions and nerve function impairments (NFI) are critical to preventing permanent neuropathies that lead to visible impairments and disability.[1,2] Greater discrimination and stigma are experienced when there are visible signs of the disease, such as lagophthalmos (inability to close eyelids completely), clawing of fingers and toes, drop foot, wounds, or ulcers.

The number of new cases reported globally each year is more than 200,000.[4] The Pan American Health Organization[6,7] reports more than 33,000 new cases in 24 countries of the Americas, of which 94% are in Brazil. Approximately 6.5% of all new cases are diagnosed late with a WHO disability grade (DG) of 2 (protective sensory loss with visible impairments of eyes, hands, and/or feet).[7] DG1 identifies people at risk of injury and ulcers and who are in danger of furthering their impairments and disability and progressing to DG2 if adequate management is not provided (Table 2.1).[1,8] Care prioritizes preserving vision, preserving nerve function, and enabling good self-care practices for those having NFI and WHO DG1 or DG2.[1,9,10,11,12]

The WHO disability grade (DG) of 0, 1, or 2 is registered at the beginning and end of treatment.[1] If the disease has been managed well, the disability grade will be the same or better at the end of treatment. Those starting with a DG2 usually continue to be DG2 at the end of treatment, although complications such as wounds and cracks can be prevented or reduced with good self-care practices.[1]

Access to clean water is needed for wound care and self-care practices.[13] The role of water, sanitation, and hygiene (WASH) is described in Table 2.2. The participation of people affected and their families in care is fundamental for preventing complications and further disability.[11] The key areas of care in Hansen's disease are summarized in Table 2.3.

Table 2.2. WASH Role in Hansen's Disease. Adapted from WHO WASH Strategy 2015-2020.[13]

Infection prevention	Care
• There is no established WASH-related primary prevention strategy. • WASH contributes to more hygienic conditions and better health, and therefore a better immune status that may make communities and individuals less susceptible to the disease.	• Permanent nerve damage requires daily skin care with water to prevent skin fissures (cracks) and infection. • Wounds need water for wound management to prevent infection and furthering of disability. • Stigma can result in the person being excluded from water and sanitation facilities. Limited access can lead to poor cleanliness and care, contributing to isolation and exclusion.

Table 2.3. Summary of Key Interventions for Hansen's Disease[1,2,9,10,12,15,18,21]

	Community health education for early detection and treatment Contact examination and BCG vaccination
Prevention	• CHE for early detection and treatment • Contact Examination and BCG
Treatment	• Multidrug therapy (MDT) for PB (≤ 5 lesions) – rifampicin, dapsone, and clofazimine • MDT for MB (> 5 lesions) – rifampicin, dapsone, and clofazimine • Treat HD reactions and neuritis with corticosteroids (prednisolone) • Wound care • Self-care practice (skin, eye, hand, foot care; protection and exercises) • Protective footwear for feet with sensory loss • Ophthalmological interventions: management of anterior uveitis (iritis), secondary glaucoma, cataract, eyelid correction for trichiasis, reconstructive surgery, etc. • Rehabilitation (physical, socioeconomic) • Surgical interventions: wound debridement, nerve decompression, reconstructive surgery, etc. • Self-care groups at the community level for prevention of disability (POD), empowerment, and inclusion • Psychosocial support and counseling • Stigma reduction

Adapted from Lehman, Geyer, and Bolton.[12] Ten steps health guide, step 1.

Preserving Nerve Function

Peripheral nerve function (PNF) and how it is affected in HD is summarized in Figure 2.1. Identifying when the nerve has a problem and taking immediate action to treat the inflammation can allow recovery of nerve function (sensory, motor, autonomic).[1,9,14] Permanent nerve function impairment (NFI) may result if the inflammation is not treated effectively. This can result in visible impairments and disability, requiring lifelong self-care practices to prevent complications.[1,10,11,14]

Think

"LOFT" for Early Detection of Nerve Function Impairment (NFI)

- ***LISTEN*** *carefully to the patient's comments (pain, tingling, no pain with injury, etc.)*
- ***OBSERVE*** *for areas of muscle wasting (atrophies), injuries, dryness, etc.*
- ***FEEL*** *for loss of sweating, temperature difference*
- ***TEST*** *sensory and motor function and take ACTION if NFI is identified*

Figure 2.2 shows the nerves most commonly affected in HD that should be evaluated.[1,2,9,14] The evaluation includes palpation of nerves for enlargement and/or pain and testing of sensation and motor function specific to each nerve. Nerve function is monitored monthly during multidrug therapy (MDT) and when the person has reactions during MDT or after completion of MDT. Documenting and comparing results helps identify changes in PNF and responses to specific neuritis treatments. A sample form is included in Figure 2.3. The inflammation of nerves in HD reactions is the main cause of NFI.[2] Identification and treatment of this inflammation is critical to preventing permanent NFI and disability.

Figure 2.1. Peripheral Nerve Lesions in Hansen's Disease[1,12,14]

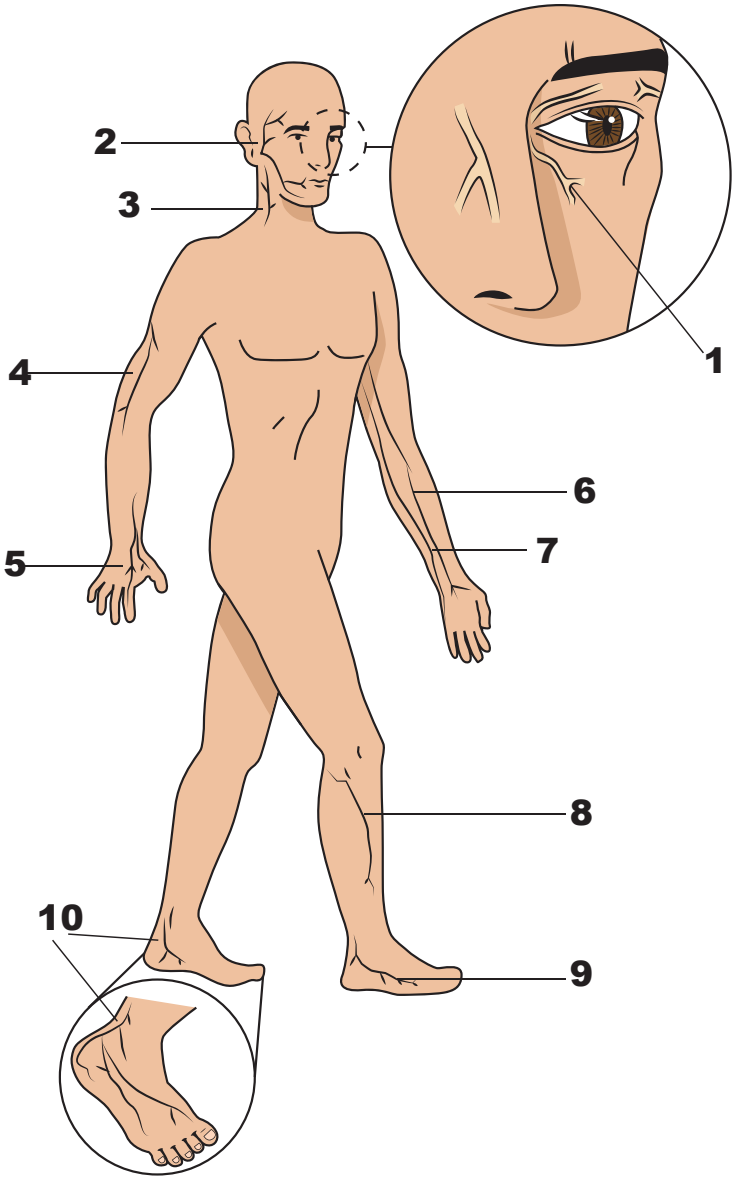
Effects of *M. leprae*, inflammatory and immune-mediated processes, and edema and mechanical processes on peripheral nerves

Primary impairments are reversible if detected and treated early and adequately Identify disease early and treat with MDT plus identify nerve function impairment (NFI) and treat early (within six months of change)		
Autonomic fibers	**Sensory fibers**	**Motor fibers**
• Impaired vasomotor reflexes • Inability to sweat normally in area affected • Loss of hair in area affected	• Decreased corneal sensation • Decrease in feeling light touch, pressure, temperature, pain	• Decreased strength, weakness, paralysis
Common observations and complaints		
• Area is dry, no sweating, and with hair loss	• Forgets to blink • Complaint that specific areas feel strange, tingly, different, or less sensitive • Complaint of difficulty identifying and removing coins from pocket • Complaint that sandals fall off feet while walking	• Difficulty in closing eyes, turning keys, writing, picking up feet • Hands look thinner (atrophy) • Calf muscle and feet look thinner (atrophy)
Secondary impairments resulting from primary impairments often not treated in time Identify who is at risk for cracks, blisters, injuries, and/or wounds; Practice daily self-care; Protect eyes, hands, and feet; Treat complications (wound care, surgery, therapy, etc.)		
Eyes: Dry eye (risk for corneal ulceration) Hands and feet: Dry skin (risk for cracks)	Eyes: Loss of corneal sensation (risk for corneal ulceration; dry eye from exposure and dryness from not blinking sufficiently) Hands and feet: Loss of sensation (risk for blisters, injuries, ulcers when doing daily activities)	Muscle paralysis increases risk for contractures and increases areas of high pressure Eyes: Lagophthalmos (risk of corneal ulceration from cornea exposure and dryness from not being able to close the eye) Hands: Clawing of fingers (risk for contractures and injury) Feet: Foot drop, clawing of toes (risk for contractures and ulcers)
Increased risks for cracks, blisters, injuries, ulcers, and secondary infections		
Destruction of bones and soft tissues		
Increased visible impairments and disability		

Adapted from Lehman et al.[12,14]

Figure 2.2. Peripheral Nerves Commonly Affected in Hansen's Disease Requiring Palpation and Simplified Sensory and Motor Function Assessment[1,12,14]

1. **Trigeminal nerve**
   - Observe blink
   - Test corneal sensation
2. **Facial nerve**
   - Check eye closure by closing as in sleep
   - Check resistance when closing eyes tightly
3. **Auricular nerve**
4. **Radial nerve**
   - Check force of "wrist up"
5. **Radial cutaneous nerve**
   - Check dorsal web space sensation (optional)
6. **Median nerve**
   - Check sensation on palmar side of thumb, index finger, and hand
   - Check force of "thumb up" in abduction
7. **Ulnar nerve**
   - Check sensation on palmar side of little finger and hand
   - Check force of "little finger out" in abduction
8. **Peroneal nerve**
   - Check "foot up" in dorsiflexion
   - Check "big toe up"



9. **Sural nerve** (lateral, dorsal side of foot)
   - Check dorsal lateral side of foot (optional)
10. **Tibial nerve** (medial side of ankle)
   - Check sensation on plantar surface of foot

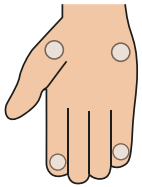
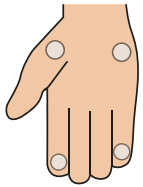
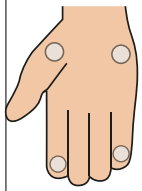
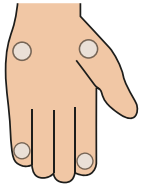
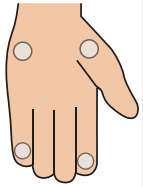
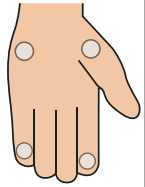
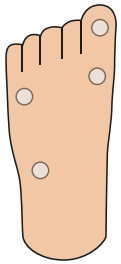
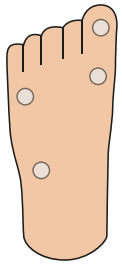
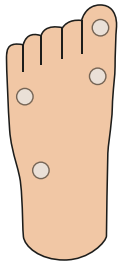
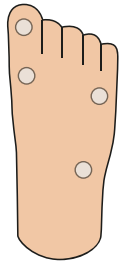
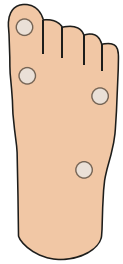
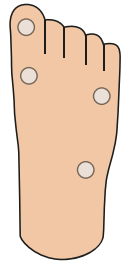
Adapted from Lehman et al.[12,14]

Figure 2.3. Simplified Vision and Nerve Function Assessment

Name: **Age:** **Occupation:**

Date (1) _____	Date (2) _____	Date (3) _____	Vision & Neurological Exam	Date (1) _____	Date (2) _____	Date (3) _____
Right			**EYES**	**Left**		
_____m _____SC	_____m _____SC	_____m _____SC	**Visual Acuity** Note finger count in meters 0-6 or number on Snellen Chart (SC)	_____m _____SC	_____m _____SC	_____m _____SC
Yes No	Yes No	Yes No	**Cornea: Loss of Sensation** Blink decreased or decreased sensation with 5-cm length dental floss	Yes No	Yes No	Yes No
P W S	P W S	P W S	**Loss of Muscle Strength** Eye Closure P = Paralyzed, W = Weak, S = Strong	P W S	P W S	P W S
_____mm	_____mm	_____mm	**Lid Gap: Light closure** of eyes Measure lid gap in mm	_____mm	_____mm	_____mm
_____mm	_____mm	_____mm	**Lid Gap: Tight closure** of eyes Measure lid gap in mm	_____mm	_____mm	_____mm
Yes No	Yes No	Yes No	**Visible Impairments of the Eyes**	Yes No	Yes No	Yes No
Right			**HANDS**	**Left**		
P E N	P E N	P E N	**Nerve Palpation: Ulnar** P = Painful, E = Enlarged, N = Normal	P E N	P E N	P E N
Evaluate Loss of Muscle Strength in Hands: P = Paralyzed, W = Weak, S = Strong or 0-5 grading						
P W S	P W S	P W S	**Little finger out (abduction)**	P W S	P W S	P W S
P W S	P W S	P W S	**Thumb up (abduction)**	P W S	P W S	P W S
P W S	P W S	P W S	**Wrist up (extension)**	P W S	P W S	P W S

Figure 2.3. (Continued)

			**Sensory Loss to Palm of Hands** SW Monofilaments (use colors) or Light Touch with Ballpoint Pen or **2g** monofilament. Mark with: **X** = Loss of sensation ✓= Feels touch			
Yes No	**Yes No**	**Yes No**	**Wounds on palmar surface of hands**	**Yes No**	**Yes No**	**Yes No**
Yes No	**Yes No**	**Yes No**	**Visible impairments of the hands**	**Yes No**	**Yes No**	**Yes No**
Right			**FEET**	**Left**		
P E N	**P E N**	**P E N**	**Nerve Palpation: Peroneal** P = Painful, E = Enlarged, N = Normal	**P E N**	**P E N**	**P E N**
P E N	**P E N**	**P E N**	**Nerve Palpation: Tibial** P = Painful, E = Enlarged, N = Normal	**P E N**	**P E N**	**P E N**
Evaluate Loss of Muscle Strength of Feet: P = Paralyzed, W = Weak, S = Strong or 0-5 grading						
P W S	**P W S**	**P W S**	**Foot Up (dorsiflexion)**	**P W S**	**P W S**	**P W S**
P W S	**P W S**	**P W S**	**Large Toe Up (extension)**	**P W S**	**P W S**	**P W S**
			**Sensory Loss to Sole of Feet** SW Monofilaments (use colors) or Light Touch with Ballpoint Pen or **2g** monofilament. Mark with: **X** = Loss of sensation ✓= Feels touch			
Yes No	**Yes No**	**Yes No**	**Wounds on Soles of Feet**	**Yes No**	**Yes No**	**Yes No**
Yes No	**Yes No**	**Yes No**	**Visible Impairments of the Feet**	**Yes No**	**Yes No**	**Yes No**
Signature	**Signature**	**Signature**		**Signature**	**Signature**	**Signature**

Adapted from Brazil, Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Vigilância e Doenças Transmissíveis. Guía prático sobre a hanseníase. Brasília, DF: Ministério da Saúde; 2017. Pages: 36-37.

HD Reactions and Peripheral Nerve Impairment

HD is "curable," but complications and disability can occur when HD reactions are not effectively managed at the time of diagnosis, during treatment, and after disease-specific treatment is completed. An estimated 25-30% of all people will experience HD reactions (type 1 and/or type 2) at one time or another, due to changes in the immune system. Almost any person with HD is at risk of getting a reaction, but it is more frequent in persons with the multibacillary (MB) form of the disease.[15] If MB cases present with nerve impairment at diagnosis they should be monitored closely, as such cases will have a 65% greater risk of increasing nerve damage.[15] If reactions are treated effectively, early nerve damage can be reversed, disability prevented, and nerve function preserved.

Table 2.4. Risk of New Nerve Damage Developing in New Cases of Hansen's Disease

	WHO Operational Classification	
	PB (≤ 5 lesions)	MB (> 5 lesions)
Normal nerve function at diagnosis	1%	16%
Impaired nerve function at diagnosis	16%	65%

Croft et al.[15]

Most reactions occur within the first year after diagnosis and, in MB-type HD, can continue several years after treatment is completed.[1,9] The typical features of reactions are: swelling, redness, heat, pain, and loss of sensory, motor, and autonomic function. This can affect the eyes, skin, and/or nerves. Swelling and pressure in the nerve can cause serious damage, resulting in a loss of sensory and motor function. Inflammation of the eye can be painful with acute loss of vision. The skin, nerves, and eyes should be checked every visit for reactions, and the person should be taught to report these signs and symptoms as soon as possible.

Checklist for Reactions in Skin, Nerves, and Eyes[1,9]

Signs of a reaction in the skin: Inflamed (red, swollen, elevated) skin patches

- Ask the person to report if there is any pain or swelling in their skin patches.
- Examine the patches for signs of inflammation.
- Examine the hands and feet for loss of sweating.

Signs of a reaction in the nerves: Pain or tenderness in a nerve, new loss of sensation, new muscle weakness

- Ask the person to report if there is any loss of feeling or loss of strength in hands and feet.
- Ask the person to report if they have difficulty with their daily tasks such as losing footwear when walking, dropping things, difficulty writing, buttoning clothing, turning keys, unrecognized burns or injuries.
- Ask them to report pain, burning, or tingling ("pins and needles") in the nerves.
- Examine the nerves for tenderness.
- Test for loss of feeling in the palms of the hands and soles of the feet, using a ballpoint pen or a monofilament.
- Test the strength of the muscles of the eyelids, hands, and feet.
- Compare results with the records of the previous examination.

Signs of a reaction in the eyes: Pain and redness in the eye, new loss of vision, new weakness in eye closure

- Ask the person to report if there is any pain in the eyes and/or recent loss of vision.
- Look for signs of inflammation: redness; small, slow-reacting pupil; irregularly shaped pupils.
- Check visual acuity with Snellen E Chart.

Adapted from International Federation of Anti-Leprosy Associations.[9]

Table 2.5. Summary of Type 1 and Type 2 Reactions in Hansen's Disease

Sign	Type 1 reaction	Type 2 reaction/ENL
Inflammation of the skin	Appearance of new skin lesions which are red, elevated (inflamed), but the rest of the skin is normal	ENL (erythema nodosum leprosum): Appearance of painful subcutaneous skin nodules with or without systemic manifestations
General condition of the person	Good, with little or no fever	Systemic manifestations with or without nerve enlargement and pain: Fever, joint pain, general malaise, orchitis, etc.
Timing of presentation if MB or PB type of disease	Usually early on in the course of MDT for both PB and MB	Usually later in the treatment in only MB types of disease
Hand and foot involvement	Nerve function impairment (NFI): Decrease in sensation and/or weakness in movement with or without nerve pain	Swelling (edema) of the limbs Sometimes NFI
Eye involvement	NFI: Weakness of eyelid closure may occur	Internal eye inflammation (iritis) is possible

Adapted from Brazil, Ministério da Saúde and International Federation of Anti-Leprosy Associations.[1,9]

Treatment for HD Reactions: Neuropathic Pain and Neuritis[1,9]

The following are important considerations when starting corticosteroids:

- Register weight, arterial pressure, and fasting blood sugars;
- Verify if the person is pregnant;
- Treat for parasites: *Strongyloides stercoralis*:
    - Thiabendazole: 50 mg/kg/day 3 times a day for 2 days or 1.5 g one time; or
    - Albendazole: 400 mg/day for 3-5 consecutive days;
- Prophylactic treatment for osteoporosis:
    - 1,000 mg/day of calcium along with vitamin D 400-800 UI/day; and/or
    - Bisphosphonates: alendronate 70 mg/week taken with water in the morning 30 minutes before eating;
- Monitor changes in vision, pain, and nerve function, and teach the person and family how to monitor changes at home.

Summary of Care for HD Reactions

Care	Type 1	Type 2
1. Monitor changes in vision, pain, and nerve function, and teach the person and family how to monitor changes at home.	x	x
2. If currently using MDT, continue MDT. If MDT is completed do not restart MDT.	x	x
3. Presence of neuritis, ocular reactions, edema in hands and feet, glomerulonephritis, orchitis, arthritis, vasculitis, necrotizing erythema nodosum: a. Start prednisone or prednisolone 1 mg/kg/day; or b. Dexamethasone 0.15 mg/kg/day in persons with hypertension and other cardio-pathologies.	x	x
4. If neuritis is present, immobilize and/or restrict repetitive movement of the affected limb during daily activities until the acute phase is over.	x	x
5. Reduce dose of corticosteroid according to therapeutic response (less pain, improved sensation and/or muscle strength).	x	x

6. Practice self-care (daily inspection, skin care, rest, protect affected area, and modify daily activities).	x	x
7. Use ASA (acetyl salicilic acid) 100 mg/day for prevention of thrombosis.	x	x
8. Refer: a. severe reactions to be managed at the hospital; b. NFI not improving within 4 weeks of corticosteroids for nerve decompression surgery.	x	x

Adapted from Brazil, Ministério da Saúde.[1]

ATTENTION: If there is chronic or frequent recurrence of reactions, precipitating factors should be investigated: periodontal infections, intestinal parasites, hormonal factors, emotional factors, metabolic factors, uncontrolled diabetes, sinusitis, contact with an undiagnosed and untreated MB patient (frequently within the same household).

Difference Between Neuritis and Neuropathic Pain[1]

When there is a decrease or loss of nerve function (sensory and/or motor) with or without pain (silent neuritis), it is called neuritis. Best functional recovery is seen when the neuritis is treated with corticosteroids within six months of the new sensory and/or motor loss. If function does not improve within four weeks, referral for surgery may need to be considered.

Neuropathic pain is characterized by having only symptoms of pain, including allodynia (pain response after a stimulus which normally does not provoke pain), hyperpathia (exaggerated levels of pain are evoked), and paresthesia (abnormal tingling or pricking sensation "pins and needles"), without progressive loss of nerve function. Neuropathic pain may be associated with nerve compression, or occur during inflammation, or result from previous neuritis. Neuropathic pain often improves when treated with tricyclic antidepressants, anticonvulsants, and/or neuroleptics.

Managing Neuropathic Pain[1]

There is a synergistic action when tricyclic antidepressants are used with neuroleptics and/or anticonvulsants when managing persistent, difficult to manage nerve pain. In general, it is less expensive and equally effective to use a low-dose antidepressant (10-25 mg/day) with a low dose neuroleptic (5-10 mg). Other options are listed below.

Table 2.6. Pharmacological Options for Managing Neuropathic Pain

Medication		Usual dose	Maximum dose
Tricyclic antidepressants			
Amitriptyline hydrochloride	25-mg capsule	25-150 mg	300 mg
Nortriptyline hydrochloride	25-mg and 50-mg capsules	10-50 mg (0.2-3 mg/kg)	150 mg
Neuroleptics			
Chlorpromazine	Drops or tablet	5 drops 12/12h 12.5 mg 12/12h	20 drops 12/12h 100 mg 12/12h
Anticonvulsants			
Carbamazepine	200-mg tablet 20 mg/ml oral	200-1,200 mg	3,000 mg
Gabapentin	300-mg and 400-mg capsule	900-2,400 mg	2,400 mg

Adapted from Brazil, Ministério da Saúde.[1]

Surgical interventions for neuritis.[1] Surgery may be needed to reduce the nerve compression when there is no clinical improvement with standard neuritis treatment. Referral for surgical decompression is used for:

- nerve abscesses;
- neuritis not improving within four weeks of standard neuritis treatment;
- reoccurring neuritis;
- neurovascular decompression of the tibial nerve to prevent or heal plantar ulcers;

- chronic nerve impairments with chronic pain;
- neuritis with other associated comorbidities (glaucoma, diabetes), which restrict the use of corticosteroids.

Preserving Vision[1,12,16,17]

One of the most important care objectives in HD is preserving vision. Persons with a sensory loss in hands or feet depend on vision to safely perform self-care, work, and other daily activities. All efforts to improve vision are important. This may include improving access to specialist eye services, prescription eyeglasses, and cataract surgery. Great disability and dependency result if the person has no vision and is without hand and foot sensation. Ocular problems in HD are usually caused by complications related to NFI in the trigeminal and/or facial nerves (Figure 2.2) and/or type 2 HD reactions.

Persons with HD reactions using prednisone or prednisolone should be monitored for glaucoma and cataracts. Type 2 HD reactions are not common, but when inflammation inside the eye occurs, immediate care is needed or it can lead to blindness. The signs will be pain, light sensitivity, sudden change in vision, eye redness, and a slow-reacting pupil. This emergency is treated with atropine and cortisone drops or ointment.

ATTENTION: Eyes that are red, painful, and with sudden loss of vision need IMMEDIATE CARE.

Self-Care for Eyes[1,11,12,16,17]

Face and eyes are washed with clean water, and eyes are observed daily for redness and for eyelashes turning in and touching the cornea. Vision is quickly checked daily by looking at the same object at 6 meters with one eye and then the other eye.

If the vision seems to have suddenly changed, blink for 5 minutes and then recheck the vision. If the vision improves, the decrease in vision was due to a "dry eye" and requires more blinking and/or moisturizing drops. It is not easy to remember to blink when there is corneal anesthesia. One must learn to "think blink." Blinking cleans, protects, and provides moisture to the eyes.

Daily eye care involves:

1. checking eyes in a mirror;
2. checking right and left eye vision;
3. keeping eyes clean and moist;
4. protecting eyes from injury during the day and night; and
5. strengthening eye closure if muscles are weak.

Care for lagophthalmos.[1,11,12,16,17] The inability to close the eye leads to corneal dryness with risk of injury and ulceration due to corneal exposure during the day and night. Managing lagophthalmos includes daily vision checks, cleaning of face and eyes, with care not to scratch the eye when drying the face and eyes. The eyes can be kept moist by using artificial tears frequently during the day, and bland oil such as castor oil at night. Care must be given not to rub the eyes with dirty cloths or rough, insensitive hands. Using a hat, cap, scarf or shawl, and eyeglasses can reduce the drying effects of exposure during the day. A fan can be used to keep flies away. At night, the exposed eye(s) should be safely covered to maintain moisture and to keep dust and insects from falling into the eye while sleeping. A simple elevated eye patch can be made from 1-cm-thick sponge with the center eye area(s) cut out and covered with a thin clear plastic and held into place by an elastic or tie headband. A cone-shaped eye shield can also be made from cardboard. Many persons request a clear plastic covering versus opaque so they have some vision if they have to get up at night to go to the toilet.

Care for corneal ulcer.[1,16,17] Corneal ulceration is an emergency and best referred to a professional trained in eye health care. The eye should be washed with clean water or saline, antibiotic eye ointment applied, and the eye closed. If the person has lagophthalmos, it is safer to cover the eye using the elevated eye patch described above. It will provide a moist, protected environment for healing.

Surgical care.[1,16,17,18,19] Referral for surgical care may be needed. Surgery can reduce corneal exposure in persons with lagophthalmos. Correction of the eyelid position and removal of inverted eyelashes scratching the cornea (trichiasis) is an important intervention in preventing corneal damage and blindness. Removal of cataracts to restore vision is essential for persons with loss of sensation in the hands and feet. This will improve safety, function, and participation in family and community life.

Table 2.7. Eye Care Summary

Eye Care Summary[1,12,16,17,18]

Questions to ask the person, family, health worker:

1. Is the eye red? Is there pain? Is there sudden change in vision? Is there recent loss of ability to close the eye?
2. Does the person forget to blink, keeping eyes open for long periods of time with no burning or itching feeling telling them to close the eye?
3. Is there difficulty closing the eye completely, and, when sleeping, does the eye stay open, exposed at night to the air, dirt, etc.?
4. Is the person able to count fingers at 6 meters or is there any other problem seeing far away and/or close up?

Basic care	Special equipment, materials, etc.	Referral to hospital, specialist, surgery
Self-care: • Inspect eyes and clean eyes and eyelashes daily with clean water and a clean cloth. • Check vision in each eye from the same location, looking at the same fixed object at the same time of day.	• Glasses or sunglasses for protection against dirt, sun, smoke, etc. • Artificial tears to lubricate the eye • Eye ointment at night to prevent dryness (lagophthalmos) • Adapt eyeglasses with headband if there is collapsed nose	• Treat immediately iridocyclitis (sudden loss of vision, red, pain, sensitivity to light) with atropine, corticosteroids • Refer corneal ulcer immediately for treatment (ointment and occlusion) • Refer low vision and loss of vision for ophthalmology evaluation

Table 2.7. (Continued)

Basic care	Special equipment, materials, etc.	Referral to hospital, specialist, surgery
Self-care: • "Think blink" (to lubricate cornea when there is a decrease or loss of cornea sensation). • Use a clean cloth to dry tears. Dry, starting at cheek and moving upward toward lower eyelid, carefully not rubbing cornea with cloth or dirty shirtsleeve. • Close eye tightly. Hold closed for 5 seconds, then open widely, hold for 5 seconds. Repeat 10 times (to strengthen weak muscles).	• Prescription glasses to improve distance and close vision • Special eye ointments • Cane for mobility • Magnifying glass to help with low vision • Use larger letters	• Eyeglasses (distant and close up) • Cataract removal • Surgical correction of entropion (eyelid turning in) and removal of eyelashes touching cornea • Surgical repair of ectropion (eyelid turning out) to help support tears and keep cornea moist • Surgical correction of lagophthalmos to decrease cornea exposure
Protection: • Remove eyelashes that are turned in and rubbing on the cornea. • Wear wide-brimmed hat and sunglasses to protect from and reduce corneal dryness. • Use mosquito net at night to prevent foreign matter from falling into eye. • For eyes that cannot close completely at night, use a protective night shield and ointment to maintain corneal moisture.		
Daily activities for persons with low vision or loss of vision (cannot count fingers at 6 meters): • Maintain all objects in the same location to allow the person to move about independently. • Adapt the environment for the person. • Use a cane. • Be sure hot water and objects are safely placed to prevent risks for burns.		

For more information, please see Annex 4.1, General Eye Health for Community-Based Primary Health Care.

Living with Permanent Nerve Damage: How to Prevent Complications and Further Disability[1,10,11,18,19,20,21]

Late disease detection and/or poor management of HD reactions can result in permanent nerve damage with protective sensory loss and visible impairments of the eyes, hands, and feet. General health services, wound management services, and specialist services such as ophthalmology, rehabilitation, reconstructive surgery, footwear, and prosthetics should be available and accessible. Interventions may be needed to improve the inclusion of people with HD and their families within all levels of health services and within the community (school, work, sports, leadership, etc.).

Enabling the practice of good self-care practices can prevent complications and worsening of physical impairments. Self-care groups promote and help sustain lifelong self-care practices as well as advocating for other needed services.[21,22] Many participants state that groups provided important psychosocial support and practical problem solving of personal, family, and community issues.[21,22]

The section below summarizes hand and foot care and referral.

Table 2.8. Hand Care Summary

Hand Care Summary[1,10,11,12,18,19]

Questions to ask:

1. Do you have pain at your elbow, wrist? Is it better, worse, or the same?
2. Is there a difference in the feeling on this side of the hand (touching the thumb side) compared to the other side (little finger side)? Is this new? Is it better? Worse? Is it the same? Do both hands feel the same, or is one different? If different, where?
3. Is there a difference in your hand strength? Is it better? Worse? Is it the same?
4. Do you have any burns, injuries, or wounds to your hands? Did you notice when it happened? What caused it?
5. Have you noticed difficulty using your hands in everyday activities, e.g., holding a pen/pencil, turning a key, buttoning buttons, picking up small objects, taking coins out of your pockets?

Basic care	Special equipment, materials, etc.	Referral to hospital, specialist, surgery

Self-care:
• Hydrate and lubricate skin to prevent dryness, cracks.
• Gently rub off calluses.
• Stretch wrist, clawed fingers and thumb to prevent contractures.
	• Protective gloves, padded handles
	• Adaptation of daily activities and instruments to facilitate doing activities
	• Splint to allow clawed finger ulcer/crack to heal with the finger in extension
	• Splints to support a drop wrist
	• Splints to stretch and open clawed fingers
	• Splints to improve thumb and hand function
		• Nerve decompression of ulnar and ulnar/median nerves not responding to corticosteroids and rest
		• Surgical debridement when necessary
		• Reconstructive surgeries:
		  • Pre- and post-therapy surgical training
		  • Tendon transfer for clawed fingers
		  • Tendon transfer for thumb
		  • Tendon lengthening
		  • Arthrodesis
		  • Amputation

Protection: • Inspect hands with loss of sensation daily. • Use gloves to protect against heat, protect at work. • Adapt cooking and work handles with cloth, rubber, foam to help hold more easily and to protect hands. • Adapt daily activities to prevent injuring hands. • Clean, cover, and rest hands with injuries/ulcers/cracks until healed – prevent infection and contractures.		
Daily activities: • Adapt handles of personal items, work and cooking instruments to make them easier to hold. • Adapt tools and daily activities to protect against injury.		

Table 2.9. Foot Care Summary

Foot Care Summary[1,10,11,12,18,19,20]

Questions to ask:

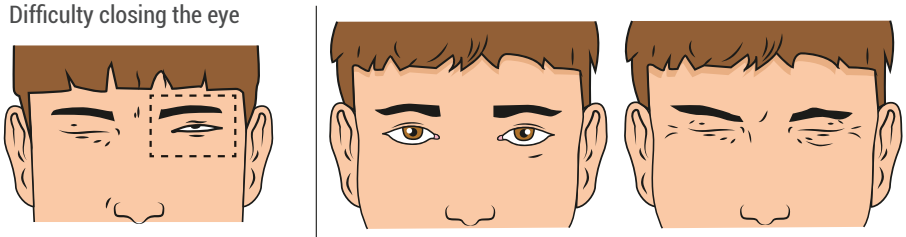
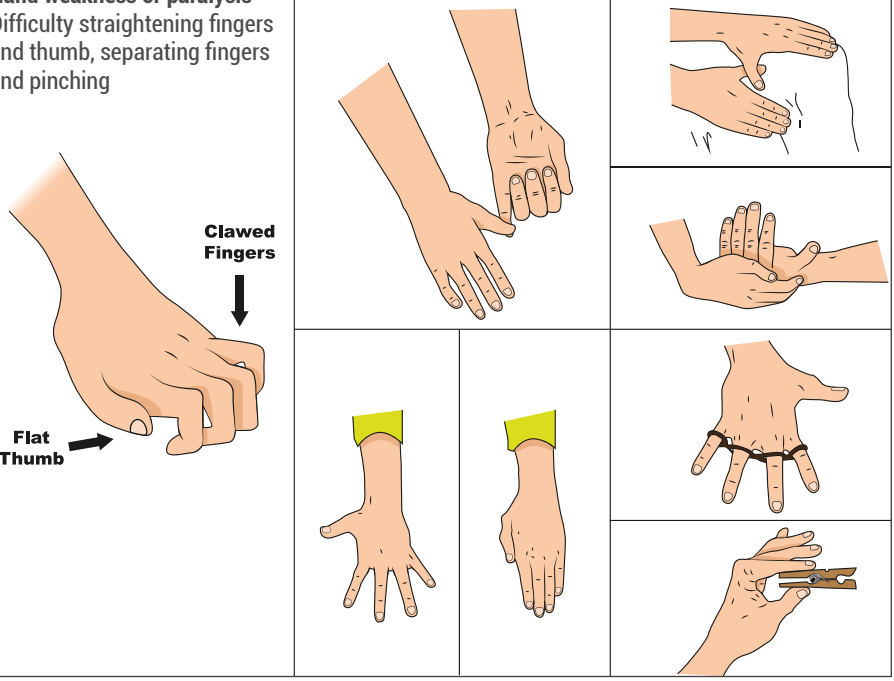
1. Do you have pain behind or on the outside leg area close to your knee? Pain on inside of ankle area, near the bone in the middle part of the ankle? Is it better, worse, or the same?
2. Is there a difference in the feeling on the sole of your foot when touching it during bathing, putting on shoes? Is this new? Is it better? Worse? The same?
3. Is there a difference in the strength to pick your foot up when walking? Does it feel heavy at the end of a long walk or the end of the day? Is it better? Worse? The same?
4. Do you have any injuries or wounds to the bottom of your foot? Did you notice when it happened? If so, what happened?
5. Have you noticed difficulty using your feet in everyday activities, e.g., walking, walking on rocks or uneven ground, climbing stairs, going uphill?

Basic care	Special equipment, materials, etc.	Referral to hospital, specialist, surgery

Self-care:
• Hydrate and lubricate skin to prevent dryness, cracks.
• Gently rub off calluses.
• Stretch foot to improve dorsiflexion (foot up), clawed toes to prevent contractures.
	• Select appropriately sized footwear
	• Use protective footwear if there is loss of sensation
	• Use dorsiflexion assist strap if there is a foot drop
	• Use prosthesis if there is an amputation
		• Nerve decompression of fibular, tibial nerves if recent pain and nerve function loss are not improving with corticosteroids and rest
		• Surgical debridement
		• Reconstructive surgeries:
		  • Pre- and post-therapy surgical training
		  • Tendon transfer for clawed toes
		  • Tendon transfer for drop foot
		  • Tendon lengthening
		  • Arthrodesis
		  • Amputation
		  • Mobility training
		  • Mobility training with prosthesis

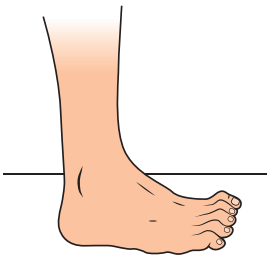
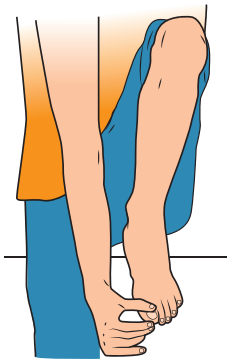
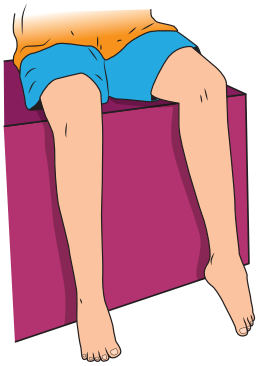
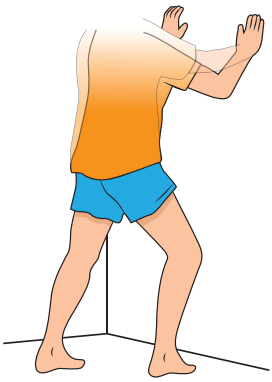
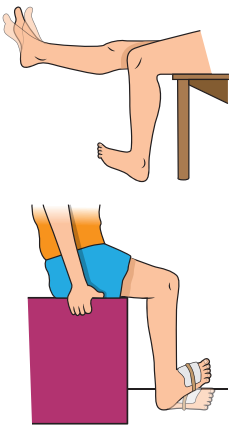
Protection: • Inspect feet with loss of sensation daily. • Use appropriate protective footwear in and outside the home if there is loss of foot sensation. • Use socks. • Clean, cover, and rest feet with injuries/ulcers/cracks until healed – prevent infection and contractures • Use cane, crutches, or other device to rest the injured foot or feet.		
Daily activities: • Use dorsiflexion assist adaptation to facilitate mobility for the person with foot drop and to protect from injury during walking. • Use assistive devices and appropriate footwear.		

Figure 2.4. Home Self-Care Exercises for Persons Affected by Hansen's Disease (Leprosy) – Part 1

Problem	Exercise
Eye weakness or paralysis Difficulty closing the eye	
Hand weakness or paralysis Difficulty straightening fingers and thumb, separating fingers and pinching	

Adapted from Lehman, Geyer, and Bolton.[12] Ten steps health guide, step 9.

Figure 2.5. Home Self-Care Exercises for Persons Affected by Hansen's Disease (Leprosy) – Part 2

Problem	Exercise	
Toe weakness or paralysis Difficulty straightening toes 		
Foot weakness or paralysis Difficulty lifting foot 		

Adapted from Lehman, Geyer, and Bolton.[12] Ten steps health guide, step 9.

Protective Footwear[1,10,12,18]

Those at highest risk for injury and ulcers are persons with a sensory loss to the sole of the foot (DG1 and DG2). They need to use protective footwear inside and outside the home to prevent injuries. This risk increases if the foot has structural changes (clawed toes, drop foot, loss of hallux, etc.) or a history of previous ulcers.

Self-care includes learning to buy, repair, and replace worn footwear. Ideally the footwear has adjustable laces, soft innersole, and a thick, firm sole to protect from thorns and rocks. Footwear needs to be checked daily for foreign objects inside the shoe such as rocks, nails, or thorns.

Properly fitting footwear can frequently be found commercially or in most markets for feet *without severe* structural changes.[12] Check the fit of the shoe to the foot while standing, looking at Figure 3.1 on page 89 in LF section in addition to ALM's Handout 10.2 (https://www.leprosy.org/wp-content/uploads/2015/06/ALM-10Steps-Step10-021816.pdf):

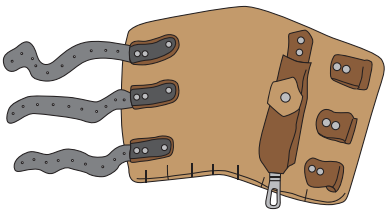
- Distance from heel to end of large toe and fifth toe;
- Distance from heel to first and fifth metatarsal heads;
- Width around the foot at the first and fifth metatarsal heads;
- Width at the heel;
- Height or depth from the arch to the top dorsal part of the foot; and
- Depth of bottom of foot to top of toes.

If the foot has severe structural changes (deformities), the person requires a footwear specialist who can make a mold of the feet and then construct the innersole and footwear around the mold.

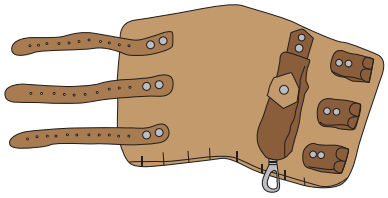
Dorsiflexion assist adaptation.[1,12] Adaptations and assistive devices are important to protecting the foot and improving function. A person who is unable to lift their foot up during walking is at risk of injuring their toes and/or ankle. It is frequently referred to as a "foot

drop." The utilization of an ankle dorsiflexion assist with a dynamic elastic strap attaching to the distal shoelaces of a shoe allows the person with foot drop to lift his foot and toes while walking, thereby protecting the foot from ankle sprains and toe injuries. An easy-to-make dorsiflexion assist strap is shown below.

Figure 2.6. Dorsiflexion Assist with Dynamic Elastic Strap That Attaches to Shoelaces



Ankle straps with Velcro closures



Ankle straps with buckle closures

Adapted from Lehman, Geyer, and Bolton.[12] Ten steps health guide, step 10.

Table 2.10. Summary of Footwear Indications and Care

Summary of Footwear Indications and Care[1,12]		
Foot situation	**Type of footwear needed**	**Care**
Sensory loss to sole of foot	• Adequate-fitting, extra-depth footwear which allows for 0.5- to 1-cm EVA (ethyl vinyl acetate) insert and has a firm thicker outer sole	• Daily checks of feet and footwear • Self-care • Repair and replace footwear as needed
Unusually sized or shaped feet with high-pressure areas	• Custom-made molded insoles and footwear to fit the foot	
Foot drop from weakness or paralysis	• Dynamic dorsiflexion assist strap	• Daily checks of feet, footwear, and assist strap
Sensory loss to sole of foot with injury/ulcer	• Adequate-fitting, extra-depth footwear which allows for 0.5- to 1-cm EVA insert and has a firm thicker outer sole	• Rest • Wound care • Check wound daily; if not better, seek help • Refer to surgeon for debridement, if needed

Adapted from Lehman, Geyer, and Bolton.[12] Ten steps health guide, step 10.

Surgical Care for Hansen's Disease[19]

Two experts in HD surgery, Srinivasan and Palande, describe that "deformities" (visible impairments) are the result of the disease process, paralysis from nerve damage or injuries, and infections in eyes, hands, and feet with sensory loss.[19] Surgeries may be preventive or reconstructive. The timing of surgery will depend on the situation. All corrective surgeries are done only after MDT has been completed and no further paralysis is possible.

Visible impairments are caused by:

1. **Disease process:** loss of eyebrows, collapse of nose, enlarged earlobes, excessive skin from infiltration.
2. **Paralysis from nerve damage** (reactions not treated or not responding adequately to corticosteroids): lagophthalmos, claw-hand, wrist drop, foot drop, clawed toes.
3. **Injuries and infections in eyes, hands, feet with loss of sensation:** cornea ulceration, scars, contractures of fingers, ulceration of feet and hands, shortening of digits, etc.

The aims of surgery are to:[19]

1. Prevent permanent paralysis of nerves, thereby preventing deformities (nerve decompression). The aim is to aid the recovery of nerves.
2. Promote the healing of plantar ulcers.
3. Prevent the recurrence of plantar ulceration.
4. Treat acute hand or foot infections.
5. Correct stigmatizing alterations to the face: eyebrow grafting, correction of earlobe and nose deformities.
6. Correct paralytic deformities and disabilities of eyes, hands, and feet.

Timing of surgery:[19]

1. Surgery for plantar ulcers, an acutely infected hand or foot, and tarsorrhaphy to save a cornea do not depend on the disease status.

2. If the patient's recent nerve function loss (sensory and motor loss) is not improving with adequate levels of corticosteroids within 4-6 weeks, nerve decompression may be needed to help decrease pain and aid in nerve function recovery.

3. Corrective surgeries are done only when there is no further muscle paralysis, and when it is not likely to recover. The following criteria are used:
    - Has shown good clinical response (treated with MDT);
    - Has had no reaction or neuritis within the previous six months;
    - Has no tenderness of nerve trunks;
    - Has had deformity for at least one year.

Table 2.11. Summary of Essential Surgeries

Summary of Essential Surgeries[19]			
Condition	**Consequence**	**Cause**	**Type of surgery**
Plantar ulcer	• Progressive destruction of foot	• Posterior tibial nerve paralysis • Unprotected, insensitive foot (no self-care and/ or protective footwear)	• Debridement and other
Clawing of toes	• High risk of plantar ulceration	• Posterior tibial nerve paralysis	• Prevention: Nerve decompression • Correction if permanent paralysis
Hand infections	• Inability to use hand, abnormal pressures on insensitive hand	• Injuries to insensitive hand	• Drainage procedure
Neuritis with early paralysis	• Paralytic deformities (clawed fingers, clawed toes, drop foot, etc.)	• Disease process and mechanical factors	• Surgical decompression

Table 2.11. (Continued)

Condition	Consequence	Cause	Type of surgery
Lagophthalmos	• Inability to close eyes, risk of blindness	• Facial nerve paralysis	• Tarsorrhaphy • Tightening of lower lid • Tendon transfer (frequently not successfully used by patient if there is loss of sensation)
Megalobule of the ears	• Cosmetic	• Direct effect of disease process	• Wedge resection
Foot drop	• High-stepping gait to clear toes when walking	• Common peroneal nerve paralysis	• Tibialis posterior tendon transfer
Claw hand	• Difficulty using hand	• Ulnar or ulnar/median nerve paralysis	• Tendon transfers and other
Cataract	• Loss of vision	• Repeated inflammation process and corticosteroid use	• Cataract removal

Adapted from Srinivasan and Palande.[19]

Care for Injuries and Ulcers[1,12,20]

Persons with protective sensory loss are at risk of mechanical, thermal, or chemical injury. The risk for corneal ulceration increases with corneal exposure and dryness from incomplete eye closure (lagophthalmos) and/or decreased corneal sensation, reducing the frequency of blinking. Blinking cleans, protects, and provides moisture to the eyes. Hands and feet at risk are those not feeling light touch with a ball point pen or touch with 4-g filament on the hands and 10-g filament on the feet. Many countries do not have monofilaments easily available, so they use only the light touch with a ball point pen. It is important to be aware that pressures applied with a pen are usually greater than 10 g and vary extensively between examiners. The ball point pen, 4-g filament, and the 10-g filament can only identify protective sensory loss but are not a sensitive monitor of early NFI.

Persons with permanent NFI require lifelong daily self-care practices to preserve vision, prevent contractures, cracks, blisters, wounds, and prevent secondary infections. Cross and Choudhary note that self-efficacy to do self-care reduces impairments such as cracks, injuries, and ulcers.[22] The daily practice of self-care and the utilization of self-care groups are key strategies to preventing wounds and secondary infections.

Corneal ulcers.[1,12,15,16] Corneal ulceration is an emergency and best referred to a professional trained in eye health care. The eye should be washed with clean water or saline, antibiotic eye ointment applied, and the eye closed. If the person has lagophthalmos, it is safer to cover the eye using the elevated eye patch described above. It will provide a moist, protected environment for healing.

Cracks and calluses on hands and feet.[1,10,11,18,20] Skin becomes very dry because of the nerve damage and the use of clofazimine in MDT. Cracks are commonly found in creases of "clawed" fingers and toes, as well as heels. If cracks become infected, the infection can spread into tendons, bones, and other parts of the hand and foot, and may result in the loss of the infected finger or toe. The contracting forces of healing cracks in the creases of clawed fingers and toes can result in soft tissue contractures and joint stiffness if not managed adequately. Callus can build up around the edges of cracks and in areas of high pressure or stress.

Hands and feet are checked daily for cracks and callus buildup. Skin is kept soft and flexible by soaking approximately 15-20 minutes in clean water, then dry, hard skin and callus are rubbed or scraped off with something rough such as a pumice stone, coconut shell, or sandpaper. Wet sandpaper used with water is less abrasive and carries away particles that can clog up the grit. A grit of 80 (medium) for feet and a grit of 100 (fine) for the hands can be held more easily by gluing or taping sandpaper to a wooden tongue blade, small round dowel, or wooden block.

Good vision and care are needed to scrape without damaging the skin. After scraping, hands and feet are rinsed with clean water,

and oil is rubbed into the skin to seal the water. Common local oils, such as shea butter, cocoa butter, and coconut butter, or Vaseline, can be used. Be careful with vegetable oils, as they can attract rats and insects. Drying carefully between the toes and within fixed claw fingers and toes reduces the chance of fungal infection and skin maceration. Joint flexibility of clawed fingers and toes is maintained by gently stretching out of fingers and toes after the skin has been hydrated and oiled. A small gutter splint can be applied to clawed fingers with cracks so that the skin heals with the joints in the most extended position possible. Individual finger gutter splints can be made quickly from smooth, hard material such as plaster, rubber tubing, plastic hoses, wood, bamboo, or other materials. These splints should be worn 23 hours each day and removed only for skin care until the crack or wound is healed.

Care of blisters.[1,10,12,18,20] The most important first step in care is discovering the cause of the blister, so future blisters can be prevented. The two main causes of blisters are from heat and friction. Common blisters found from heat are from cigarettes, hot cups, hot liquids, hot pots, fires used for cooking and heating, and feet walking on hot sand. Blisters from friction are found from skin rubbing back and forth over hard surfaces. This is commonly seen with persons using unpadded cleaning, cooking, farm and work tools, and using poorly fitting footwear.

Blisters should not be opened but gently washed with clean water and soap, covered, and protected until they heal. Adaptation of work tools with padding can reduce shear stress and improve grip. Long wooden cooking tools or protective gloves can be used when preparing food. Solutions can vary from adapting how an activity is done to adapting tools and footwear.

Care of ulcers.[1,10,12,18,19,20] Ulcer care involves the health worker, the person affected, and family working together to find solutions. Persons with sensory loss can be easily injured from sharp objects, thorns, or glass piercing through the skin, or from repetitive pressure and shear forces from unpadded tools, poor

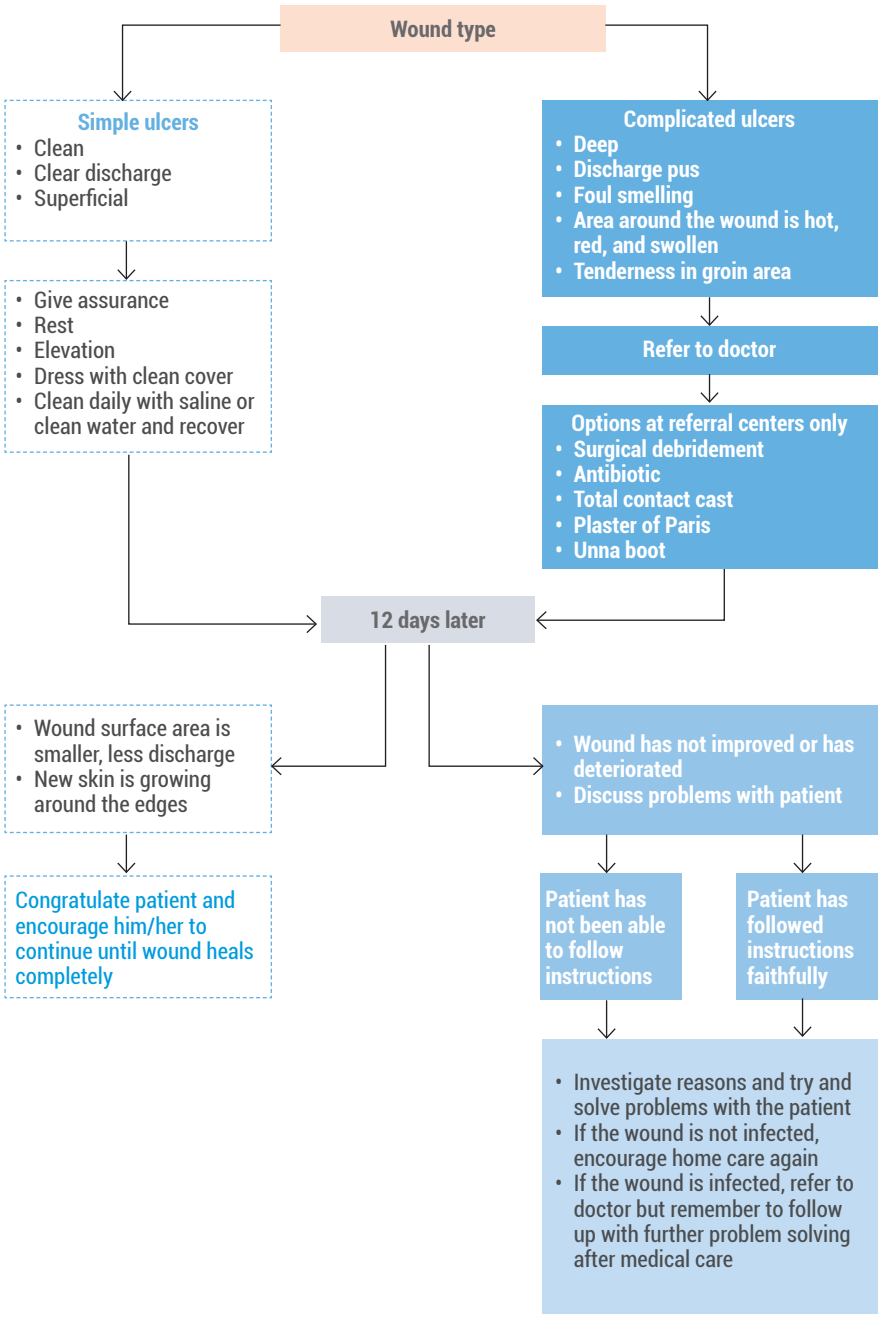
fitting footwear, and walking. The first intervention is removing the cause of tissue stress and then allowing the injured part to rest so that damaged tissue can repair itself. If the person with the wound is healthy, damaged tissue will repair itself with rest.

The gold standard for offloading pressures in plantar ulcers found in HD or diabetes is the total contact cast (TCC).[12,18] However, in resource-limited environments, the materials are not easily available or accessible. In addition, health workers applying the TCC require training and good application technique. The next-best option for plantar ulcers is to spend as much time as possible resting the foot with it raised above the level of the heart. In practice, this is difficult, as people will walk to take care of personal and family needs. Alternative options for resting need to be explored. It may involve using assistive ambulatory devices such as crutches and walking sticks along with using protective footwear and walking more slowly and resting more often. It may temporarily involve exchanging work tasks with another person and using other transportation options such as riding a bicycle or donkey. Rest and good hygiene help prevent secondary infections. Attention is also needed to bathing and latrine areas because their drains can be reservoirs for infection. Routine cleaning with bleach (hypochlorite) around areas with drains will reduce infection risks. Figure 2.7 compares the care for simple and complicated ulcers.

Facilitate Wound Healing

- Keep the wound and surrounding skin clean by washing with clean running water or saline solution
- Remove dead skin, bones, tissues and foreign bodies (like cotton wool or threads of gauze)
- Manage infection with systemic antibiotics
- Keep wound bed moist (not too wet and not too dry)
- Reduce swelling
- Protect the wound and surrounding skin from physical or chemical injury
- Cover with clean cloth or bandage and change if there is "strike through" (exudate appearing on the outside of the bandage) or it gets wet

Figure 2.7. Wound Care and Monitoring for Simple and Complicated Ulcers[10]



Care of chronic venous leg ulcers.[10,12,20] Venous ulcers can also be present, especially among the older HD population. Compression bandaging, elevation, and movement are important components of the wound management. The "Unna boot" is very effective in managing the wound, as it provides both compression and protection and allows for the person to be ambulatory until the wound is healed. When healed, daily use of compression bandages or stockings can control the edema and decrease the reoccurrence of the ulcer.

See Unna paste ingredients and preparation as described below. Table 2.13 provides a quick check of key resources and steps for wound care that can be used by supervisors, health workers, families, and persons affected by ulcers.

Table 2.12. Unna Paste Preparation for Unna Boot Used for Venous Leg Ulcers

<table>
<tr><th colspan="2">Unna Paste Preparation for Unna Boot Used for Venous Leg Ulcers[10,12]</th></tr>
<tr><th>Ingredients</th><th>Preparation</th></tr>
<tr><td>100 g of gelatin powder, no color or flavor
350 g of distilled water
100 g of zinc oxide
400 g of glycerin</td><td>1. Prior to application, wash the leg with clean water and elevate the leg while preparing the paste.
2. Mix gelatin powder and distilled water together and set aside for approximately 5 minutes.
3. While waiting, mix together zinc oxide and glycerin in separate container.
4. Heat up gelatin mixture until the gelatin dissolves but does not boil.
5. Once dissolved, add zinc oxide mixture.
6. Soak bandages (gauze or preferably elastic) in paste.
7. Remove cooled soaked bandage rolls from paste and apply bandage from toes up to the knee.
8. Repeat process to complete 3-4 layers.
9. Cover with dry bandage.
10. Encourage the person to walk, to do daily activities and keep Unna boot dry.
11. Remove Unna boot carefully with blunt-ended scissors.</td></tr>
<tr><td colspan="2">• The Unna boot provides protection of fragile skin and light compression to reduce edema.
• Initially the Unna boot may be changed more frequently due to reduction of edema or excessive exudate.
• As edema and exudate reduce, the Unna boot can be changed weekly.
• Have compression stocking available to put on when the last Unna boot is removed.
• Good skin care is done daily.</td></tr>
</table>

Lehman LF, used since 1985
Adapted from International Federation of Anti-Leprosy Associations.[10]

Table 2.13. Checklist for Wound Care Management
If done, mark (x)

	Ensure clean water is available and accessible
	Ensure materials and supplies to do wound care are available and accessible
	Organize materials before starting wound care
	Wash hands before wound care procedure
	Use gloves appropriately
	Remove gauze and bandages without damaging new skin
	Clean wound with clean water or saline solution to remove debris and dead tissue without damaging new skin
	Check to see if wound is improving, getting worse, or the same
	Move joints near or at the wound before new dressing and bandage are applied
	Apply clean Vaseline gauze or other moisture-retentive dressing
	Bandage with light compression distal to proximal
	Bandage without restricting circulation or movement
	Tape end of bandage; do not tie a knot to secure bandage
	Follow special care procedures for skin grafts under 10 days old
	Dispose of contaminated material safely
	Rest the affected part
	Protect the affected part
	Keep bandage clean and dry
	Change bandage if outer bandage becomes wet
	Ask for help if not improving or getting worse

Adapted from Lehman, Geyer, and Bolton.[12] Ten steps health guide, step 6.

MALIGNANCY CAN DEVELOP IN CHRONIC ULCER:
An unusual raised border or "cauliflower growth" is typical of squamous cell carcinoma and can be confirmed with a biopsy. Generally, amputation is recommended. Important discussions are needed with the person affected and their family, not only to obtain approval for the amputation but to plan for the needed support following the amputation.

Other care support in wound management.[12,21,22] Remember that good nutrition and psychosocial support are important to wound prevention and wound healing. The Stigma Elimination Programme (STEP) in 10 southern Nepal villages adopted an approach to empower people affected by HD through self-care group associations. The key to their success in reducing ulcers, fissures, and claw fingers was the result of developing the individual's self-esteem to do self-care versus the traditional self-care that focused on formal transfer of knowledge and simple skills from a health worker. The STEP program demonstrates that self-care and self-care groups are valid approaches to managing impairments due to HD.

The health system will also need to develop and strengthen referral and counter-referral protocols, procedures, and access for managing wounds that would include surgical debridement, nerve decompression, wound grafts and flaps, correction of clawed toes, and amputation.

Table 2.14. Checklist for Care and Self-Care Practices

Self-care practices for the eye		Inspect and clean eyes every day with clean water and clean cloth.
		If you notice any recent loss in vision, pain with or without redness, or other problem, contact your health worker.
		If muscles are weak, do specific exercises to make them stronger.
		Check vision daily.
		"Think blink" – blink often and/or help your eyes close if it is difficult.
		Gently blot to dry tears with clean cloth.
		Protect eyes during the day with a hat and dark glasses.
		Protect eyes at night when sleeping with mosquito net and protective glasses/cloth.
		If there is low vision, the following will help: • Maintain all objects in the same place. • Adapt the environment to help make it easy to get around. • Adapt areas where there is hot water or fire. • Use a stick or cane to help you get about. • Teach people how to walk with you.
Self-care practices for the hands		Inspect and care for skin every day to prevent cracks (hydrate, lubricate).
		If you notice any recent loss in sensation, muscle strength, or other problem, contact your health worker.
		Remove excess callus.
		Gently stretch clawed fingers and thumb to maintain full movement and prevent contractures.
		If muscles are weak, do specific exercises to make them stronger.
		If small open wound/injury is identified, wash with clean water, cover, protect, and rest. Check daily; if worse, ask for help.
		Protect hands that have lost sensation while working, cooking, etc.
		Adapt handles on work tools to make them safer and easier to hold.
Self-care practices for the feet		Inspect and care for skin every day to prevent cracks (hydrate, lubricate).
		If you notice any recent loss in sensation, muscle strength, or other problem, contact your health worker.
		Remove excess callus.
		Gently stretch clawed toes and foot to maintain full movement and prevent contractures.
		If muscles are weak, do specific exercises to make them stronger.
		If small open wound/injury is identified, wash with clean water, cover, protect, and rest. Try not to walk until it is healed. Check daily; if worse, ask for help.
		Protect feet that have lost sensation by wearing adequate footwear.
		If it is difficult to lift up your foot while walking, use a strap to assist. Talk with your health worker to get one made.
		If you have feet with deformities, special shoes will need to be made.

KEY MESSAGES

1. The persons affected and their families are put at the center of treatment planning and problem solving.
2. Detect and treat HD early with MDT before there are WHO DG1 and/or DG2 disabilities.
3. Detect and treat nerve function impairment (NFI) to preserve nerve function at time of HD diagnosis, during MDT, and after MDT.
4. Preserve vision to enable persons with sensory loss to do self-care and prevent injury during daily activities.
5. Identify persons with protective sensory loss of eye, hands, and feet who are at risk of ulcers and involve them in self-care and self-care groups.
6. Protect and offload high pressures on skin areas that have sensory loss by padding work tools and using protective footwear.
7. Clean, moisturize, cover, rest, and protect wounds until healed.
8. Improve self-esteem and provide physical, psychological, and social support with self-care groups.

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3

Care in Lymphatic Filariasis

This chapter aims to:

1. Review the causes of lymphatic filariasis (LF), how it is transmitted and treated.
2. Summarize how LF affects patients and is a burden on the community.
3. Describe the two strategies WHO uses in the Global Programme to Eliminate Lymphatic Filariasis (GPELF) to achieve the elimination of this disease as a public health problem.
4. Explain the contributions of vector control and WASH in LF prevention and care.
5. Summarize the "minimum package of care" for LF-related disease.
6. Describe the economic benefits of investing in care for people with LF.
7. Review common LF issues requiring self-care, community-based primary health care services, surgery, and/or referral for further care.
8. Promote a people- and family-centered approach to care and self-care practices.

Care in Lymphatic Filariasis

General Overview of Lymphatic Filariasis and Disease Burden

Lymphatic filariasis (LF) is a parasitic disease caused by a thread-like roundworm (*Wuchereria bancrofti, Brugia malayi,* or *Brugia timori)* that infects the circulatory systems of humans.[1-5] The adult worms can live for an average of 6-8 years and during their lifetime produce millions of microfilariae (immature stage 1 larvae) that circulate in the blood and lymph. LF is spread from person to person by mosquitoes that ingest microfilaria-infected blood from one person and then transmit the more developed infective larvae, via another bite, into a second person, where the parasites migrate to the lymphatic vessels and eventually develop into adult worms.[1-5]

If the microfilariae are removed from, or prevented from reaching, the blood, e.g., by chemotherapy, then transmission of the infection cannot take place from one person to another. Such breaking of transmission can be achieved with the co-administration of two anthelminthic drugs once a year for at least five years.[1-5] This combination of two drugs has been shown to be more effective in reducing the numbers of parasites in the blood than a single drug.[1,3,5] In November 2017, the World Health Organization (WHO) introduced an additional approach using three anthelminthic agents in the document *Guideline: Alternative mass drug administration regimens to eliminate lymphatic filariasis,* along with the *Guidelines for validation of elimination of LF as a public health problem*.[6,7]

Thus, the chemotherapeutic approaches used in different settings are:

1. A combined dose of albendazole (400 mg) plus ivermectin (150-200 µg/kg) once a year in areas co-endemic with onchocerciasis.
2. A combined dose of albendazole (400 mg) plus diethylcarbamazine citrate (DEC) (6 mg/kg) once a year in non-onchocerciasis areas.
3. The recently WHO-approved use of a triple therapy (ivermectin, diethylcarbamazine, and albendazole – IDA) as an additional approach for LF. This regime is being rolled out in non-onchocerciasis and non-loiasis endemic countries; DEC is contraindicated in areas co-endemic for these two filarial infections as it has induced serious adverse reactions that include severely reduced vision and death.
4. In areas endemic for *Loa loa*, albendazole (400 mg) twice per year is the current WHO recommendation.

ATTENTION: **DEC is available in tablet form and in a fortified salt formulation for daily intake at mealtimes (although the latter is not often used now). It is an inexpensive and effective antifilarial drug; however, it cannot be used where the other filarial infections onchocerciasis (river blindness) and/or loiasis (Loa loa) are present. It can cause severe adverse events, including death, if used in areas where these latter infections are present.**[1,3-6]

LF is not always detectable by the presence of clinical symptoms and requires a blood test for accurate detection of the infection. In most parts of the world, including the Americas, the parasites have a "nocturnal periodicity" that restricts their appearance in the blood to only the night hours of 22:00 to 02:00.[4] Historically, the method of diagnosis involved the examination of thick smears from finger-prick blood, best done between 22:00 and 02:00. Today, diagnosis has been simplified by the development of rapid point-of-use tests (e.g., the filarial test strip – FTS) with high sensitivity and specificity for detecting adult worm antigen within minutes of sampling, and which can be performed at any time of the day;[3,4] in addition there are supporting laboratory-based tests for antigen and antibody detection.[3]

In children under 4 or 5 years of age, infection with LF is usually symptomless,[4] although subclinical pathological changes may be taking place. These are usually not clinically detectable because the damage and dysfunction in the lymphatic vessels develops slowly.[4] Nevertheless, swollen lymph glands can be observed in children as young as 2 years of age, and at around 7 years of age, ultrasound-detectable irregular ballooning of the tiny walled lymphatic ducts can be observed.[4]

Disease progression in girls is often different than in boys.[4] Girls may start showing clinically detectable signs of infection of the lymph vessels in the leg at 11-13 years of age. The cumulative damage to the lymphatic drainage system predisposes patients to lymphedema of the leg, arm, breast, or genitals in adulthood.[4] It is less common for boys to develop lymphedema of the extremities than it is for girls.[4] Boys around 11 years of age start to show detectable ballooning of lymphatic vessels in their scrotum and inguinal vessels, a change that is associated with the development of hydrocele (collection of fluid inside the scrotal sac causing the scrotum to swell).[4]

In adulthood, men may develop scrotal and inguinal cord nodules, and following bacterial infections, develop further hydrocele enlargement that can be unilateral or bilateral.[4] Repeated bouts of *acute filarial attacks* (AFA) or adenolymphangitis (ADL) developing from the collective complications in skin, lymph

vessels, and lymph nodes (acute dermato-lymphangio-adenitis – ADLA) contribute to the progression of lymphedema and disability in LF. Symptoms and signs seen in AFA include debilitating pain, inflammation, lymphadenopathy, limb swelling, general malaise, chills, and fever.[2,8-10] AFA can be prevented or reduced with skin hygiene, wound care, and wearing appropriate footwear.[2,8-15] The chronic and disfiguring nature of clinical LF often leads to social stigmatization, mental depression, loss of income, and increased medical expenses for the affected person, as well as their caregivers.[1-15]

WHO states that 947 million people in 54 countries are living in areas that require preventive chemotherapy to stop the spread of LF infection.[2] They estimate that at least 36 million men have hydrocele; over 15 million people in the world have lymphedema; and as many as 40% of the infected people also have kidney damage, causing proteinuria and hematuria.[3]

WHO launched its Global Programme to Eliminate Lymphatic Filariasis (GPELF) in order to eliminate LF as a public health problem by 2020.[3,6] The two key pillars aim to stop the spread of LF infection and alleviate suffering among people with chronic lymphedema and hydrocele.

The elimination aims of the Global Programme to Eliminate Lymphatic Filariasis (GPELF) are twofold:[7]

1. Stop the spread of infection through MDA (mass drug administration).
2. Alleviate suffering by managing morbidity and preventing further disability.

Large-Scale Annual MDA Preventive Chemotherapy

MDA involves single coadministration of two antifilarial medications every year to entire at-risk populations for five years;[3] in addition, as mentioned above, certain countries are moving to a triple drug approach. An area is then eligible for a transmission assessment survey (TAS) to assess whether to stop MDA; this can take place if at least 65% of the at-risk population has completed five years of MDA, and will assess if infection levels are below required levels.[1,3] In areas with *W. bancrofti* infection, to stop MDA, the prevalence of infection must be reduced to below 1% microfilaremia or 2% antigenemia (e.g., rapid diagnostic test [RDT] positivity) in sentinel and in spot-check communities considered to be at high risk.[1,3]

GAP. *Inclusion of care within national LF elimination programs.*

Despite the availability of effective measures to treat and prevent clinical manifestations of LF, Sodahlon et al. note that many national elimination programs still neglect addressing morbidity involving lymphedema and hydrocele.[9]

The GPELF mandates that to achieve validation of LF elimination, countries must ensure and document that LF MMDP services are available countrywide.[7]

Vector Control

Mosquito control is a supplemental strategy to aid LF elimination supported by WHO. It is useful for reducing not only transmission of LF but also other mosquito-borne infections. Measures such as insecticide-treated nets, indoor residual spraying, or personal

protection measures can help protect people from infection.[2] Vector control has, in selected settings, contributed to the elimination of LF in the absence of large-scale preventive chemotherapy.[2]

Communities and primary health services working together can ensure that vector control and WASH (water, sanitation, and hygiene) implementation are of good quality, available, and accessible for all, including those with disabilities. Community-owned and -led interventions play a crucial role for the sustained behavior change needed for LF disease prevention and home-based self-care practices.[1,8-14]

Table 3.1. Role of WASH in Lymphatic Filariasis

Infection prevention	Care
Improved sanitation and water management can reduce breeding sites of the vectors that transmit the microscopic disease-causing worm.	Chronic lymphedema from LF requires daily personal hygiene, using water and soap, to prevent secondary infection. Stigma can result in people being excluded from water and sanitation facilities. Limited access can lead to poor cleanliness and care, contributing to isolation and exclusion.

Adapted from World Health Organization. Water, sanitation & hygiene for accelerating and sustaining progress on neglected tropical diseases: A global strategy 2015-2020. Geneva: WHO; 2015. http://www.who. int/water_sanitation_health/publications/wash-and-ntd-strategy/ en/

Morbidity Management and Disability Prevention (MMDP) in LF

The second major aim of the LF elimination program, GPELF, is to alleviate suffering of those affected by LF by managing morbidity and preventing further disability through the provision of services to decrease morbidity and reduce and prevent disability.[7] The clinical manifestations of LF (lymphedema and hydrocele) cause a significant public health burden, and they have serious mental health implications and economic consequences.[7]

Validation criteria for MMDP in LF:[7] A country claiming to have achieved elimination of LF as a public health problem is requested to document MMDP availability and, where possible, be validated by independent reviewers. The data required are:

1. Patient estimation: The number of patients with lymphedema or hydrocele, reported or estimated by implementation unit (IU) or similar health administrative unit (regardless of whether the IU required MDA).
2. Availability of the recommended minimum package of care: In all areas with known patients (100% geographical coverage), the availability of the recommended minimum package of care to all patients.
3. Readiness and quality of available services: In select designated facilities, document the readiness and quality of available services.

In other words, a GPELF minimum quality care package must be of good quality, available, and accessible to all persons and address the following areas:[7]

1. **Treatment of acute attacks:** treating episodes of ADL among people with lymphedema or elephantiasis;
2. **Management of lymphedema:** preventing debilitating, painful episodes of ADL and progression of lymphedema;
3. **Management of hydrocele:** providing access to hydrocele surgery; and
4. **Provision of appropriate antifilarial medicines:** to destroy any remaining worms and microfilariae by MDA or individual treatment for LF infection.

Overview of LF Disability Burden

LF is the most common cause of lymphedema and hydrocele, and it is one of the leading causes of global disability with significant comorbidity of mental illness experienced by both the person affected and their caregivers.[1,8-10,12,13] Enlarged limbs are heavy, painful, and difficult to move.[13] This can limit the ability to carry out daily activities and can restrict participation in family, school, work, leisure, and community activities.[14] In addition, it is difficult to find footwear and clothes that fit. Dreyer et al.[14] note that psychological and social effects, uncontrolled odor, sexual impairments, and painful acute bacterial infections are often kept hidden. Stillwaggon et al.[12] show that lymphedema and episodes of acute filarial attacks in filariasis-endemic areas diminish the quality of life due to pain, stigma, numerous days of illness each year, restricted mobility, and reduced participation in family and community life. This results in a substantial economic cost on affected persons and their families, and diminishes the potential economic strength of communities.[12]

General Clinical Aspects and Pathophysiology of Lymphedema

The lymphatic system is a network of tissues and organs distributed throughout the body that helps the body eliminate toxins, waste, and other unwanted materials. This system also removes excess water and destroys infectious organisms such as bacteria. Muscle contraction during exercise is essential to help move the fluid through the lymphatic vessels towards the heart to enter the venous system in subclavian veins at the base of the neck. Bacteria can be found in large numbers on the surface of the skin and from time to time these reach the lymphatic system but are usually destroyed and cleared without causing any overt sign of infection.[9]

The adult worms of LF cause lymphatic dysfunction, which alone or in combination with other factors, can lead to lymphedema (chronic swelling).[14] The adult filarial worms living in the lymphatic vessels induce growth of the lymphatic vessels with consequential dilation and dysfunction leading to the lack of lymphatic flow.[14] People with damaged lymphatic vessels and lymphedema often have more bacteria on the skin than usual because of reduced immune function of the skin, and because they are unable or do not know how to properly wash and care for the affected area.[14,16] The first appearance of swelling is commonly associated with an AFA but can occur independently from this acute event; for example, with the development of a second affected limb.

Shenoy and others have observed that the earliest structural change in LF is the dilation of lymph vessels associated with the presence of adult worms.[15] This has been demonstrated by ultrasound examination of the lymphatic vessels of the spermatic cord in people who are clinically asymptomatic except for presence of microfilariae in their circulation, by lymphoscintigraphy of the affected limbs, and also by direct examination of lymph vessels resected at surgery. It is believed that the initial pathological change to lymph vessels is caused by inflammatory mediators and growth factors produced by local inflammatory cells stimulated by the secretions of the adult parasites, these mediators causing vessel dilatation and altered muscular contractility.[16] In course of time this initial pathology leads to wide lymphatic dysfunction.[16] However, at the early stage of LF infection, the person harboring the adult parasites does not present with clear evidence of clinical filarial disease, a phase that is termed *asymptomatic microfilaremia*. It has been generally believed that once fully established, the pathological changes in the lymphatics and associated tissues are irreversible, even after treatment or death of the filarial parasite.[15] However, at least some reversal of symptoms and signs has been seen in recent studies following the implementation of disease management activities.

Lymphedema Care

The research results of Stillwaggon et al. confirm the strong economic benefit of investing in the care of people affected by LF.[12] The economic benefits of such interventions far exceed the costs and generally result in very significant benefits to filariasis-affected people and their communities.[8-13] Reasons for this include:

1. Limb care allows affected people to better support themselves and provide for their families.
2. Children and other dependents of affected persons have greater access to better nutrition and the opportunity to attend school if the wage-earner is healthier.
3. Family members are relieved of the burden of caring for persons who are bedridden due to acute filarial attacks or advanced lymphedema.
4. The affected person is better able to contribute to household income and domestic tasks.
5. The community's economy is strengthened if fewer of its members are disabled by lymphedema and ADLA, and fewer of its families are faced with poverty.

In addition, Cantey et al. note an "increasing compliance with MDA programs for LF in India through education and lymphedema management."[11] People with chronic lymphedema depend on good-quality health care services and daily self-care practices throughout their lives.[2,3,11,12] The participation of the persons affected, their families, and the community in good care practices can help sustain LF disease prevention and improve the quality of life of affected people.[2,3,11,12]

The major goal of lymphedema management in filariasis-endemic areas is to prevent acute attacks caused by bacterial infections in association with other factors.[17] Dreyer et al. encouraged the prevention of the initial acute attack to avoid the

appearance of lymphedema, and the prevention of recurrent AFA in persons with lymphedema so as to prevent the worsening of the condition.[13]

The practice of daily self-care can prevent the lymphedema from getting worse and prevents and reduces the frequency and intensity of AFA. A typical daily, minimum home-based self-care program includes hygiene, skin and wound care, elevation, strong muscle contracting exercises, and wearing comfortable footwear.[7,11,18-24] In brief, the procedures are based on the GPELF recommendations.

1. **Hygiene:** The affected area should be washed at least once daily with soap and clean water at room temperature and dried carefully with a clean towel or gauze; this is a key in reducing acute attacks and preventing progression of the condition.

2. **Skin and wound care:** The skin should be protected from injury and any wounds or abrasions treated (e.g., with antiseptics and antibiotic creams). Antifungal creams are useful for keeping deep skin folds and interdigital areas healthy; toenails should also be kept trimmed.

3. **Elevation:** The affected area should be raised at night and when possible during the day to promote lymphatic flow.

4. **Exercising:** Lymphatic flow is promoted by frequent strong, active contraction of muscles.

5. **Wearing of comfortable footwear:** Comfortable footwear adapted to the size and shape of the foot should be worn to protect the feet against injury.

Additional Helpful Lymphedema Management Interventions

Artzberger's manual edema mobilization (MEM) techniques (see Annexes 3.5 and 3.6) can be utilized to gently stimulate the lymphatics to facilitate the flow of excessive tissue fluid from

an edematous area.[18,22-24] MEM techniques can obtain additional edema-reduction benefits by combining deep diaphragmatic breathing, very light (<20 mm Hg) self-massage, and exercise. Bandaging with thin soft foam strips (5-10 mm thick by 10 cm width by 1 m length)[18,23] or using soft stretch material on the area also helps to reduce edema.[18,22-24] An example of a simplified MEM is included in Annexes 3.1-3.4.[15] MEM and foam bandaging require special training to clean and use them correctly, and are not considered part of the GPELF basic care package. Additional resources on clinical, surgical, and home-based self-management interventions used with LF are included in the references section of this manual, along with their websites.[9,10,13-20,25,26] Most can be viewed online and downloaded free of cost.

Note:

Soiled bandages can be a source of contamination of the skin. This is especially important in situations where there is no ready source of clean bandages. In hot climates, the use of bandages is often contraindicated.

Community- or home-based care (Annexes 3.1-3.4)

To provide community- or home-based care, the following actions are needed:

1. **Identify people with lymphedema and hydrocele** to gain an overall understanding of the burden of cases in the community as a whole, and provide needed community- or home-based care interventions.

2. **Train and provide resources** for health workers, community caregivers, people affected, family, and friends to do care.

3. **Practice daily self-care for lymphedema**

   - **Inspect and identify entry lesions and/or offensive odor:** (Annex 3.1a)

     - Look carefully for entry lesions in skin folds or between interdigital spaces, fungal infections of the nails, small wounds, blisters, scratches, cracks, cuts. Note presence of offensive odor.

- If entry lesions are found, then clean, rest, and use antifungal or antibiotic ointment on all entry lesions to prevent infection.

- **Wash:** (Annex 3.1a)
  - Gently clean skin with soap and clean, room-temperature water. Washing is important to clean the skin and protect it from infection.
  - Pay careful attention to the cleanliness of interdigital spaces and skin folds. Wash until water becomes clear.
  - Rinse until water is clear and clean.
- **Dry:** (Annex 3.1a)
  - Gently dry skin with a clean cloth to avoid damaging the skin.
  - Take extra care to dry well within skin folds and interdigital spaces.
  - Avoid any strong wiping and rubbing actions that may damage the skin further.
  - The use of supportive lotions (especially oils) is encouraged; note that creams (except for specific therapeutic needs) can block the pores of the skin and thus be harmful.
- **Elevate:** (Annexes 3.1b and 3.2)
  - Raise and support the affected part during the day and night.
- **Exercise:** (Annexes 3.1b and 3.2)
  - Move frequently anytime and anywhere. Strong muscle contraction is needed to help the lymph system to remove fluid out from the local tissues.
  - Specific exercises combined with diaphragmatic breathing and self-massage are recommended for those with lymphedema.[18,22,23,27,28]
- **Wear comfortable footwear:** (Annex 3.1b)
  - Protect feet from injury by using comfortable, well-fitting footwear.
  - Keep footwear clean and repaired.
  - Custom-make footwear for feet that are unusually shaped or very large.

- **Identify an acute filarial attack:** (Annex 3.1c)
  - Very intense pain of swollen limb or pain and gland swelling in the groin or axilla
  - Red, itchy, swollen, and painful skin, sometimes peeling skin
  - Fever, headache, and shivering
  - Nausea and/or vomiting
- **Immediately treat an acute filarial attack:** (Annex 3.1c)
  - Soak in cold water or apply cold compress until pain stops.
  - Drink plenty of water.
  - Rest.
  - Take treatment to bring down the fever (paracetamol every 4-6 hours until fever goes down).
  - As soon as pain is gone, return to carrying out skin care.
  - In severe cases, antibiotics (tetracyclines) may be prescribed.
  - If no improvement within 24 hours or gets worse, get more help/refer.

ATTENTION: WITH AFA DO NOT:
- Put anything warm or hot on the skin
- Cut the skin to remove excess fluid or blood
- Bandage the limb
- Rub onto the skin herbs, ashes, or anything that has not been prescribed by a doctor or nurse
- Open a blister or cut it
- Exercise during AFA

1 **Refer for additional medical care or surgery**

a. AFAs that do not improve within 48 hours or get worse rapidly within the first two days

b. Hydrocele for surgery

c. Severe cases with either lymphedema or hydrocele in persons with probable coexisting conditions such as hypertension, diabetes, or obesity

2. **Provide psychosocial counseling and support to persons with LF and their caregivers**

   Self-care groups and counseling are important interventions to address psychosocial issues and improve mental health and well-being. Many persons with LF are badly stigmatized—by their communities as well as suffering from self-stigmatization. Counseling should be provided wherever possible. Efforts to educate the persons, their families, and their communities can improve their understanding of the cause and implications of this condition on daily life. Together they can work to develop a better, inclusive community.

3. **Advocate for health services, WASH, and community facilities and activities to be accessible (universal design) and inclusive of people with LF and other disabilities**

4. **Routinely monitor and evaluate care intervention and modify as needed**

Figure 3.1. Additional Details on Footwear Measurements[18]

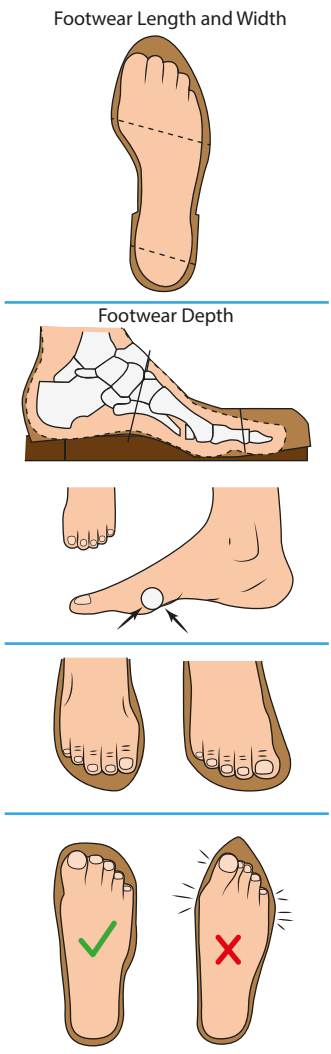
Footwear is an important part of self-care for preventing entry lesions. It includes learning to buy, repair, and replace worn footwear. Ideally the footwear has adjustable straps, soft innersole, and a thick, firm sole to protect from thorns and rocks.

Footwear needs to be checked daily for foreign objects inside the shoe such as rocks, nails, or thorns.

Properly fitting footwear can frequently be found commercially or in most markets for feet without severe structural changes.[14] Check the fit of the shoe to the foot while standing and look at the following:

- Distance from heel to end of large toe and fifth toe;
- Distance from heel to first and fifth metatarsal heads;
- Width around the foot at the first and fifth metatarsal heads;
- Width at the heel;
- Height or depth from the arch to the top dorsal part of the foot; and
- Depth of bottom of foot to top of toes.

If the foot has severe structural changes (deformities), the person requires a footwear specialist to make a mold of the feet and then construct the innersole and footwear around the mold.



Self-care groups. Self-care practices in LF are similar to self-care practiced by persons with Hansen's disease (leprosy), diabetes, venous insufficiency, and lymphedema from other causes, and permit integrated group approaches to self-care. Learning self-care, individually or in a group, improves persons' perceived beliefs about their capacity to take care of themselves. Developing a strong sense of *self-efficacy*[15] improves compliance in practicing

daily self-care and improves sense of well-being. As a result, the person feels they have the capability to exercise control over their disease, health condition, and disability. Self-efficacy is developed by:

1. Developing the ability to successfully do a task and solve problems;
2. Seeing people similar to oneself do a task and solve problems successfully;
3. Verbal encouragement and support by others and seeing self-improvement;
4. Optimistic self-belief in the worth of doing self-care.

Community-based groups can be an effective way to learn and encourage lifelong self-care practices, discuss and problem-solve issues (physical, social, psychological, and spiritual), provide psychosocial support and informal counseling, and advocate for inclusive communities.

Daily, remember to practice the following seven self-care actions

(see images in Annexes 3.1-3.3)

1. Inspect for entry lesions and, if found, treat entry lesions.
2. Wash affected part.
3. Dry carefully between fingers, toes, and skin folds.
4. Elevate and move frequently, using strong muscle contractions.
5. Exercise frequently, using strong muscle contractions.
6. Protect from injury at all times (e.g., wear shoes, trim toenails, etc.).
7. Identify acute attacks and treat immediately.

Management of Urogenital Problems in LF[9]

In men, LF can cause the genitals to become enlarged. Either fluid collecting inside the sac (hydrocele) or the skin (lymphedema) can enlarge the scrotum and its contents and penis.[11] Men suffering from these problems will often be embarrassed and hide the problem.[9] It can lead to social isolation and have severe emotional impact. The identification of the problem, counseling, teaching of daily self-care, and the provision of hydrocele surgery can improve their quality of life and improve social and mental health and well-being.

Hydrocele

Figure 3.2. Anatomy of Hydrocele

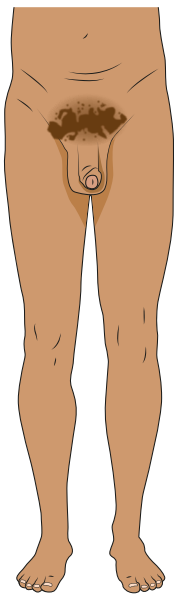
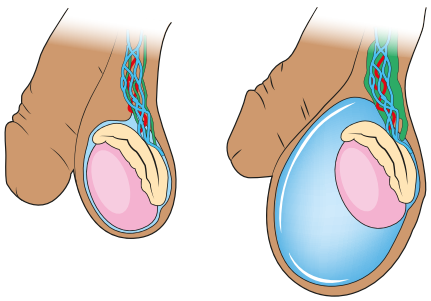
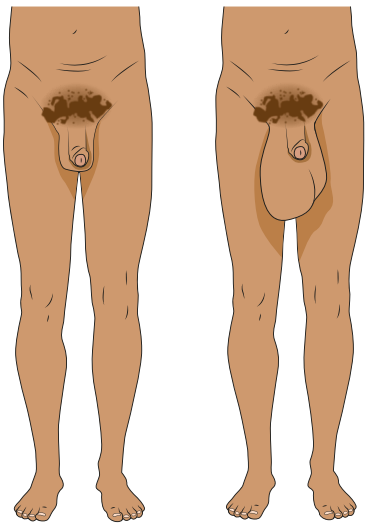
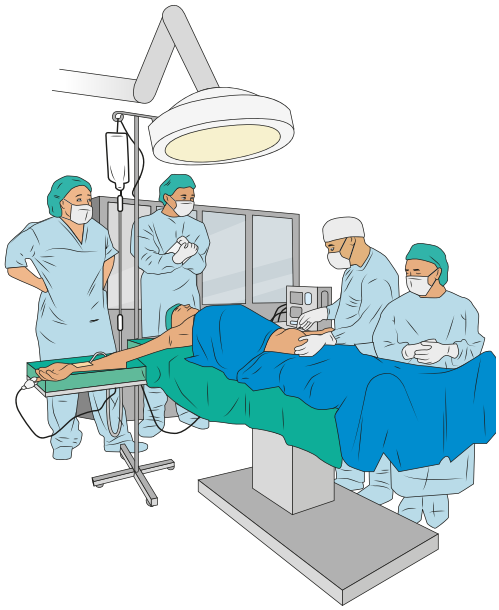
Hydrocele is the accumulation of excessive fluid inside a vestigial component of the scrotal sac	Hydrocele can be successfully treated with surgery
	

Figure 3.2. (Continued)

Hydrocele is the accumulation of excessive fluid inside a vestigial component of the scrotal sac	Hydrocele can be successfully treated with surgery
	

The illustrations were made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of Helen Keller International and do not necessarily reflect the views of USAID or the United States Government. [27,28]

Hydrocele is the accumulation of excessive fluid inside a vestigial component of the scrotal sac and can be successfully treated with surgery. Suspected increases in volume within the scrotal sac should be referred for evaluation for surgery or differential diagnosis for other diseases.[9] In filariasis-endemic areas, men with hydrocele frequently have adult filarial worms in their lymphatic vessels and should be treated with antifilarial drugs to kill the filarial worms.[9] Surgical correction of diagnosed hydrocele is a very successful procedure and should be encouraged.

Men with a large hydrocele may be prone to fungal skin infections in the contact area between the leg and the scrotum because of increased moisture.[9] Daily self-care practices are needed to wash, dry well, and in some cases use antifungal creams. A large bilateral hydrocele may completely hide the penis, making sexual intercourse and hygiene impossible, and may also create problems urinating.[9]

Lymphedema

Lymphedema of the skin and subcutaneous tissue of the genital region is less frequent in women and more common in men (scrotum and penis). The skin becomes thicker and harder than normal and loses its normal texture. Lymphedema always affects both sides of the scrotum.[9] AFA causes progression of lymphedema in the scrotum or penis.[9] The practice of daily self-care can prevent the progression of lymphedema. A clean dressing made from cloth may be needed to absorb or collect leaking fluids. Cloth dressings must be changed often, washed well, and hung in the sun to dry. The dressing covering the affected area should be placed underneath the underwear. Additional measures to maintain good hygiene may include keeping pubic hair short, if it is culturally acceptable. Scissors should be used to trim any hair, and razors always avoided.[9] The man and his partner should be advised to wash their genital areas carefully both before and after intercourse; this may reduce the risk of AFA.[9]

Men with lymphedema of the penis can use a condom to prevent sexually transmitted diseases and for birth control. If condoms make the lymphedema worse, the situation should be discussed with the doctor or nurse to evaluate the risks of not using condoms (pregnancy and sexually transmitted disease). Severe edema of the penis can interfere with urination and hygiene and may require referral to a skilled nurse or doctor to help teach hygiene techniques.

Counseling

Counseling and psychosocial support are important for both the man and his partner to discuss and problem-solve hygiene issues, sexual problems, treatment and surgical options, and feelings of embarrassment and shame.

Surgery

Hydrocele is the main LF manifestation in males and can, in the vast majority of cases, be successfully corrected with surgery. Improved diagnostic tests are now available to confirm filarial causes of hydrocele. Currently these include a rapid diagnostic test (RDT) for the presence of filarial antigen, the filarial test strip (FTS), and Og4C3 enzyme-linked immunosorbent assay (ELISA), as well as ultrasound examination for detection of adult parasites in the inguinal cord and scrotum.[22,23] If adult parasites are found, or blood tests are positive, the person should be treated with antifilarial medication.

Surgery can successfully treat most cases of hydrocele and is a priority in the GPELF minimal package of care of LF. GPELF/WHO provides an algorithm for management of scrotal swellings and describes surgical approaches and care.[22] The two main approaches used are: a) the eversion of the tunica vaginalis; or b) the excision of the tunica vaginalis. The former is best used in early cases, while the latter, resection of the tunica, the tissue that holds the collected fluid, is the preferred technique by most surgeons in endemic countries. Removing the tunica does not affect the future function of the male reproductive system in any significant way if the surgery is carried out following good surgical procedures, and with adequate pre- and post-surgical care. Surgery should never be carried out during an AFA.

Complications of hydrocele

- Interference with sexual activity
- Interference with ability to work
- Interference with urination, due to the penis getting buried in the scrotal sac
- Negative impact on the person's family
- Dragging pain
- Liability to trauma in view of the nature of the person's work or mode of transportation, such as cycling
- Possible effect on the testis of long-standing hydrocele
- Psychosocial issues

Cosmetic or reconstructive surgery to remove the swelling of the leg, scrotum, or penis is not considered a public health measure: it is expensive, difficult, and often the results are not satisfactory.[9] In the vast majority of cases, the best treatment approach for these problems is hygiene and care of entry lesions to prevent AFA.[9] Rarely, cosmetic surgery is recommended to remove knobs to decrease the possibility of trauma and potential entry lesions, or to remove excessive skin ("baggy arms and legs"[9]) if lymphedema is greatly reduced; note, though, that tissues affected by lymphedema for long periods of time generally do not heal well, and special medical care is needed to assist healing in this type of surgery.

Other Care Challenges

Amputation. Some persons with advanced lymphedema and their families may request amputation as a quick solution to their problem. Rarely is it a good solution, as it creates new challenges with mobility during daily activities. Good hygiene and care of entry lesions will nevertheless still need to be done. It should be noted that the skin in lymphedematous limbs does not heal well, and the development of severe scarring and keloids is very common.

Before amputation is decided upon, a serious consideration of the patient's overall situation must be made. The patient's personal situation, mobility options, and costs need to be explored and discussed in detail. Frequently, the biggest limitation is having a good prosthetics and assistive technology professional and other needed resources (crutches, walker, wheelchair, other) easily accessible and available. Prosthetic, medical, rehabilitation, and psychological evaluations can help individuals and their family understand both the physical and psychosocial risks of amputation, and allow them to make the best-informed decision.

Planning and Implementing the Minimal Package of Care

People-centered and community-led care empowers people and communities to take charge of their own health and care rather than being passive recipients. The goal here is to maximize the person's, family's, and community's capabilities and ownership. National, regional, and district NID programs can accomplish this by including persons and communities affected by LF within their planning, implementation, monitoring, and evaluation discussions, and as part of the roll-out of these different activities. Their input can often uniquely identify important support and resources that are needed to address the issue of appropriate LF care.

Important activities in the planning, implementation, monitoring, and evaluation of LF care include the following:

- First, people with lymphedema and hydrocele need to be identified and their community location mapped to facilitate the planning, implementation, monitoring, and evaluation of interventions and resources needed for community home-based care and hydrocele surgery.
- Second, the individual clinical situation is documented to monitor and evaluate outcomes of care interventions and practices. This can include a simplified lymphedema grading,[11] limb circumferential measurements, the presence of wounds, and AFA.[11] Examples of simplified lymphedema grading and individual follow-up forms are included in Table 3.2.[14,16] Additional information can be collected on activity limitations, participation restrictions, depression, and stigma.
- Third, self-care is taught to the person affected, their family, friends, community caregivers, and health workers, using local resources to do care. Utilization of self-care groups can encourage and sustain lifelong self-care practices.
- Fourth, persons with AFA who fail to improve within 24 hours following simple interventions need to be referred to a higher-level health service or hospital. Referral and counter-referral systems need to function well.

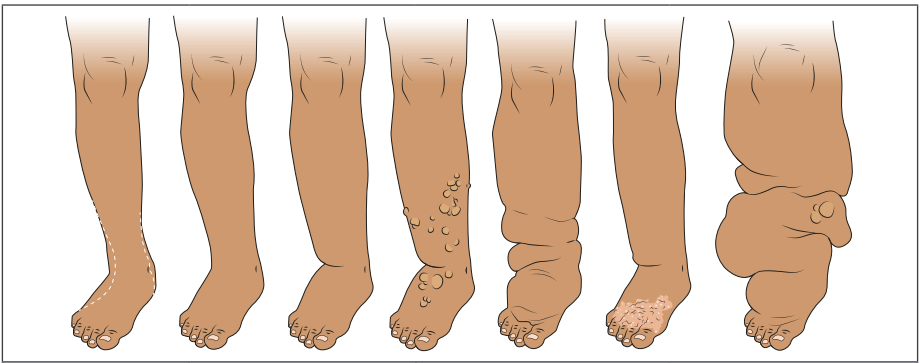
- Fifth, uncomplicated hydrocele cases need to be referred to a surgeon at the primary health center or rural/community hospital, and complicated hydrocele cases referred to a district hospital that has a greater capacity and more resources to address any associated complications.
- Sixth, care is included within monitoring and evaluation activities.

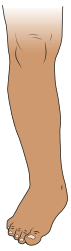
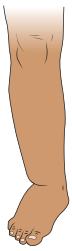
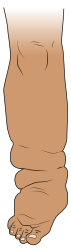
Table 3.2. Example of Individual LF Clinical Situation Assessment

Date	Simplified lymphedema staging 0, 1-mild, 2-moderate, 3-severe						Wounds present		Acute attack		Hydrocele present		Referral needed	
	Leg		Arm		Breast									
	R	L	R	L	R	L	Yes	No	Yes	No	Yes	No	Yes & what	No

Adapted from WHO/SEARO.[17]

Figure 3.3. Simplified Staging of Lymphedema for Community-Level Health Workers



1-7 stage classification	Stages 1, 2	Stage 3	Stages 4-7
Simplified	1 – Mild	2 – Moderate	3 – Severe
			
Clinical description and preventive care			
Skin	No skin folds Skin is smooth and looks normal	Skin folds usually present Skin aspect is normal	Skin folds present Skin is thick, hard and has wart-like lesions, particularly toes (elephantiasis)
Edema	Pitting edema	Mostly non-pitting edema	Gross increase in volume and hard
Reduction of swelling or edema	Disappears overnight Disappears with elevation and frequent, strong muscle contraction exercises	Swelling does not reverse overnight May reduce with elevation and frequent, strong muscle contraction exercises	Swelling does not reverse at night Little to no reduction with elevation and frequent strong muscle contraction exercises
Prevent acute attacks	Good hygiene, skin and nail care	Good hygiene, skin and nail care	Good hygiene, skin and nail care
	Use comfortable footwear	Use comfortable footwear	Use custom-made footwear

WHO/SEARO.[17]

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Table 3.3. Prevention and Care Summary Table[1,2]

Prevention	Primary health care intervention
Antifilarial treatment given to at-risk communities in LF endemic regions	• Annual mass drug administration (MDA) campaign to whole communities for at least 5 years All people with filariasis who are positive in the filarial test strip (FTS) or have microfilaremia should receive antifilarial drug treatment to eliminate microfilariae (and adult worms when diethylcarbamazine is used). They can be treated with one of the following regimens: i. A single dose of a combination of albendazole (400 mg) with ivermectin (150–200 mg/kg) in areas where onchocerciasis is co-endemic; in areas where onchocerciasis is non-co-endemic, either ii. A single dose of a combination albendazole (400 mg) plus diethylcarbamazine (6 mg/kg) or iii. Diethylcarbamazine 6 mg/kg alone for 12 days. iv. The new IDA (ivermectin, diethylcarbamazine, and albendazole) protocol as described above. Consider using for the follow-up of positives in post-treatment settings.
Vector control to reduce transmission of LF and other mosquito-borne diseases	• Health promotion and education: o Sleep under a mosquito net; o Wear long sleeves and trousers; o Use mosquito repellent on exposed skin. • Vector controls

Table 3.4. Lymphatic Filariasis: Care Issues, Primary Care Interventions, and Referral Care Interventions

Care issues	Primary health care intervention	Referral care intervention
Lymphedema		
Prevent LF lymphedema	• Teach community and individuals good personal hygiene practices • Teach injury prevention • Promote use of footwear	
Lymphedema management to prevent AFA	• Identify persons with lymphedema and put on registry for self-care training (individual or group) Self-care: • Inspect and identify entry lesions or offensive odor • Practice good skin and nail care (wash and dry correctly) • Treat entry lesions to prevent infection with antifungal or antibiotic ointments or creams • Elevate affected areas • Exercise • Use comfortable well-fitting footwear • Recognize AFA and treat when needed • Include advanced lymphedema management measures, such as simplified manual edema mobilization techniques within self-care practices where appropriate • Refer chronic lymphedema cases needing advanced management	Refer person with lymphedema to a primary health care unit when: • Concern for non-filarial lymphedema • Patient in need of psychological services Refer persons with chronic lymphedema and elephantiasis for specialized advanced lymphedema management • Manual edema mobilization (MEM) techniques • Foam bandaging and light compression** ** Attention: This is not recommended unless there is a consistent supply of clean foam and bandages; this point is especially important in excessively hot, humid climates
Prevent complications from harmful traditional practices	Discuss traditional practices with the community and persons affected and modify practices that are harmful. Harmful traditional practices to avoid: • Cutting the limb to remove excess fluid or blood • Opening or cutting of blisters • Rubbing onto the skin herbs, ashes, or anything that has not been prescribed by a doctor or nurse • Excessive rubbing with towels etc. when drying the skin • Using warm or hot compresses	

Table 3.4. (Continued)

Care issues	Primary health care intervention	Referral care intervention
Lymphedema		
Acute filarial attack (AFA)	Teach care during AFA • Soak in cold water or apply cold compress until pain stops • Drink plenty of water • Rest, do not exercise • Take medicine to bring down the fever (paracetamol, or equivalent, every 4-6 hours until fever goes down) • As soon as pain is gone, return to doing skin care • If necessary, take antibiotics or antifungal ointment or creams prescribed by a doctor or nurse • Use footwear • Refer if no improvement within 24 hours or AFA gets worse Teach what NOT TO DO during AFA • NO warm or hot compresses • NO bandaging of the limb • NO cutting the limb to remove excess fluid or blood • NO opening or cutting of blisters • NO rubbing onto the skin herbs, ashes, or anything that has not been prescribed by a doctor or nurse • NO exercise	Refer to health service or hospital health care unit when: • Patient with acute attack does not improve after 48 hours of antibiotics or gets worse • Acute attack is accompanied by confusion, vomiting, or high fever • Patient with acute attack is pregnant • Patient develops entry lesions that have drainage, a foul odor, redness or swelling, or if a fever develops • Patients with advanced lymphedema with repeated acute attacks despite good hygiene practices
Urogenital problems[11,20]		
Acute inflammatory disease (funiculitis and epididymo-orchitis (inflammation of the testis, epididymis, or spermatic cord)	Treat with • Rest • Analgesics • Antibiotics if needed	
Hydrocele (scrotal swelling from collection of fluid in the tunica vaginalis)	• Identify scrotal swelling and refer for surgery consultation • Place on surgery registry • Teach good hygiene practices • Identify hydrocele complications* • Check for presence of adult filarial worms and treat with antifilarial drugs if needed	Differential diagnosis of hydrocele Surgery utilizing GPELF/WHO document as a guide[20]

Table 3.4. (Continued)

Care issues	Primary health care intervention	Referral care intervention
Urogenital problems[9,20]		
*Hydrocele complications: use the transillumination test (shining a light through the scrotum) to detect non-fluid masses and altered fluids in the scrotum[21]		
Pyocele (collection of pus)	• Check for non-transluminescence of the contents of the tunica vaginalis sac • Treat immediately with broad spectrum antibiotic • Immediate referral for surgical drainage	Urgent surgical drainage Possible need for orchidectomy
Hematuria (red urine)	• Check for non-transluminescence of the contents of the tunica vaginalis sac • Refer person complaining of red urine (blood in the urine) to doctor or clinic for further evaluation	Referral evaluates and treats blood in urine
Chyluria (milky urine)	• Check for non-transluminescence of the contents of the scrotal sac and tunica vaginalis sacs • Orient person affected and family how to manage:[11] - Eat foods low in fat and high in protein like fruits, vegetables, white meat, egg whites, and beans - Avoid eating fried foods, coconut, avocado, pork, skin and dark meat of chicken, cheese, milk, yellow part of egg, chocolate, junk food, oil/margarine or butter[11] - Drink lots of fluids - During episodes of milky urine: - Rest - No lifting of heavy objects - No walking up stairs • Refer for more help if milky urine continues for more than 30 days, or reappears one or more times a month, even when eating recommended foods	Nurse or nutritionist advises about local availability of foods Doctor or nurse evaluation and treatment of urination issues

Table 3.4. (Continued)

Care issues	Primary health care intervention	Referral care intervention
Urogenital problems[9,20]		
Neoplasm	• Check for non-transluminescence of the contents of the tunica vaginalis and scrotal sac • Refer for differential diagnosis, treatment, and surgery	Differential diagnosis and treatment
Lymphedema of skin and connective tissue of scrotum and penis	• Teach good hygiene practices • Identify and treat entry lesions • Teach how to safely clean and dry bandages • Treat AFA • Provide counseling to affected person and partner on condom use, sexual practices, surgical options, and other issues • Refer severe edema of penis to specialist for additional help with hygiene and urination issues, or any needed plastic surgery (in severe cases)	Specialist teaches massage techniques to reduce swelling needed for adequate hygiene Specialist to address urination difficulties

Table 3.5. Checklist for Monitoring Care

Checklist for monitoring care (Yes = Y, Problem requiring interventions to improve = P)		
	1.	Persons with lymphedema and hydrocele identified
	2.	Care is available, accessible, acceptable, and affordable
	3.	Surgery for hydrocele is available and accessible
	4.	Good-quality water is available and accessible to all (universal design)
	5.	Sanitation is available and accessible to all (universal design)
	6.	Person affected, family, caregiver are able to demonstrate good daily self-care
	7.	Entry lesions and offensive odor are identified and resolved
	8.	Acute filarial attacks (AFA) are identified and resolved
	9.	Urogenital problems are identified and resolved
	10.	Specific urinary tract problems are identified and resolved
	11.	Counseling and psychosocial support are provided
	12.	Advocacy for communities to be inclusive of persons with LF
	13.	Referral and counter-referral systems are established and used
	14.	Care is person-/family-centered
	15.	Minimal home-based care is planned, implemented, monitored, and evaluated
	16.	Adequate resources and technical support are provided to health workers and people affected to implement care

KEY MESSAGES

1. Person-centered and community-led initiatives are essential to successful LF control and care.
2. GPELF aims to stop the spread of LF infection with MDA campaigns to all endemic communities and alleviate suffering among people with hydrocele and/or lymphedema through the implementation of a minimum package of care.
3. Good daily hygiene and self-care practices for lymphedema can reduce AFA and progression of lymphedema.
4. Footwear plays an important role in reducing entry lesions and infection.
5. Men with hydrocele or lymphedema of scrotum and penis will often be embarrassed and hide the problem.
6. Hydrocele can be treated with surgery, improving quality of life.
7. Self-care practice improves one's sense of well-being and control over the disease.
8. Care needs to be accessible, available, acceptable, and affordable to persons affected by LF.

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    "The illustrations in this document were made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of Helen Keller International and do not necessarily reflect the views of USAID or the United States Government."

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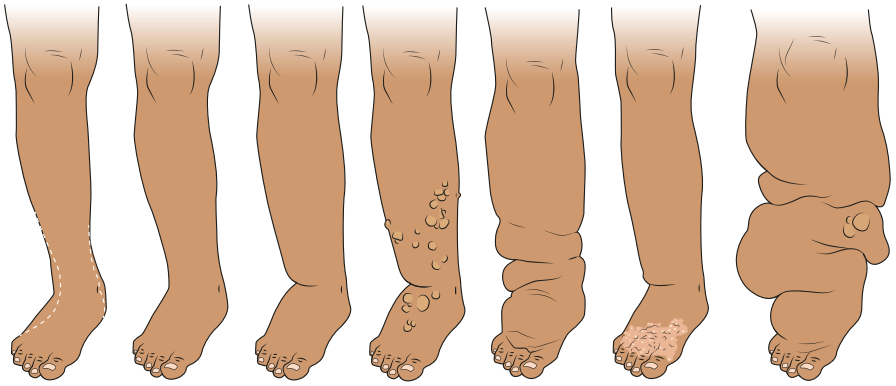
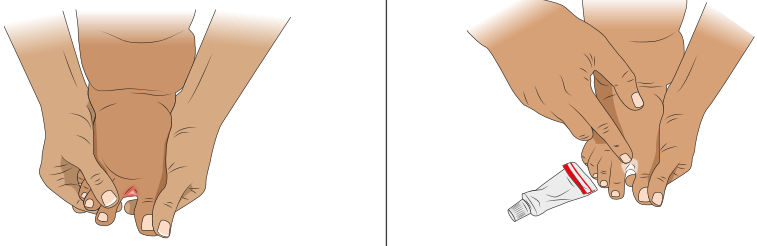
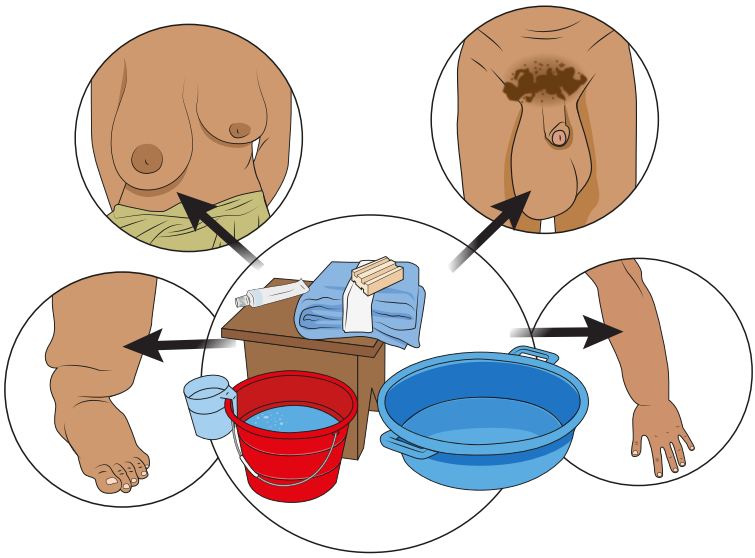
Annex 3.1a. Summary of Daily Self-Care Practices for Lymphatic Filariasis - Part 1



1. Inspect for entry lesions and if found, treat entry lesions.



2. Wash affected part.



Annex 3.1a. (Continued)

3. Dry carefully between fingers, toes, and skin folds.

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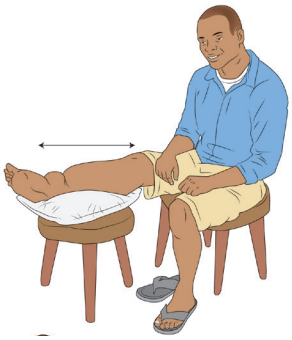
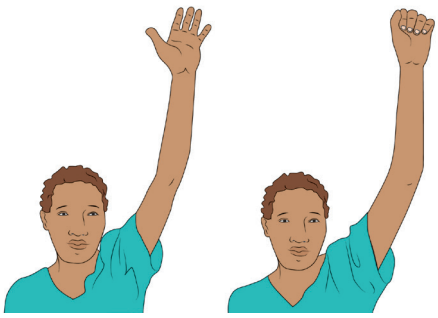
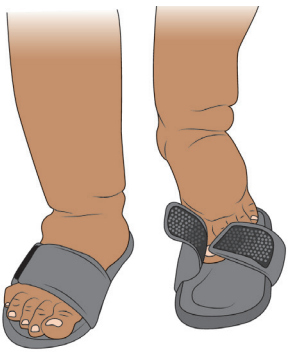
Annex 3.1b. Summary of Daily Self-Care Practices for Lymphatic Filariasis - Part 2

4. Elevate and move frequently, using strong muscle contractions.	
	
5. Exercise frequently, using strong muscle contractions.	
	

Illustrations: Valerie Simonet

6. Protect from injury at all times.	
	

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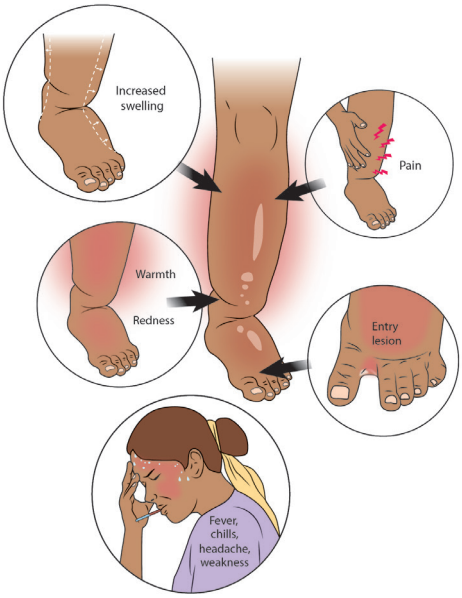
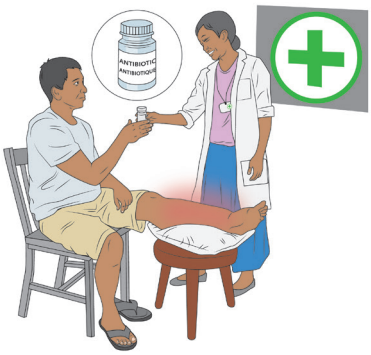
Annex 3.1c. Summary of Daily Self-Care Practices for Lymphatic Filariasis - Part 3

Identify acute attacks and treat immediately	
	

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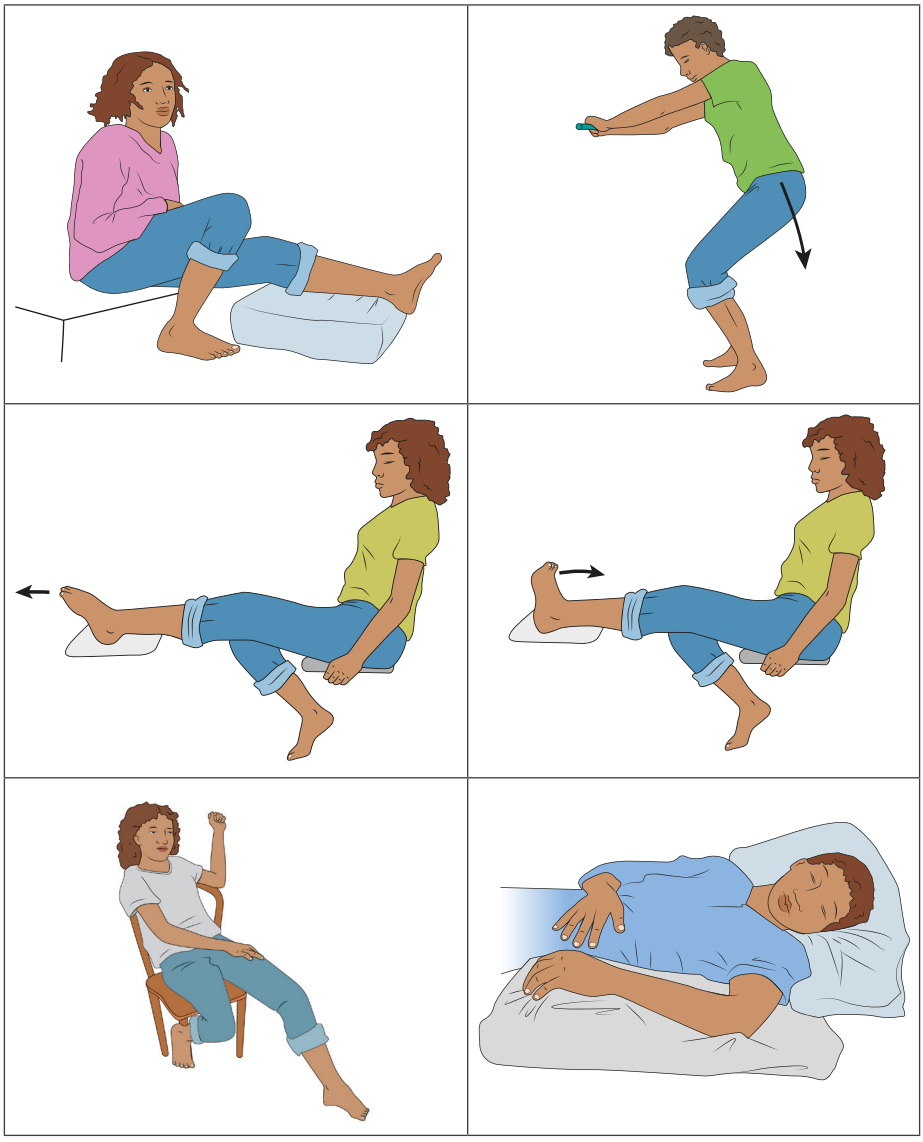
Annex 3.2. Additional Images of Elevation and Exercises for Lower and Upper Extremities with Lymphedema



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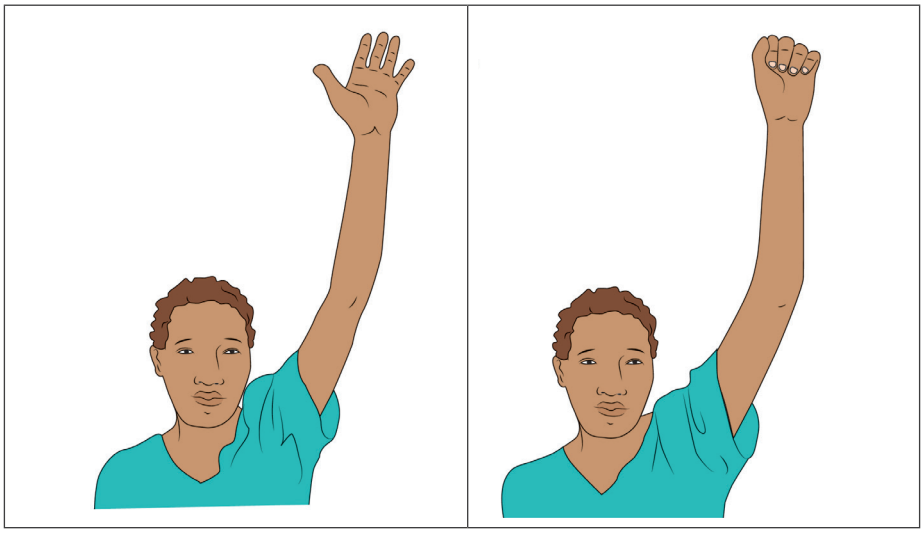
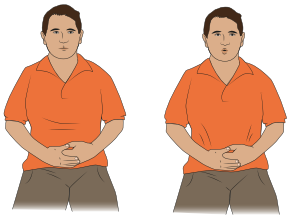
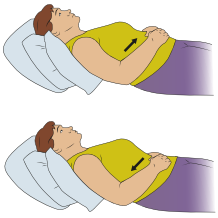
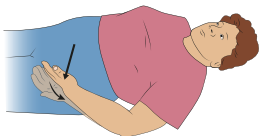
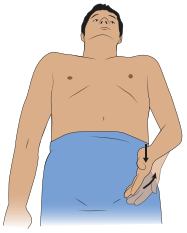
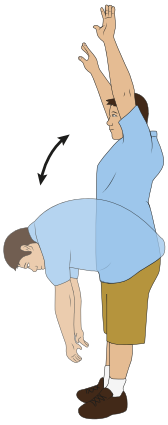
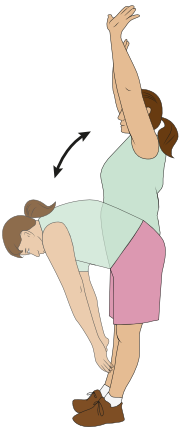
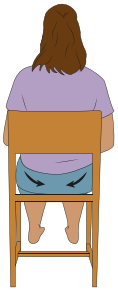
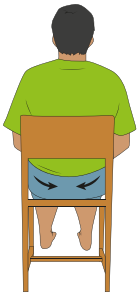


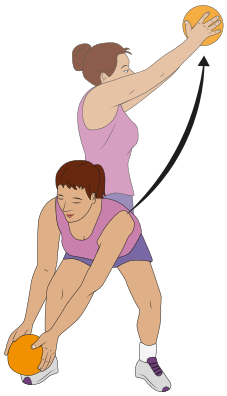
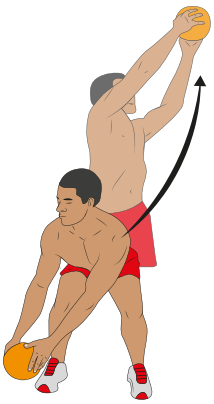
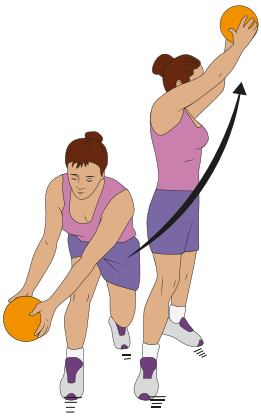
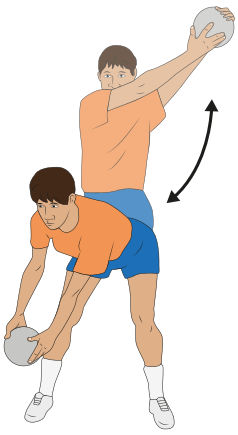
Illustrations: Valerie Simonet (originals). Redraw: Erick Hidalgo

Adapted from Lehman LF, Geyer MJ, Bolton L. Step 8: Managing swelling (edema). In: Ten Steps: A guide for health promotion and empowerment of people affected by neglected tropical diseases. Greenville, SC: American Leprosy Missions; 2015. http://www.leprosy.org/ten-steps/

Annex 3.3a. Images of Simplified Manual Edema Mobilization (MEM) – Breathing, Exercise, and Self-Massage by Artzberger for the Lower Extremity (Descriptions on how to do are found in Annex 3.3b)

1. Diaphragmatic breathing – "belly breathing" with tight "belly" and buttocks muscle contraction		
2. Self-massage		
3. Exercise: Trunk stretch and bend		
4. Exercise: Buttocks squeeze		

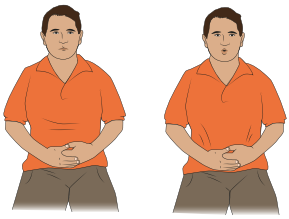
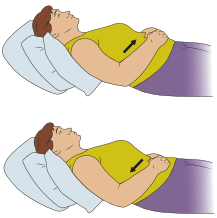
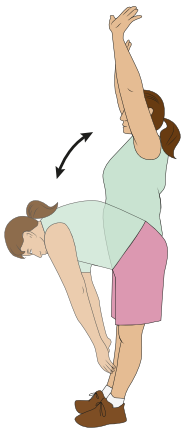
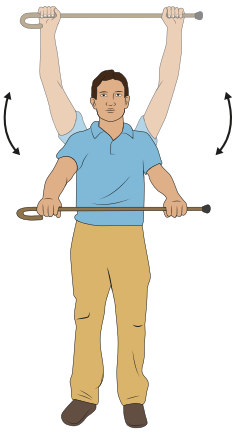
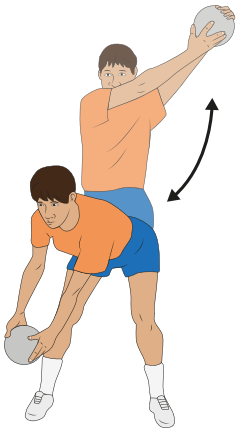
Annex 3.3a. (Continued)

5. Exercise: Diagonal trunk twists with partial squat to pick up ball		
6. Exercise: Diagonal trunk twists with trunk bend to pick up ball		

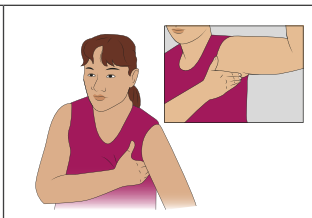
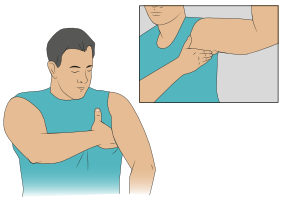
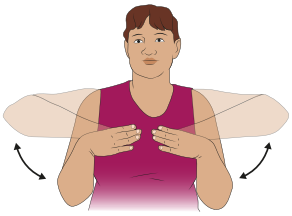
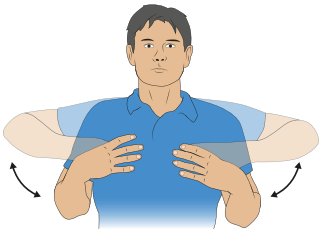
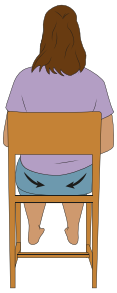
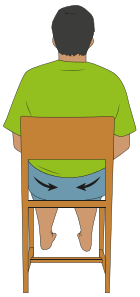
Annex 3.3b. Descriptions of Simplified MEM – Breathing, Exercise, and Self-Massage by Artzberger for the Lower Extremity

MEM sequence	Description on how to do in Annex 3.3a
1. Diaphragmatic breathing – "belly breathing" with tight "belly" and buttocks muscle contraction	While sitting or lying down, place hands over your stomach/belly (over navel). Inhale through the nose, making the navel move OUT toward hands. (If unable to do, tell the person to push their stomach out as if to show someone they are pregnant and to inhale at the same time filling the stomach.) Slowly, exhale through puckered lips, hands follow navel IN (tighten stomach muscles to pull stomach in). Try to squeeze the buttocks together at the same time as tightening "belly" muscles. Watch and make sure the movement is at the "belly" and that the chest does not move. Repeat 5-10 times.
2. Self-massage	Start at uninvolved limb side first. Place small finger side of hand against the hip crease. Gently press the side of the hand down, rolling from the tip of the finger outward toward the lateral side of the hip. Repeat 10 times. Repeat at involved side.
3. Exercise: Trunk stretch and bend	Inhale through nose while extending arms above head and close hands, making a tight fist. Exhale through pursed lips while bending at the waist, keeping arms and hands stretched to the floor. Repeat 5-10 times.
4. Exercise: Buttocks squeeze	While sitting, squeeze buttocks together. Hold for 10 seconds. (If difficult to understand how to do, have them think of squeezing tight to hold a $100 note.) Repeat 5-10 times.
5. Exercise: Diagonal trunk twists with partial squat to pick up ball	Squat to pick up a ball next to your right foot and then raise it over your head as you twist to the left. Repeat 5 times. Squat to pick up a ball next to your left foot and then raise it over your head as you twist to the right. Repeat 5 times.
6. Exercise: Diagonal trunk twists with trunk bend to pick up ball	Bend to pick up a ball next to your right foot and then raise it over your head as you twist to the left. Repeat 5 times. Bend to pick up a ball next to your left foot and then raise it over your head as you twist to the right. Repeat 5 times.

Annex 3.4a. Images of Simplified Manual Edema Mobilization (MEM) – Breathing, Exercise, and Self-Massage by Artzberger for the Upper Extremity (Descriptions on how to do are found in Annex 3.4b)

1. Diaphragmatic breathing – "belly breathing" with tight "belly" and buttocks muscle contraction		
2. Exercise: Raising arms over head with and without cane/stick		
3. Exercise: Big diagonal movements (PNF patterns)		

Annex 3.4a. (Continued)

4. Self-massage axilla (armpit)		
5. Exercise: Chicken wing movements		
6. Buttocks squeeze		

Visual Health Information Images (VHI) Copyright 1999–2000. VHI permission to use. http://www.vhikits.com
Adapted from Lehman LF, Geyer MJ, Bolton L. Step 8: Managing swelling (edema). In: Ten Steps: A guide for health promotion and empowerment of people affected by neglected tropical diseases. Greenville, SC: American Leprosy Missions; 2015. http://www.leprosy.org/ten-steps/

Annex 3.4b. Description of Simplified MEM – Breathing, Exercise, and Self-Massage by Artzberger for the Upper Extremity

MEM sequence	Description on how to do in Annex 3.4a
1. Diaphragmatic breathing – "belly breathing" with tight "belly" and buttocks muscle contraction	While sitting or lying down, place hands over your stomach/belly (over navel). Inhale through the nose, making the navel move OUT toward hands. (If unable to do, tell the person to push their stomach out as if to show someone they are pregnant and to inhale at the same time filling the stomach.) Slowly, exhale through puckered lips, hands follow navel IN (tighten stomach muscles to pull stomach in). Try to squeeze the buttocks together at the same time as tightening "belly" muscles. Watch and make sure the movement is at the "belly" and that the chest does not move. Repeat 5-10 times.
2. Exercise: Raising arms over head with and without cane/stick	Standing, hold a cane/stick at waist height with arms straight. Cane/stick is raised above the head and then lowered to touch the floor. Repeat 5-10 times.
3. Exercise: Big diagonal movements	Standing, hold a cane/stick at waist height with arms straight. Raise the cane/stick above the head. Twisting and bending at the trunk, the cane/stick is dipped down and up to draw a large figure-eight pattern. Return stick/cane stretched above the head. Repeat 5-10 times.
4. Self-massage axilla (armpit)	Start at uninvolved side first. Using full weight of the flat hand with flat fingers in the hollow of the arm (armpit/axilla), make 10-20 circles in the same place, pausing briefly at the top after each circle. Repeat in-place circles at involved armpit side.
5. Exercise: Chicken wing movements	With thumbs in armpits, or on the chest, and elbows at sides, lift elbows toward the ears, then lower to the sides. Repeat 5-10 times.
6. Buttocks squeeze	While sitting, squeeze buttocks together. Hold for 10 seconds. (If difficult to understand how to do this, have them think of squeezing tight to hold a $100 note.) Repeat 5-10 times.

Adapted from Lehman LF, Geyer MJ, Bolton L. Step 8: Managing swelling (edema). In: Ten Steps: A guide for health promotion and empowerment of people affected by neglected tropical diseases. Greenville, SC: American Leprosy Missions; 2015. http://www.leprosy.org/ten-steps/

4

Care in Trachoma

This chapter aims to:

1. Define and describe the SAFE strategy in trachoma.
2. Summarize the trachoma burden.
3. Clarify that trachoma is a blinding disease if not detected and treated early.
4. Define trachoma grading and what interventions are needed.
5. Describe the critical contributions of WASH in trachoma prevention and care.
6. Emphasize the importance of community-owned and -led water, sanitation, and hygiene practices to sustain behavior change in daily practices.
7. Describe community primary health care interventions based on the SAFE strategy.
8. Explain that counseling, training, and supportive supervision are needed for successful trachomatous trichiasis (TT) surgical programs.
9. Describe and encourage low-vision and blind skills training for persons with irreversible cornea opacity (CO) that facilitates daily activities and participating fully in community life.
10. Promote a people- and family-centered approach to care and the development of self-efficacy in self-care practices.

Care in Trachoma

This chapter will focus on primary health care interventions in prevention, care, and referral for persons with trachoma. It is important that national health programs alert health services in trachoma-endemic areas to be aware of the disease, how to identify new trachoma cases in areas under surveillance, and how to care for chronic disabling conditions. Community-owned and -led interventions for water, sanitation, and hygiene are critical to sustained behavior change needed for trachoma disease elimination. The World Health Organization (WHO) states that trachoma can be eliminated as a public health problem by implementing a comprehensive package of interventions.[1] The SAFE strategy targets the various routes of transmission, as well as treating infection and its disabling effects.[1-8] SAFE is an acronym for the following interventions that need to be addressed together:

- **S**urgery to correct *trichiasis*
- **A**ntibiotic treatment for *Chlamydia trachomatis* infection
- **F**acial cleanliness to reduce transmission
- **E**nvironmental improvement to reduce risk of transmission and infection

General Overview of Trachoma and Disease Burden[1-8]

The WHO Alliance for the Global Elimination of Trachoma by the Year 2020 (GET 2020) recognizes that trachoma is a neglected tropical disease and, when left untreated, is the world's leading infectious cause of blindness.4 The bacterial infection to the eye is caused by *Chlamydia trachomatis*. The bacteria are spread by:

- direct contact with ocular and nasal discharges from infected individuals;
- contact with inanimate objects that carry infection, such as towels, washcloths, or bedding; and
- eye-seeking flies.

Infection is associated with inflammatory changes of the conjunctivae known as "active trachoma."[1] Repeated episodes of active trachoma can result in scarring of the eyelid, which in some individuals leads to trichiasis (one or more eyelashes are pulled inwards to touch the eye) with or without entropion (in which the eyelid margin is rolled inwards).[1] Trichiasis is an extremely painful condition that can be corrected by eyelid surgery.

Initially, those with active trachoma may complain of discomfort or the feeling of "sand" in the eye and/or experience a red eye with ocular discharge. If trichiasis is left untreated, it may, in combination with other changes to the eye induced by trachoma, lead to corneal opacification, low vision, and irreversible blindness.[1] Eyelid

scarring also causes poor tear secretion and drying of the eyes, which further increases the risk of corneal ulceration. Smoke, dust, and sunlight make it more painful, often resulting in the person's preferring to stay indoors. Visual impairment or blindness results in a worsening of the life experience of affected individuals and their families, who are normally already among the poorest of the poor.[1]

Incidence of trachoma is highest in many poor-health communities where access to water and sanitation is limited.[1-5] In trachoma-endemic communities, children are frequently infected with *C. trachomatis*, due to their tendency to have close contact with others and not keep their faces free of secretions.[1] The blinding effects of repeated infection generally do not develop until adulthood.[1] Women are affected by trichiasis up to four times more often than men, probably due to their close contact with infected children and thereby getting more often reinfected themselves.[1]

This infectious disease is responsible for approximately 1.4% of the world's blindness.[4] According to 2010 data, trachoma is responsible for visual impairment of about 1.9 million people, of whom 450,000 are irreversibly blind.[1] However, the number of people known to live in trachoma-endemic areas has declined from 317 million in 2010 to 190 million in 2016, due to improved data and implementation of the SAFE strategy.[5] Primary health care services can prevent blindness by actively collaborating with communities to detect the disease and implement the SAFE strategy. The S intervention is provided to individuals with trichiasis, while A, F, and E are delivered to entire trachoma-endemic districts (usually defined as an area with a population of 100,000-250,000) in which prevalence of the active trachoma sign "trachomatous inflammation – follicular" (TF) is 5% or more.

In the Region of the Americas, there is evidence of trachoma in primarily three countries: Brazil, Colombia, and Guatemala.[5] Mexico announced the elimination of trachoma as a public health problem in April 2017.

WHO:

defines targets for the elimination of trachoma as a public health problem with the following criteria:

- *a prevalence of trachomatous trichiasis (TT) "unknown to the health system" of <0.2% in people aged ≥15 years (which approximates to <1 case per 1,000 in individuals of all ages);*
- *a prevalence of TF of <5% in children aged 1-9 years, in each formerly endemic district;*
- *in addition, there must be evidence that the health system can continue to identify and manage incident cases of TT.*[4]

Early disease detection and treatment is the best disability prevention. There are standardized WHO-supported training modules for trachoma mapping surveys (baseline, impact, and surveillance) with technical resources from Tropical Data, which is based on the previous Global Trachoma Mapping Project (GTMP) approach.[6,7]

Trachoma Grading and SAFE Strategy[8]

Standardized grading of trachoma is essential to:

1. Determine active disease and measure the prevalence of defined clinical stages of trachoma for decisions on the A, F, and E components.
2. Determine trichiasis that requires eyelid surgery (S component).

In the normal eye, the cornea is transparent and shiny, and the eyelashes do not touch the eyeball. The inside of the eyelids (tarsal conjunctiva) is pink, smooth, transparent, and thin with large deep-lying blood vessels visibly running vertically over the area. Tables 4.1 and 4.2 show and define the trachoma grade and what actions or interventions may be indicated.

Table 4.1. Trachoma Grading

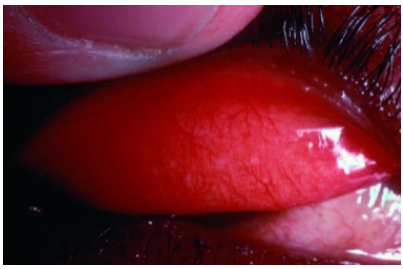
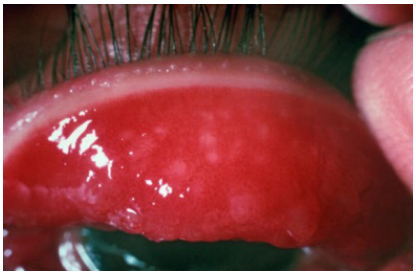
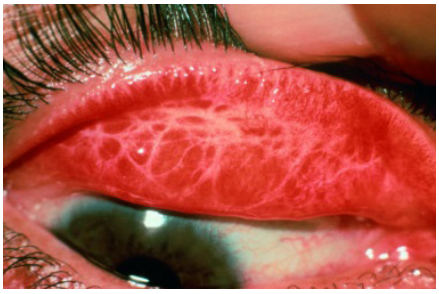
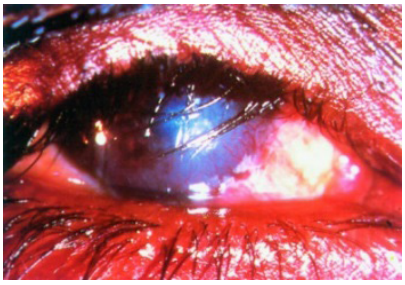
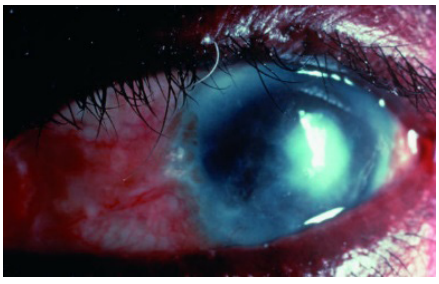
TF: trachomatous inflammation – follicular	TI: trachomatous inflammation – intense
	
TS: trachomatous scarring	**TT: trachomatous trichiasis**
	
CO: corneal opacity	
	

Table 4.2. Trachoma Grading with SAFE Interventions[8]

Grade	Signs	Actions
Trachomatous inflammation – follicular (TF)	Presence of five or more follicles at least 0.5 mm in diameter, in the central part of the upper tarsal conjunctiva	Implement **AFE** of **SAFE** when TF is 10% or more in children 1-9 years of age (TI is not measured for the decision on public health interventions)
Trachomatous inflammation – intense (TI)	Pronounced inflammatory thickening of the upper tarsal conjunctiva obscuring more than half the normal deep tarsal vessels	
Trachomatous conjunctival scarring (TS) without TT	Presence of easily visible scars in the tarsal conjunctiva	Lubricating eye drops/ointment and close follow-up as these patients are at risk of developing TT
Trachomatous trichiasis (TT)	At least one eyelash rubs on the eyeball, or evidence of recent removal of in-turned eyelashes in the presence of TS	Measure visual acuity and correct as possible Moisturize eyes with drops/ointment Follow national policies for manually removing eyelashes (epilate). This is only a temporary solution and requires training and follow-up so further damage is not caused[14] Register and refer for eyelid surgery for best permanent solution Implement the S component of the SAFE strategy for district interventions if TT is present in at least 2/1,000 population 15 years or older (or 1/1,000 in the entire population)
Corneal opacity (CO)	Presence of easily visible corneal opacity over the pupil, so dense that at least part of the pupil margin is blurred when viewed through the opacity	Measure visual acuity Refer for: • Blind and low-vision skills training • Cornea surgery

See WHO Trachoma Grading Card8 side 1 and 2
http://www.who.int/blindness/publications/trachoma_english.jpg?ua=1
http://www.who.int/blindness/publications/trachoma_english1.jpg?ua=1

Critical Role of WASH (Water, Sanitation, and Hygiene) in Trachoma Prevention and Care[9,10]

The vicious cycle of poverty and trachoma is linked to poor access to and use of water, sanitation, and hygiene (WASH). Communities and primary health services working together can ensure WASH is of good quality, available, and accessible for all, including those with visual impairments and other disabilities.[10] Community-led interventions play a crucial role for the required sustained behavior change to reduce ocular *C. trachomatis transmission*.[11,12]

Table 4.3. Critical Role of WASH in Trachoma Prevention and Care

Infection prevention	Care
• Facial cleanliness (F) and environmental improvements (E) are primary prevention components of the trachoma SAFE strategy	• Sustained behavior changes with regular face washing for clean faces, particularly in children, and environmental changes to reduce the number of eye-seeking flies are important to sustainably reduce transmission of infection • Trichiasis surgery needs clean water and hygienic conditions • Visually impaired people and other persons with disability require access to inclusive WASH infrastructure

Note: Community-led inclusive interventions are critical for successful and sustainable behavior change in WASH practices

Adapted from WHO WASH Strategy 2015-2020.[9]

Health Care Interventions for Trachoma[12-33]

IMPORTANT: PEOPLE-CENTERED AND COMMUNITY-LED APPROACHES TO CARE

- The concept of people-centered care approach is important throughout this manual. People-centered health services means putting people and communities, not disease, at the center of health systems, and empowering people and communities to take charge of their own health, rather than being passive recipients of services.[17,18] The health service aims to maximize the person's, family's, and community's capabilities and ownership.

The Precede-Proceed Health Promotion and Education Model by Green and Kreuter (2001)[19] identifies behavioral and environmental factors that are thought to result in behavior change and sustain it. Table 4.4 summarizes factors that can be applied to trachoma health promotion and education messaging which facilitates or impedes behavior change. It is important to involve the community in identifying barriers to adopting preferred practices and develop "community tailored" mechanisms to overcome these barriers.[17] Poor quality of services is known to be a major barrier, and thus using agreed standardized "preferred practices," quality training, supportive supervision, good counseling, and good monitoring and evaluation are crucial components for success.[12,17] WHO recognizes that active community participation is essential in the following health promotion and education messages and interventions (http://www.who.int/servicedeliverysafety/areas/qhc/community-engagement/en/):[18]

- Educate people about trachoma and how it is spread;
- Encourage acceptance of quality surgery;
- Increase acceptance of antibiotics;
- Encourage sustained facial cleanliness;
- Promote a clean environment;
- Create demand for and use of good household latrines.

Table 4.4. Behavioral and Environmental Factors Affecting Behavior Change[18]

Predisposing factors	**MOTIVATE** a person or community: knowledge, beliefs, values, attitudes, self-efficacy
Enabling factors	**FACILITATE ACTION** (environment, skills, or resources needed to do or attain a specific behavior): programs, services, availability and accessibility of resources, skills required to enable behavior change
Reinforcing factors	**REWARDS or REINFORCEMENTS** of desired behavior change: family and social support, economic benefits, changing social norms, laws, etc.

Surgery

The International Coalition for Trachoma Control (ICTC) and the Morbidity Management and Disability Prevention (MMDP) website[20] provide detailed resource materials on data, mapping, planning, and interventions. Surgery is the first part of the SAFE strategy, as it addresses the needs of those in immediate risk of visual impairment and blindness.[19] Planning for surgical services should follow recommended planning and implementation guidelines and preferred practices.[19-29] Health education informs the community who is at risk, when and where surgery is available, and what is involved for the person to have surgery. Trained case finders typically identify and refer cases to the nearest facility.[20,21]

Correction of the eyelid takes away the pain of lashes scratching on the eyes and may improve early visual impairments, but it does not remove scarring or restore sight at later stages.[20-22] Surgery is for TT-stage disease to correct in-turned eyelashes of persons with trichiasis. WHO recommends the Trabut and Bilamellar tarsal rotation (BLTR) procedures.[20,21,23] Lid surgery is a relatively simple procedure that can be offered close to the community—e.g., at a nearby health center—but it requires good training and supportive supervision.[20,24,25,26] Acceptance of surgery is best accomplished when community-wide surgery is offered and good counseling is done.[22] Surgical failure and reoccurrence of post-OP TT are more common when adequate training, supportive supervision, and follow-up are not provided.[20,24-26] To improve training (initial and refresher), bridge the gap between classroom teaching and live surgery, and foster continuous practicing, the mannequin-based Head Start training approach is now widely accepted and used.[28] Once a patient has developed corneal opacity, there is usually little that can be done to restore vision in typical trachoma settings. It is therefore imperative that TT patients are identified and referred early to prevent the occurrence of visual impairments and blindness.

Note: Post-operative TT:

- Surgical failure – any TT within first 6 months after surgery
- TT-reoccurrence – any TT reoccurring 6 months or later after surgery

Antibiotics

Antibiotics treat active trachoma and reduce the reservoir of infection in the community.[29] All activities should follow recommended planning and implementation guidelines and preferred practices.[29-31] Health education informs the community about why antibiotics are needed and when, where, and how antibiotics will be distributed. It also informs the community about the benefits and potential side effects of the antibiotic.

Two antibiotics are currently used: tetracycline eye ointment applied locally twice per day for 6 weeks; or a single dose of systemic azithromycin by mouth (PO), either as tablets or as syrup for small children. Depending on the prevalence of active trachoma (measure by TF; see above) in the community, health officials may choose to either mass treat all individuals in the community (entire population at risk) or treat only people with active disease and their family, typically through health facilities.[29] National policies regulate who is excluded from systemic mass treatment, such as children under 6 months of age, pregnant women, breastfeeding mothers, and persons who are too ill. Pfizer donates azithromycin through the International Trachoma Initiative (ITI) to eliminate active trachoma in eligible communities.[29] The medicine is too expensive for most individuals to buy.

Table 4.5. Antibiotics for Control of Trachoma[29-31]

Azithromycin	One oral dose (20 mg/kg body weight) OBSERVATION: • If available, first-line antibiotic • Well-tolerated • Use tetracycline eye ointment for children under 6 months of age and other non-eligible persons as per national guidelines (see below)
1% tetracycline eye ointment	Administer in both eyes twice daily for 6 weeks. OBSERVATION: • Universally available and low cost • Can be difficult and unpleasant to apply, especially in young children (needs good training of caregivers) • Low compliance

Facial Cleanliness[10,11,15,16,17]

Facial cleanliness is emphasized, especially with children, mothers, or other caregivers. Dirty faces are more likely to transmit the disease if they have active infection. Dirty faces with discharge from eyes and nose attract eye-seeking flies that carry the infection to other people. Rubbing the sore and dirty eyes with hands, clothing, bedsheets, or other objects can contribute to the transmission of trachoma to others. Health education demonstrates to the community how to wash and keep faces clean with small amounts of water. It also informs the community how improving the environment prevents transmission of trachoma and other infections. Community-led approaches are key for sustained behavior change.[15-17]

Environmental Improvements

Environmental improvements of basic infrastructure for water, sanitation, and waste disposal reduce the risk of trachoma infection and reinfection. To accomplish this, health services must collaborate with non-health sectors such as education, water, and rural sanitation.[10,11,15-17] Communities and primary health services working together can ensure WASH is of good quality, available, and accessible for all (barrier free), including those with disabilities and/or visual impairments.[10,11,17] Health education discusses why latrines are viewed as socially desirable. It also shows how good and accessible latrines can be constructed, sustainably used, and maintained. Community-led approaches are key for sustained behavior change.[15,16,17]

Blind and Low-Vision Skills Training[31,32]

People with irreversible visual impairments from the CO (corneal opacity) stage of trachoma benefit from skills training to learn to move about independently and safely at home, within and outside their community. The referral to specialized blind and low-vision professionals and services can improve the person's ability to fully participate in their valued activities and reduce the impairment burden on the person, family, and community. This training develops orientation and mobility capabilities, skills to do daily activities, and use of assistive technology. Communities can also learn how to modify the environment to make it more accessible and safer for those with visual impairments.

Orientation and Mobility (O & M) Capabilities
Orientation develops the ability to know where you are and where you want to go. Mobility develops the ability to move safely, efficiently, and effectively from one place to another. This means walking confidently without tripping or falling, crossing roads, and using public transportation. It may include learning how to use a cane and using strategies such as listening for traffic patterns.
Essential Daily Living Skills
These are the essential skills and strategies used to be independent in performing your daily activities, such as personal hygiene care, food preparation, clothing care, housekeeping, money management, shopping, mobile phone use, social and recreation involvement, and other.
Assistive Technology (AT)
Assistive technology is dependent on skills, financial capabilities, and availability of and accessibility to equipment. It may include smartphones and tablets, GPS devices, portable recording and listening systems, computers, or other.

Overview of Key Eye Self-Care Issues for Trachoma

Learning self-care, individually or in a group, can improve the person's perceived beliefs about their capacity to take care of themselves. Developing a strong sense of *self-efficacy*[15] improves

compliance of practicing daily self-care and improves a sense of well-being. As a result, the person feels they have the capabilities to exercise control over their disease and visual impairments. Table 4.6 has observations, questions, and actions important for self-care, and Table 4.7 provides a checklist for monitoring activities.

For additional information, general eye health issues and care are summarized in Annex 4.1 in Tables A4.1, A4.2, and A4.3.

Table 4.6. Observations and Questions for Self-Care in Trachoma

1. Are your face and hands clean?
2. Is there eye or nasal discharge?
3. Is there a feeling of "sand" in your eyes? Are your eyes itching?
4. Are your eyes red? Is there irritation or pain?
5. Are you sensitive to light? Do you prefer to stay indoors with less light?
6. Is there a change in your vision/ability to see?

Self-care	Get help to:

• Look at face, eyes, and hands to see if they are clean
  • No eye or nose discharge
  • No dust, dirt, or food on face or hands
• Clean face and hands, removing dust, dirt, discharge, and food, and dry with your own clean washcloth and towel
• Do not share washcloth or towel with others or use another person's washcloth, towel, or eye makeup
• Wash hands after toilet
• Use antibiotics for trachoma infection as prescribed by health service
• Moisturize or lubricate dry eyes with artificial tears and/or ointment
• Use wide-brimmed hat and sunglasses to shade and protect eyes against dirt, sun, smoke, flies
• Use mosquito net at night to protect face and eyes from flies during sleep
• Safely dispose of all waste to prevent flies; avoid open defecation
• Ask trained caregiver to remove eyelashes touching the eye with good-quality tweezers until the preferred eyelid surgery can be done
• If with low vision/blind
  • Adapt environment to reduce falls, to improve independence
  • Use a cane for orientation and mobility
	• Treat acute infection
	• Surgically correct eyelids for trichiasis
	• Treat dry eyes with eye drops and ointment
	• Treat corneal ulcer
	• Improve vision
	  • Eyeglasses (distance and close-up)
	  • Cataract removal
	• Learn how to live more independently and safely with blindness or low vision

Table 4.7. Checklist for Care
(Yes = Y, Problem requiring interventions to improve = P)

		Clean water is safely available and accessible to all
		Sanitation is safely available and accessible to all
Self-care practices for trachoma		Faces, eyes, and hands are clean
		Avoids sharing of personal washcloths and towels
		Washes hands after using the toilet
		Takes trachoma antibiotic treatment correctly
		Moisturizes dry eyes
		Protects eyes from flies and drying effects of sun, smoke, wind, etc.
		Safely disposes of waste
		Counseled about eyelid surgery if TT present
		Has TT eyelash manually removed (epilated) only by trained and supervised caregiver until TT surgery is provided
		Good-quality TT surgery provided
		Training given for blind and low vision to improve independence and safety
		If there is low vision, check the following
		Maintains objects in the same place
		Adapts the environment to help make it easy to get around
		Adapts areas for safe mobility around traffic, fire, hot water
		Uses a stick or cane to help get about
		Teaches people how to assist in walking

KEY MESSAGES

1. Person-centered and community-led initiatives are essential to successful trachoma elimination and care.
2. The SAFE strategy combines surgery, antibiotics, facial cleanliness, and environmental improvements to reduce trachoma infection, visual impairment, and blindness.
3. Facial cleanliness and environmental improvements can prevent infection and transmission of trachoma.
4. Timely eyelid surgery to correct eyelid and eyelash position can reduce pain and prevent injury and corneal scarring that can lead to visual impairment and blindness.
5. Good counseling, training, and supportive supervision are essential for the success of TT surgery.
6. Manual eyelash removal (epilation) should be done only by a trained caregiver with quality epilation forceps for persons refusing surgery or until persons receive TT surgery.
7. Persons with low vision or blindness can benefit from skills training to improve mobility, independence in safely doing daily activities, and participating in community life.
8. Self-care practices improve one's sense of well-being and control over one's disease and visual impairments.

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Annex 4.1. General Eye Health for Community-Based Primary Health Care*

Good vision is important for performing activities at home, work, school, and play. Vision is also needed for the person to inspect his or her skin, eyes, hands, and feet so injuries and other problems can be identified early. Vision is even more important for people who have lost their ability to feel in their hands and feet, because they depend 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 visual impairment and blindness. Other simple ways to preserve eye health include eating vitamin A-rich foods, such as sweet potatoes, carrots, dark leafy greens, and chiles; 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 that can cause diseases.

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. People with 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. Tables A4.1, A4.2, and A4.3 summarize some of the key eye issues seen and care techniques used by primary health care services.

* Adapted from Lehman LF, Geyer MJ, Bolton L. Ten steps: A guide for health promotion and empowerment of people affected by neglected tropical diseases. Greenville, SC: American Leprosy Missions; 2015. http://www.leprosy.org/ten-steps/

Table A4.1. Summary of General Eye Health Care for Community-Based Primary Health Care

Preventive actions	Details
1. Practice good personal hygiene	• Discourage face-seeking flies by washing face and hands frequently with clean water, and preferably soap, and drying with a clean cloth • Properly dispose of human waste to reduce the number of flies (avoid open defecation) • Wash hands, preferably with soap, prior to and after touching the eye or playing with children • Do not wipe sweat from the eyes using dirty hands or clothing • Prevent exposure of eyes to dust, pesticides, and other contaminants. • Do not share personal items; e.g., handkerchiefs, towels, bedding, eye makeup.
2. Practice good household cleanliness	• Properly store/dispose of household, animal, and human waste (i.e., burn, bury, put in good and accessible latrine; preferably separate for women/girls and men/boys, especially at public places) and move livestock away from the house to reduce the number of flies • Construct, use, and maintain universally accessible latrines and refuse pits

3. Eat healthy foods	• Provide vitamin A according to national policies
	• Grow and eat foods rich in vitamin A, for example:
	  • Red, yellow, and orange vegetables and fruits
	  • Dark green and red lettuce
	  • Liver and dairy products
	  • Herbs and spices (red pepper, basil, etc.)

4. Immunize	• Protect against disease with measles vaccine and other vaccines
5. Protect eyes	• Shade eyes with a wide-brimmed hat and/or sunglasses • Protect eyes from injury during work (woodworking, welding, etc.) • Protect eyes from smoke, blowing sand, dirt, and other debris • For eyes that do not close completely, protect from dryness • For eyes with loss of feeling, "Think blink" frequently and self-check vision daily

6. Refer	• Contact supervisor and/or refer to hospital immediately if an eye injury occurs or one of the following is present:
	  • Sudden change in vision
	  • Difficulty closing the eye completely
	  • Eyelashes turned in and touching the eye

Table A4.2. Community Eye Problems, Care, and Referral

Problem identified	Community-level care	Refer
1. Sudden decrease in vision with pain 2. Complaints of pain and/or sensitivity to light with recent change in vision	• Check visual acuity with Snellen E Chart or other recommended by national program • Urgent, refer to specialist immediately	• Specialized eye examination, diagnosis, and treatment • Feedback to community-level primary health care
3. White, dull area which is an ulcer or foreign body	• Clean with running water, cover with a shield, refer • AVOID applying any pressure on the eyeball	• Specialized eye examination, diagnosis, and treatment • Feedback to community-level primary health care
4. Chronic vision loss is greater in one eye compared to the other with no other problems 5. Cannot see smaller than line 6 on the Snellen E Chart in either eye	• Place on list for possible corrective glasses • Check for cataracts and put on list for cataract surgery evaluation	• Specialized eye examination, diagnosis, and treatment • Schoolchildren are a priority for corrective lenses • Surgical removal of cataracts • Feedback to community-level primary health care
6. Cannot see the largest E on the Snellen E Chart	• Good personal and environmental hygiene • If combined with sensory loss to hands and feet, the practice of good personal and environmental hygiene may be difficult • Self-care practice training with and without caregiver • Check for cataracts and put on list for cataract surgery evaluation • Adaptive skills training for low vision • Refer for specialist examination	• Specialized eye care examination, diagnosis, and treatment • Schoolchildren are a priority for corrective lenses • Surgical removal of cataracts • Feedback to community-level primary health care

7. Unable to count fingers at 3 meters with dull white central area present (cataract or cornea opacity)		• Specialized eye care exam, diagnosis and treatment
		• Surgery for:
		  • Cataracts
		  • Cornea transplant
		• Feedback to community-level primary health care

Table A4.2. (Continued)

Problem identified	Community-level care	Refer
8. Complaints: burning, itching, sand-like feeling (dry eye) 9. Red eye 10. Inability or difficulty closing eyes	Check for foreign body (on the cornea or under the eyelids) or eyelashes turning in and touching the eye Good personal and environmental hygiene Artificial tears to moisten eyes Assist with or strengthen eye closure Protect eyes from dirt, smoke, sunlight Check for eyelashes turning in and touching the eye • Temporary lash removal with quality tweezers	If foreign body is detected, shield the eye and refer immediately for specialized services If no foreign body present and no improvement in 1 week, refer for specialist eye examination, diagnosis, and treatment for: Antibiotics Surgery of trichiasis, lagophthalmos Feedback to community-level primary health care
11. Forgets to blink	In Hansen's disease/leprosy with sensory loss to cornea, "Think blink" training Protect eyes from dirt, smoke, sunlight	
12. Excessive tearing 13. Lower eyelid turning out (ectropion)	Check for foreign body (on the cornea or under the eyelids) or eyelashes turning in and touching the eye Teach to dry the eyes safely with a clean cloth Heath education for self-care	Refer immediately for specialist eye care examination, diagnosis, and treatment of trichiasis, removal of foreign body, or treatment of other causes Surgical correction of lower eyelid (ectropion) In case of TT: Surgical correction of eyelids Referral-level feedback to community-level primary health care
14. Secretions	Check for foreign body (on the cornea or under the eyelids) or eyelashes turning in and touching the eye Clean eyes and eyelashes daily Good personal and environmental hygiene Protect eyes	If foreign body detected shield the eye and refer immediately for specialized services If no foreign body present and not improved in 1-2 weeks, refer for specialist eye care examination, diagnosis and treatment Feedback to community-level primary health care
15. Inside upper eyelid is red, has bumps/lumps	Clean Good personal and environmental hygiene Artificial tears to moisten eyes	Refer immediately for confirmation of trachoma or other causes and treatment

Table A4.2. (Continued)

Problem identified	Community-level care	Refer
16. Eyelid turned inward 17. Eyelashes turned inward touching the eye	Good personal and environmental hygiene Artificial tears to moisten eyes Place on list for corrective surgery Check whether lid closure is complete (if not refer urgently for specialized services and keep eye moist; e.g., frequent lubricants during the day and eye ointment at night)	Refer as soon as possible for surgical correction of eyelid and eyelashes
Groups at risks for other relevant eye health problems		
18. Children	Avoid playing in sandy areas that might have cat feces	
19. Females	Vaccinate for measles, TB, and other	
20. Pregnant women	Avoid ingestion of food or water contaminated with cat feces Screen for gonorrhea, syphilis, HIV	
21. Mothers with gonorrhea	Use 1% silver nitrate drops in eyes of	

Table A4.3. Techniques Used in Eye Care at Community Level

Daily self-check of vision for persons who have: • Dry eye • Difficulty closing eyes completely • Forget to blink enough	If the eye is dry and not moist enough, vision will become blurry. 1. Stand and look at the same object at the same time of day. 2. Check clarity of object with each eye separately. 3. If vision seems worse or more blurry, "Think blink" for five minutes and recheck. If vision improves, you need to remember to blink more often. If worse, seek help.
Always wash hands with soap and water before proceeding with eye care. Use only clean water (boiled and cooled down). Always wash hands with soap and water before proceeding with eye care and use only clean water.	
Cleaning the eyes	1. Wash eye by putting clean water into a cupped had and place over the eye, with the eye open. 2. Rinse the eye thoroughly by tilting the head forward and backward. 3. Wash hands with soap and water again and repeat with the other eye if needed.
Cleaning the eyelids	1. When cleaning the upper eyelid, look down and gently lift the upper lid up. Moisten a cotton swab, gently rolling the swab across the eyelid, away from the eye. 2. When cleaning the lower eyelid, look up and gently lower the lower lid down. Moisten a cotton swab, gently rolling the swab across the eyelid, away from the eye.

Table A4.3. (Continued)

Putting in eye drops • Used to moisten eyes • Used if there is an infection • Used if there is glaucoma	Follow the doctor's prescription and practice putting drops in eye without touching the eyelashes or eye. If unable to do the following, get help. 1. Look up. 2. With the clean thumb and index finger, gently pinch and pull out the lower eyelid making a small "pouch." 3. Place one drop in the "pouch," gently close the eye (do not squeeze!), and release pinch. 4. Keep eye gently closed for 20-30 seconds. 5. If a second drop is needed, wait about five minutes and repeat the same procedure.
Using eye ointment	Follow the doctor's prescription and practice putting ointment in eye without touching the eyelashes or eye. If unable to do the following, get help. 1. On a new, clean cotton swab for each eye, place a small amount of ointment on the tip of the swab. 2. Look up and gently pull out the lower eyelid creating a "pouch." 3. Gently place the cotton swab on the lower lid and roll the ointment into the "pouch." 4. Gently close the eye and release the pinch. 5. Keep the eye gently closed for 20-30 seconds
Protection during the day • Protect eyes that cannot close completely	In order to decrease eye exposure to the sun and the drying effects of the wind, and to protect the eye from dirt and other foreign objects: 1. Use a wide-brimmed hat. 2. Use sunglasses. 3. If vision becomes worse, seek professional help.
Protection during the night • Protect eyes that cannot close completely	In order to decrease eye exposure to the sun and the drying effects of the wind, and to protect the eye from dirt and other foreign objects falling into the eye at night: 1. Put in eye ointment/oil prior to sleeping. 2. Cover the exposed eye with an eye shield/cover that does not touch the eye (dome or cone shaped cover).
Making an eye shield/ cover	If someone is unable to close their eye completely (lagophthalmos), the following eye shield/cover is safe to use at night or when covering the eye if there is an ulcer. It prevents the patch from touching the eye that cannot close completely. 1. Cut a circle out of a piece of cardboard or used, cleaned transparent X-ray film or other thin plastic sheet. 2. Make a cut from one edge of the circle to the middle and stop. 3. Overlap the edges, making a cone. 4. Put adhesive tape on the inside and outside to hold the dome/ cone shape. 5. Tape the cone over the eye or attach elastic or ties to fix the patch in place over the eye. **Note:** Patients whose hands and feet cannot feel prefer the shield/cover to be transparent when it is necessary to cover both eyes. They need their sight for mobility.

Table A4.3. (Continued)

Foreign body/eyelash turned in and touching the eye	If the foreign body is metal, DO NOT try to remove but close the eye, cover, and send immediately to the eye specialist. If other: 1. Look for a foreign body/eyelash without turning over the upper eyelid. If the foreign body/eyelash is not found: 1. Ask the person to look down but not to close the eye. 2. Take the eyelid between the thumb and forefinger and, with a matchstick/cotton tip or finger, turn the eyelid up so the whole inner eyelid is in view. 3. Look for the foreign body/eyelash. 4. When you have found it, carefully remove with a clean, moistened cotton swab or the tip of a clean, moistened cloth. If eyelashes are turning in and touching the eye: 1. If only one or two, remove with clean tweezers. 2. If many, refer for surgical removal.

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5

Care in Chagas Disease

(American Trypanosomiasis)

This chapter aims to:

1. Review the causes of Chagas disease, how it is transmitted and treated.
2. Summarize how Chagas disease affects the person, as well as its burden on the community.
3. Explain the important role of early diagnosis and treatment of Chagas disease.
4. Discuss the important goals of eliminating transmission and providing early access to health care for infected persons and populations at risk.
5. Describe protocols of cardiovascular and digestive rehabilitation at the primary health service.
6. Describe methods to improve swallowing and voice quality at the primary health service.
7. Identify common issues needing treatment at the primary health service and/or referral.
8. Promote a people- and family-centered approach to care and self-care practices.
9. Promote actions to reduce stigma and strengthen empowerment in the primary health setting.

Care in Chagas Disease

(American Trypanosomiasis)

General Overview of the Burden of Chagas Disease (American Trypanosomiasis)

Chagas disease, also known as American trypanosomiasis, is a chronic and neglected infectious condition, caused by the protozoan parasite *Trypanosoma cruzi* (*T. cruzi*).[1-3] In Latin America, *T. cruzi* are mainly transmitted by contact with feces/urine of the infected blood-sucking triatomine bugs.[3] These bugs can carry the parasites and typically live in the wall or roof cracks

of poorly constructed homes in rural or suburban areas.[3] Normally, they hide during the day and become active at night when they feed on human blood.[3] They usually bite an exposed area of skin such as the face, and the bug defecates close to the bite.[3] The parasites enter the body when the person instinctively smears the bug feces or urine into the bite, the eyes, the mouth, or into any skin break.[3] In addition, there are other ways the parasite is transmitted, which are listed below.

Transmission of *T. cruzi* is by:[1,2,3,4,5,6]

- Bite and contact with feces/urine of infected blood-sucking triatomine bugs;
- Consumption of food or drink contaminated with *T. cruzi* from: infected triatomines, triatomine feces/urine, secretion of the anal gland or in the urine of infected marsupials of the genus *Didelphis*;
- Intake of breast milk from mothers diagnosed with: acute Chagas disease, *T. cruzi*-HIV coinfection in the AIDS stage, documented reactivation of Chagas disease, or bleeding from fissures of the nipples;
- Blood transfusion from an infected donor;
- Passage from an infected mother to her newborn during pregnancy or childbirth;
- Organ transplants using organs from infected donors; or
- Laboratory-acquired (accidental inoculation with contaminated needle or by suspensions of *T. cruzi* in pipettes) in the context of research or diagnostic procedures.

About 7 million people worldwide, mostly in Latin America, are estimated to be infected with *T. cruzi.*[3,4] Chagas disease represents the leading cause of cardiac lesions in young, economically productive adults in endemic Latin American countries (in terms of disability-adjusted life years lost – DALY).[2] The disease is distributed on the American continent, from the southern United States (rare) to southern Argentina; human migration is the most likely reason for diagnosis in nonendemic areas (Europe, Oceania, and others).[3,4,5]

The disease is potentially life-threatening and can cause chronic cardiac and/or gastric complications affecting the person's quality of life.[1-3] Persons diagnosed with Chagas disease and their families often experience depression, anxiety, and fear

about the potential effects of the disease on the person's health, risk of transmission, and the family's livelihood.

Chagas disease presents two phases, acute and chronic. The initial acute phase, lasting for 3 to 8 weeks, is often asymptomatic but can prove fatal.[1,2,3,6] The acute phase is usually more severe in young and immunocompromised persons (e.g., HIV coinfection).[1,2,6] They can present myocarditis (inflammation of heart muscle) and meningoencephalitis (inflammation of meninges and brain), leading to death in 3% to 10% of the acute phase cases.[1,2]

The second, chronic phase develops if the acute phase of disease is undiagnosed or untreated. The symptoms of chronic disease can remain silent for the rest of the person's life and be known as the *indeterminate form* of Chagas disease.[1,2,3] Fifty percent or more of people infected with Chagas disease in the Americas have the indeterminate chronic form of the disease or have the early stages of the cardiac and digestive chronic forms of the disease. All of this group can be detected and treated at the primary health care level.[1,2,6]

Alternatively, the chronic disease can remain asymptomatic for 10 to 20 years after the acute phase.[1,2,3,6] Up to 30% have cardiac impairments, and 10% suffer from digestive impairments, usually from an enlarged esophagus or colon. The impairments may be mixed cardiac and digestive forms of the disease with less frequent *neurological forms* of the disease.[1,2,3] In later years, the infection can lead to sudden death due to cardiac arrhythmias or progressive heart failure caused by the destruction of the heart muscle and its nervous system.[3] Concurrent immunosuppression, such as HIV or heart transplantation, can result in reactivation as myocarditis or severe meningoencephalitis.[1]

There is no vaccine for Chagas disease. Vector control is considered by WHO as the most effective method of prevention in Latin America.[3] The large number of triatomine species cannot be eradicated, but disease control can target eliminating transmission and providing early access to health care for infected persons and populations at risk.

WHO Approach to Chagas Disease Prevention and Control[2,4]

- *Spray houses and surrounding areas with residual insecticides;*
- *Improve houses and house cleanliness to prevent vector infestation;*
- *Adopt personal prevention measures, such as the use of bed nets;*
- *Screen blood donors;*
- *Test organ, tissue, or cell donors and receivers; and*
- *Screen newborns and other children of infected mothers to provide early diagnosis and treatment.*

Goals

1. *Eliminate parasite transmission.*
2. *Facilitate early access to treatment and health care for infected persons and populations at risk.*

Morbidity Management and Disability Prevention in Chagas Disease

Assessment of suspected or confirmed Chagas disease should include a thorough medical history (including identification of risk factors for exposure to the vector and parasite in endemic or nonendemic settings) and a full assessment of systems, with a focus on signs characteristic of Chagas disease in the heart and gastrointestinal tract.[1,2,6] The objectives of the clinical treatment for *T. cruzi* infection are to:[1,6]

- Eliminate the parasites in the human hosts with antiparasitic (trypanocidal) treatment;
- Manage the clinical situations that result from the irreversible lesions associated with the disease; and
- Provide psychosocial support to affected people and their families.

The parasite can be killed by trypanocidal treatment with benznidazole or nifurtimox.[3] Both medicines are effective in

treating the disease if given soon after the infection at the onset of the acute phase, including cases of congenital transmission.[1,3] The efficacy of both medicines decreases the longer the person has been infected.[3] Treatment is also indicated for persons with reactivated infection and for persons in the early chronic phase of the disease.[1,3] Infected adults with no symptoms should be offered treatment because antiparasitic treatment can also prevent or reduce the disease progression and prevent congenital transmission in pregnant women.[1,3] The diagnosis and follow-up of infected pregnant women allows for the timely investigation and treatment of the child in the first year of life, leading to a parasitological cure in more than 90% of cases. However, fewer than 10% of people who need antiparasitic treatment for Chagas disease have access to the drug.

The digestive form of Chagas disease is not a contraindication for antiparasitic treatment. In severe cases of megaesophagus (enlarged esophagus), it is difficult to predict the drug absorption and effects. Moreover, megaesophagus correction should be performed in order to ensure full transit of the drug and, subsequently, its absorption.[1] In advanced cardiac forms, benznidazole will be not offered because there is no treatment benefit at this stage of disease.

Careful assessment of the benefits of medication should be weighed against the long duration of treatment (up to two months) that can possibly have adverse reactions (occur in about 40%). Children generally have fewer adverse effects than adults and can tolerate higher doses.[1]

Antiparasitic treatment is not recommended for pregnant women.[1] The indication in patients with other serious disorders, such as hepatic or renal failure, must be carefully assessed case by case, according to severity, as well as prior adverse events to drug components that may constitute relative contraindications.[1,6]

ATTENTION:

- Benznidazole and nifurtimox are not recommended for pregnant women and should be taken with care by people with kidney or liver failure, considering the risk-benefit ratio.[3]
- Nifurtimox is contraindicated for people with neurological or psychiatric disorders.[3]
- Additional treatment specifically for cardiac or digestive complications may be required.[1,3]

Even if transmission could be eliminated now, care for people already infected will be needed for the next 30 or 40 years.[1,3] The morbidity and mortality burden of Chagas disease can be prevented or minimized by a combination of actions at the individual, family, community, health, and political levels.[6] Table 5.1 summarizes the strategies beginning at Level 1, focusing on disease prevention, to Level 4 that focuses on care of older persons with chronic severe cardiac and digestive forms of the disease with comorbidities.

Table 5.1. Summary of Interventions by Level of Complexity

Attributes	Level 1 interventions	Level 2 interventions	Level 3 interventions	Level 4 interventions
Target population	People at risk of infection	Infected and asymptomatic people	People with manifestation of Chagas disease	People with manifestation of Chagas disease and comorbidities
Chagas disease form	No Chagas disease	Chronic indeterminate form	Early cardiac and digestive forms	Older persons with comorbidities, late cardiac and digestive forms
Objectives	Prevent transmission	Prevent progression of chronic indeterminate form to symptomatic forms	Minimize morbidity and decrease mortality Prevent and/or improve cardiac and digestive issues (including dysphonia)	Prevent overmedicalization and medical invasion Assure adequate hydration, food intake, respiratory and voice health

Table 5.1. (Continued)

Attributes	Level 1 interventions	Level 2 interventions	Level 3 interventions	Level 4 interventions
Health responsibility	Government policies and laws Primary health care level	Primary health care level	Primary, secondary, or tertiary health care level, depending on severity of cardiac and digestive presentation	Primary, secondary, or tertiary health care level

The morbidity and mortality burden of Chagas disease is prevented or minimized by a combination of actions:

- Early detection and treatment of *T. cruzi* infection;
- Diagnostic disclosure by an ethical, qualified, and participative counseling process;
- Assessment of family contacts in epidemiological risk settings (reduce disease burden in family nucleus and social network);
- Early management of clinical forms (especially digestive and cardiac clinical forms) of Chagas disease that is person- and family-centered;
- A comprehensive assessment of different health-related issues, including the presence of comorbidities (systemic hypertension, diabetes mellitus, dyslipidemia, obesity, etc.) and their adequate treatment and follow-up;
- Enablement of daily practice of self-care by persons with cardiac, digestive, swallowing, or speech difficulties;
- Psychosocial support; and
- Available, accessible, and inclusive health care services (primary, secondary, and tertiary) and communities.

Figure 5.1 shows the progression of the disease from the acute infection to the chronic disease. It also summarizes activities done at the primary, secondary, and tertiary levels for disease prevention and control and care.[7] Initially, interventions on social and environmental issues that are fundamental to the prevention and control of Chagas disease include access to adequate housing and intra-urban improvements.[1] Later interventions focus on managing the disease, preventing complications, and improving quality of life when impairments and disability are present. Figure 5.1 summarizes target populations, forms of Chagas disease, intervention objectives, and responsibility by level of intervention.

Figure 5.1. Model of Natural History and Prevention of Chagas Disease

<table>
<tr><td colspan="2" rowspan="3">Interaction between triatomines (T. cruzi reservoir) and susceptible human population</td><td>Acute infection</td><td colspan="2">Chronic stages</td></tr>
<tr><td colspan="2">Indeterminate form OR early “determined” forms</td><td>Late “determined” forms</td></tr>
<tr><td colspan="3">Cardiac and/or digestive forms</td></tr>
<tr><td colspan="2">Tissue changes (impairments)</td><td colspan="2">Impairments and disability or recovery</td><td>Death</td></tr>
<tr><td colspan="5">Chagas disease prevention and control actions</td></tr>
<tr><td colspan="2">Pre-pathogenesis period</td><td colspan="3">Pathogenesis period</td></tr>
<tr><td colspan="2">Primary prevention</td><td colspan="2">Secondary prevention</td><td>Tertiary prevention</td></tr>
<tr><td>Health promotion</td><td>Specific protection</td><td>Early diagnosis & immediate treatment</td><td>Disability prevention</td><td>Prevention of complications & rehabilitation</td></tr>
<tr><td>Health education</td><td>Vector control (governmental- and community-led participative initiatives)</td><td>Access to diagnosis and treatment in primary health care (PHC)</td><td>Evaluation of donors rejected for blood and organ transplant</td><td rowspan="2">General physical rehabilitation (physical therapy, occupational therapy, speech therapy, psychology, social worker, etc.)</td></tr>
<tr><td>Environmental education</td><td>Screening of blood and donors</td><td>Prenatal diagnosis</td><td>Specific treatment (trypanocidal) as needed</td></tr>
<tr><td>Environmental policies</td><td>Screening of organ and tissue donations</td><td>Serum epidemiological surveys</td><td>Good-quality routine follow-up</td><td>Cardiovascular rehabilitation</td></tr>
</table>

Figure 5.1. (Continued)

Primary prevention		Secondary prevention		Tertiary prevention
Housing improvement policies	Environmental monitoring	Surveillance of infection in laboratories	Early clinical management of cardiac, digestive, and other forms	Swallowing and speech rehabilitation
Environmental monitoring	Health surveillance	Psychosocial support for person and family	Early management of swallowing and voice impairments	Self-care practices
Health surveillance	Safe practices for food production	Specific treatment (trypanocidal) as needed	Self-care practices which promote independence in activities of daily living (ADL) and improve quality of life (QOL)	Energy conservation techniques during ADL (e.g., support of arms) that promote independence and participation
Social policies	Safe practices for blood collection	Integration with malaria control program (acute phase – febrile syndromes)		
	Reservoir monitoring	Inclusive health care and community practices	Energy conservation techniques during ADL	Work adaptations and modifications as necessary
		Testing of vulnerable and risk populations	Work adaptations and modifications as necessary	Psychosocial support for patients and their families
			Psychosocial support for person and family	Inclusive health care and community services
			Inclusive health care and community practices	Community-based support groups, rehabilitation

Adapted from Ramos et al.[7]

Primary Health Care Interventions

Primary Prevention

Objective: Prevent transmission of *T. cruzi* to susceptible individuals.[1,6,7,8]

Actions:

- Health education about disease and disease transmission for unaffected family members and all "at risk" vulnerable communities.
- Counseling for persons affected by Chagas disease not to donate blood, tissues, or organs (transmission risk to recipients).
- Define and strengthen protocols and procedures within the health system to confirm diagnosis.
- Counseling of known untreated women of childbearing potential about transmission risks to child during pregnancy.
- Conduct entomological investigation and control, if new case detected (any clinical presentation).

The primary health care professional is key to prevention and control of Chagas disease in rural or urban areas of endemic countries. In general, the primary health care (PHC) teams are the main sensors for transmission and morbimortality of the disease at the local level. They play an important role in discussing Chagas disease issues within the local community political and health councils to obtain community-led initiatives in surveillance, environmental education, and vector control. Their leadership and presence in local communities helps with surveillance activities to provide environmental education to identify the presence of triatomines and to suspect situations of oral transmission from contaminated food sources.[1,6,7]

Entomological surveillance has been enhanced with community-based support, responsible for the network of Triatomine Information Posts (TIPs). The development of strategies to ensure such participation should be incorporated as a component of the entomological surveillance process.[1]

Two pillars of entomological surveillance (triatomines) for Chagas disease

1. Passive surveillance: Population participates in the notification of triatomines.

2. Active surveillance: Entomological teams of the municipalities in partnership with regional health services look for triatomines without being based on prior resident notification.[1,6]

Most of the known species of triatomines live in the wild, associated with a diversity of fauna and flora. It is important to keep in mind that this habitat association is dynamic; that is, a species now considered exclusively wild can become domesticated. This process is complex, involving mainly changes in the ecosystem and environment, in addition to the intrinsic characteristics of the species.[1,6]

Unconfined domestic animals can act as a link between wild and domestic transmission cycles. Dogs and cats may be excellent reservoirs of *T. cruzi*. Pigs also become infected with the parasite, but their role as reservoir still needs to be better understood. Just like wild mammals, the importance of domestic animals as reservoir varies in different locations, but they are always exposed, and their infection usually precedes that of man.[1]

In Brazil, a probable source of infection is food contaminated with *T. cruzi*, including: açaí, bacaba, jaci (*Syagrus*), sugar cane juice, and palm hearts of babaçu nuts.[1] Cooling or freezing of food does not prevent oral transmission by *T. cruzi*, but cooking above 45 ºC, pasteurization, and lyophilization (freeze-drying) are effective.

In some areas, like Amazonia, vector control is not possible. In these areas, PHC teams provide health education to teach the population how to prevent exposure to sylvatic triatomines and how to practice safe food production.[1,6] In addition, PHC teams play a fundamental role in establishing an accessible and available system of referral and counter-referral for affected people requiring greater complexity of care.[6]

Secondary Prevention

The importance of early diagnosis is emphasized for people with both acute and chronic disease phases, as both can benefit from disease-specific treatment.[1,7]

Objective: Prevent future complications, as well as identify potential impairments and disabilities in the affected person.[1,7]

Actions:

- Emphasize early diagnosis of *T. cruzi* infection and timely antiparasitic treatment with involvement of suspected/affected persons, their family, and social network.
- Early diagnosis of cardiac, digestive, and other less common forms of Chagas disease with timely management and routine follow-up can prevent progression to more serious stages. This improves quality of life and survival for people with Chagas disease.
- Antiparasitic treatment in chronic Chagas disease (especially chronic indeterminate form) is important to avoid progression to the symptomatic phases.
- Diagnosis and antiparasitic treatment in women of childbearing age may decrease the chance of mother-to-child transmission of *T. cruzi* when infected women are treated prior to gestation.
- Identification and treatment of dysphagia can help prevent dehydration, malnutrition, and respiratory complications from aspiration.
- Identification and treatment of dysphonia can help prevent harmful voice practices and improve speech quality.
- Encourage the adoption of healthy lifestyles: controlling smoking and alcohol intake, increasing physical activity levels, and improving healthy eating habits.

The chronic indeterminate form has the highest prevalence with a low potential for progression (benign nature) and can be managed by PHC services.[1,6] A medical assessment and electrocardiography can be done at least once a year.

Due to the low rate of annual progression to heart disease, it is recommended that a medical assessment and electrocardiography be done at least once a year. It is important to remember that some electrocardiographic changes are common with advancing age, such as deviations of the electrical axis of the heart or incipient blocks of electrical conduction, not typical changes of Chagas heart disease.[1,6,9]

KEY POINTS TO REMEMBER

1. All people infected require available, accessible, acceptable, and affordable health care. This includes supportive services, e.g., physical therapy, general rehabilitation, dietary supervision, careful hydration and perfusion (in the case of heart failure), periodic pulse check, and heart failure management.
2. Primary health care (PHC) services should be able to do the following: suspect the disease, confirm the diagnosis, define the clinical form and its degree of severity, provide the specific antiparasitic treatment (if indicated) and symptomatic treatments, determine prognosis, and implement needed social security support.
3. The majority of those infected can be seen in the outpatient clinic, most of them in PHC, with the hospital being reserved for severe acute cases, advanced stages of chronic cardiomyopathy, and persons requiring surgical intervention.
4. Pediatric cases and advanced cardiomyopathy require continuous, ongoing, good-quality care at all levels. PHC workers need to learn how to do basic management and know when and where to refer.
5. Recognize signs/symptoms of worsening and know where to get help—shortness of breath (dyspnea), edemas (swelling), fainting, pain, and abdominal distention (tympanism) in advanced megacolon; volvulus (intestinal twist obstructing bowel) is an emergency.
6. Individuals with a severe cardiac impairment usually suffer from fatigue and dyspnea and require appropriate interventions to decrease symptoms and increase quality of life.
7. Depression, anxiety, and fear are very common in people with advanced stages of Chagas disease. Provide psychosocial support for affected persons, their family, and caregivers.
8. Some people in advanced stages develop dysphonia (voice impairments) and dysphagia (swallowing impairment) that can lead to dehydration, malnutrition, and aspiration pneumonia. Both impairments require appropriate intervention to improve health and provide a better quality of life.
9. Special review of medications is needed for people using multiple medications that can have potential adverse drug reactions.

Confirmation and disclosure of diagnosis. The process of confirming diagnosis of Chagas disease, diagnostic disclosure, and adequate counseling is important to the person affected, the family, and the caregiver. It is based on three elements:[6]

1. Etiologic evaluation (acute or chronic phase of *T. cruzi* infection);
2. Syndromic evaluation (clinical form); and
3. Prognostic definition.

Chagas disease affects socially vulnerable populations and has a progressive characteristic for people at any age or clinical form. The disease is generally not visible but has an impact on the person, the family, health policy, and health systems.[1,6] An enormous economic and social burden for families can result from the death or disability of the family provider(s). This may result in families taking children out of school to work to provide income for the family or to care for the person with disability.[10,11,12] Informal and formal counseling can help reduce fears and anxiety about the disease, the diagnosis, treatment, and future interventions.

Counseling during diagnostic disclosure:

- Allow the patients to share their perceptions, anxieties, and fears about the disease and its effects on their future.
- Clarify information about the disease, the treatments specific to the disease, and interventions for complications.
- Assure access to routine follow-up and provide an opportunity to ask questions needing clarification.
- Request psychological support if necessary.
- Discuss treatment options with the patients, their family, and caregivers and allow them to participate in developing an intervention and follow-up plan.
- Encourage continued independence and participation in family, school, work, leisure time, and social activities.
- Encourage family and caregiver participation.
- Teach relaxation techniques as needed.

There are important and routine disease management implications for people living with the chronic forms of Chagas disease. The PHC team has an important role in teaching general information about the disease, as well as enabling the people affected, their family, and caregivers to fully participate in self-care and daily life.[10] It is important that they know the prognosis is variable but generally benign. This is especially true in larger asymptomatic groups who are confirmed with the chronic indeterminate form of the disease.[1,3,6] It is important to emphasize that they cannot donate blood or organs.[1,6]

The mortality risk in the chronic indeterminate form is comparable to that of the general population not infected by *T. cruzi*.[1] There is no restriction on sexual activity.[1] Pregnant woman classified with this form must be aware of the possibility of vertical transmission and seek for their newborn to be adequately evaluated.[3,6] Women with chronic infection should not restrict breastfeeding, except in the case of nipple bleeding.[1,2,6] Chagas disease in chronic indeterminate form also does not increase risk in surgical procedures in comparison with the general population.[1,6]

The chronic indeterminate form does not interfere with the management of associated diseases and does not justify neglecting the follow-up and treatment of comorbidities. Health professionals should avoid practices that might stigmatize people with the chronic indeterminate form of Chagas disease.[13] The multiprofessional PHC team plays an important role in clarifying and guiding the population about the specifics of this form of the disease.[6]

ATTENTION:

- **In the case of immunosuppression in people with Chagas disease, special attention should be given to the possible exacerbation of *T. cruzi* parasitemia, which may result in severe myocarditis and/or meningoencephalitis.[1]**

Cardiac involvement is associated with a worse health-related quality of life in people affected by Chagas disease.[14,15] In chronic cardiomyopathy, the prognosis is variable and most cases can be followed-up in PHC services, if there is information related to normal ventricular systolic function.[1,14] The decrease of health-related quality of life is mainly associated with impairments in functional capacity.[10,11] Thus, simple and inexpensive therapeutic interventions, such as exercise therapy, are effective for improving it.[10,11,12,14,15] Learning and applying energy-conservation techniques and adapting how activities of daily living (ADL) are performed can enable the person to do ADL and participate in family and community life.

Personal habits and behaviors of affected people play a proactive role in the continuous routine clinical management of the disease.[16] Support groups for affected persons and their families are very important for learning and sustaining healthy behaviors and practices related to smoking, alcohol, eating habits, mental and physical health, occupational conditions, social participation, etc.[1,6,10]

Work considerations:[1,2,6]

- The positive serological result for *T. cruzi* antibodies does not require termination of employment in most professions. However, many experts recognize it could be an issue for pilots or drivers responsible for collective transportation or for people responsible for controlling heavy mobile equipment.
- Generally, work does not worsen the person's condition, regardless of the clinical form.
- Adequate and permanent medical care should be available and accessible to all, whether the person is working or not.
- Rarely, people with acute forms may temporarily be unable to work due to specific treatment.

IMPORTANT:

- The diagnosis of a person with Chagas provides an opportune time to examine family and other close social networks for possible disease.[1,6]
- The quality of disease management and care (clinical, psychological, social, functional) provided by the PHC team corresponds to improved disease prevention and control, as well as prevention of the progression of chronic heart disease and its consequences (social vulnerabilities, high cost of treatment, and death).[1,2,6]
- National and local resources are needed to assure that diagnosis, treatment, referral, medication, and follow-up of cases can be done.[8]
- Chagas disease tends to be progressive, rarely having a spontaneous cure.[6] Therefore, all persons, regardless of clinical stage, should be periodically assessed.[1]
- Family involvement and participation is especially important with terminal and pediatric cases. PHC professionals take care to avoid inciting fear or a fatalistic prognosis.[6,10,11,12]

Tertiary and Quaternary Prevention

Tertiary and quaternary prevention interventions are needed for those people with chronic disease who also have degenerative morbidities due to aging.[1] Prevention aims to prevent overmedicalization, drug interactions, overdiagnosis, and iatrogenic interventions; protect people with Chagas disease from unnecessary medical procedures; and inform those affected and their families of interventions that are ethically acceptable.[1,10,11,12,13,16] Lifestyle strategies should be strongly emphasized.

Objective: Address the physical, psychological, and social issues of persons with chronic disease and disability to prevent or minimize furthering of complications and impairments, and maximize function and social participation. Prevent overdiagnosis and overmedicalization.

Actions: Primary, secondary, and comprehensive rehabilitation interventions are critical.[2] Surgical interventions for the correction of digestive tract pathologies (megaviscera), implantation of pacemakers, and more extensive cardiac surgeries are included in this group of actions. The principal actions include:[1,2,3,6,7,14,17]

- Implementation of cardiovascular rehabilitation (CR) protocols.
- Cardiac surgeries, e.g., implantation of pacemakers and defibrillators.
- Implementation of digestive rehabilitation protocols.
- Surgeries of the digestive system.
- Implementation of rehabilitation protocols to improve drinking, eating, and voice quality.
- Implementation of socioeconomic rehabilitation protocols.
- Modifications of daily activities that enable self-care and participation.
- Psychosocial support for affected people and their families to improve mental health and social participation.

Cardiac Form of Chagas Disease[1,2,6,14,15]

The cardiac form of Chagas disease is the most important clinical presentation of Chagas disease, due to its incidence and impacts on morbidity and mortality. In the acute phase, myocarditis is one of the principal causes of death, and it is an important manifestation in patients with reactivation in immunosuppression. The key signs and symptoms of this syndrome are described below.

KEY SIGNS AND SYMPTOMS OF ACUTE CHAGAS MYOCARDITIS

1. Dyspnea of variable intensity
2. Tachycardia (even without fever)
3. Palpitations
4. Chest pain
5. Raised jugular venous pressure
6. Soft heart sounds
7. Gallop rhythm
8. Heart murmurs in the apical region and tricuspid area
9. Pericardial effusion
10. Hypotension
11. Cardiac tamponade
12. Tachyarrhythmias (including atrial fibrillation)
13. Bradyarrhythmias (atrioventricular block)
14. In children: tachypnea, irritability, sweating, vomiting, anorexia, hepatomegaly, and edema of the lower limbs

Twenty to thirty years after the acute phase, approximately one-third of infected people develop chronic Chagas cardiomyopathy (CCC), evident in an abnormal electrocardiogram (ECG) pattern. In people with the chronic indeterminate form, ECG is repeated yearly to evaluate possible progression. CCC is a frequent cause of death in people affected by Chagas disease. It causes work absenteeism and limits economic productivity. It affects mental health and restricts participation in family, work, and social life, which affects overall quality of life. CCC happens earlier and is more severe in males.[1,6] The prognosis is principally related to ventricular dysfunction (left ventricular ejection fraction below 45% in echocardiogram) and clinical syndrome of heart failure. People at initial stages of CCC have a better prognosis and can be followed at the primary health care level.

Table 5.2 shows the initial staging of myocardial dysfunction in CCC, based on the results of ECG, echocardiogram (ECHO), and presence of clinical symptoms of heart failure, and defines which level of health care services is responsible for care.[1]

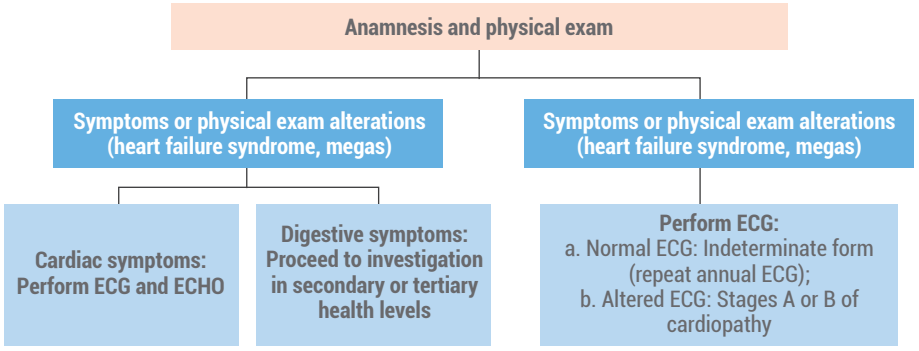
Table 5.2. Initial Staging of Myocardial Dysfunction in Chronic Chagas Cardiomyopathy[1]

Stage	Electrocardiogram	Echocardiogram	Heart failure	Health care level
A	Altered	Normal	Absent	Primary
B1	Altered	Altered, LVEF[a] ≥45%	Absent	Primary or Secondary
B2	Altered	Altered, LVEF[a] <45%	Absent	Secondary
C	Altered	Altered	Compensated	Secondary or Tertiary
D	Altered	Altered	Refractory (difficult to control)	Tertiary

[a]LVEF: left ventricular ejection fraction.
Adapted from Dias et al.[1]

The approach to the individual with Chagas disease at all levels of attention begins with the objective search for cardiac or digestive clinical syndromes. Asymptomatic people must have an ECG and, in the case of normal ECG, are characterized as being in chronic indeterminate form, as described in Figure 5.2.

Figure 5.2. Initial Clinical Approach to Chagas Disease



ECG: electrocardiogram; ECHO: echocardiogram

People with isolated ECG abnormalities considered to be nonspecific (sinus bradycardia, low voltage, first degree atrioventricular block, incomplete right bundle branch block, left-anterior fascicular block, or nonspecific changes in ventricular repolarization) should remain at the primary health care level. There is no need for specific additional treatment. ECG must be done annually to evaluate the possibility of progression to the chronic form.

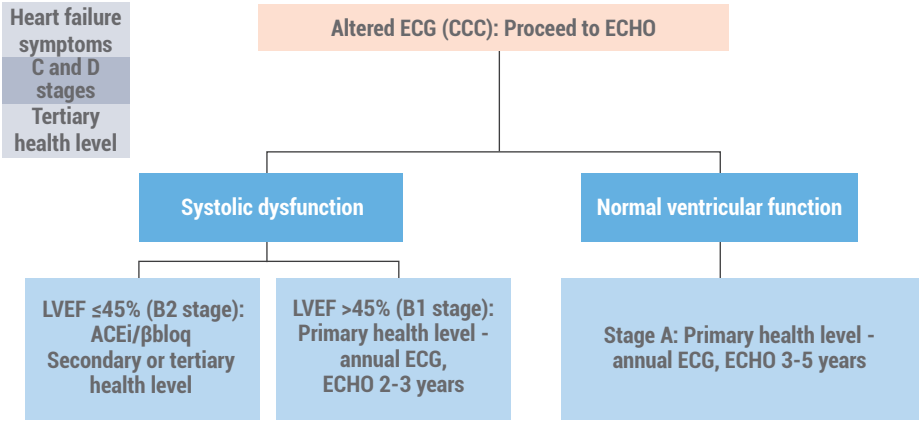
People with other ECG changes, even if asymptomatic, should ideally have an ECHO; if not available, chest radiography must be done, evaluating the cardio-thoracic index (CTI). People with altered ECG (independent of the alteration) and with increased CTI probably have a high systolic dysfunction and should be referred for symptomatic treatment of heart disease. Drugs that promote neuro-humoral blockade (angiotensin-converting-enzyme [ACE] inhibitors/angiotensin receptor blockers [ARBs] and beta-blockers) should be initiated. The onset of these drugs in the asymptomatic stage of the disease helps prevent the clinical progression to heart failure, increasing survival.

People identified with altered ECG are diagnosed with CCC and should ideally be submitted to ECHO to define the cardiac stage and level of impairment, as described in Figure 5.3.

Asymptomatic people with altered ECG presenting in the ECHO a normal systolic function with segmental alterations or mild systolic dysfunction (EF >45%) are classified as *stage B1*. There is a lesion of the myocardial structure. Treatment with ACE inhibitors/ARBs and beta-blockers may be considered to prevent the progression of cardiac dysfunction. These persons should be followed at PHC services and repeat ECG annually and ECHO every 2-3 years. This evaluates progression of dysfunction and need for referral to a cardiologist.

Asymptomatic people with altered ECG and moderate to severe (EF ≤45%) dysfunction are classified as *stage B2* and should be followed by cardiologists at the secondary care level. Full-dose ACE inhibitors/ARBs and beta-blockers are given to prevent the progression of dysfunction or development of symptoms. Follow-

Figure 5.3. Evaluation of Patients with Chronic Chagasic Cardiopathy



ECG: electrocardiogram; ECHO: echocardiogram; LVEF: left ventricular ejection fraction; ACEi: angiotensin-converting-enzyme inhibitors; βbloq: beta-blockers

up by a cardiologist is done every 3-4 months, with ECG and ECHO done annually or whenever there is a change in the clinical situation.

Patients with heart failure (HF) symptoms should be evaluated with ECG and ECHO to determine the diagnosis and prognosis of CCC and to exclude other associated cardiac diseases that could be responsible for the symptoms (rheumatic heart disease, hypertensive or hypertrophic heart disease, congenital diseases). These persons should be treated according to standard treatments for other etiologies, following the guidelines for HF. They are subdivided into persons with HF easily compensated (*stage C*) and HF difficult to control (*stage D*). Both groups should receive education on diet to maintain ideal weight, control intake of water (1.5-2 L) and salt (3-4 g), and receive education on how to reduce aggravating factors (alcohol, NSAIDs, infections, arrhythmias). People affected in this stage must receive an annual dose of influenza vaccine and a pneumococcal vaccine every three years. HF clinics with a multiprofessional vision, where persons have the support of cardiologists, nursing, nutritionists, pharmacists, physiotherapy, and psychologists and cardiac rehabilitation professionals, often experience the best treatment outcomes.

Cardiac transplant is indicated for all people with HF who remain symptomatic, in functional class III-IV, or refractory ventricular arrhythmias, despite full therapy. In the past, progression after immunosuppression was feared, due to the risk of Chagas disease reactivation and the development of neoplasia. However, this subgroup of persons with Chagas disease and transplant has a better prognosis than do other cardiomyopathies. Additional care is needed to diagnose early reactivation (direct blood parasitemia or myocardial biopsy) of Chagas disease after transplant and promptly treat with benznidazole.[18]

Special subgroup 1 in CCC – bradyarrhythmias:

- Asymptomatic bradyarrhythmias: Do not require specific treatment.
- Symptomatic bradyarrhythmias (pre-syncope or syncope): Refer to the tertiary care level for a pacemaker implant, preferably bicameral. The diagnosis is the same as for other heart diseases: high-grade atrioventricular block or sinus node disease. In specialized arrhythmia services, the need for an implantable cardioverter defibrillator (ICD) can be assessed in the case of concomitant and confirmed ventricular tachycardia risk.

Special subgroup 2 in CCC – ventricular tachyarrhythmias:

- Asymptomatic cases: Premature ventricular contractions (PVC) occur frequently in CCC but treatment is not required.
- Symptoms of non-sustained ventricular tachycardia (NSVT) with palpitation, particularly in the presence of myocardial dysfunction: Amiodarone is the antiarrhythmic drug of choice for persons with CCC. However, the use in people with NSVT for the prevention of sudden death has not yet been demonstrated and remains controversial.
- Symptomatic PVCs (palpitation and low-output symptoms, such as pre-syncope or syncope): Refer to specialized arrhythmia services for support for ICD implantation, and amiodarone is maintained to reduce shocks of the device.
- Symptomatic with sustained ventricular tachycardia or aborted sudden death: Refer urgently for ICD implantation and maintained with amiodarone.

Special subgroup 3 in CCC – supraventricular tachyarrhythmias:

- Atrial fibrillation (AF) is the most frequent supraventricular arrhythmia in CCC. It is usually present in people with significant ventricular remodeling. The strategy is for heart rate control (with beta blockers and/or digitalis) or rhythm control (with chemical or electrical cardioversion, after the presence of atrial thrombi is excluded). In addition, anticoagulation is used.
- In case of reversed AF or atrial flutter, amiodarone may be used to prevent arrhythmia recurrence.

Special subgroup 4 in CCC – prophylaxis of thromboembolic events:

- Oral anticoagulation is indicated for all people with a history of thromboembolic events, atrial fibrillation, and apical thrombi. Warfarin should be used to control the international normalized ratio (INR) between 2 and 3. People should be followed at the secondary care level with frequent consultations (every 7-15 days) until the dose of anticoagulant is normalized (approximately 1-2 months).
- CCC has a higher emboligenic potential than the other cardiomyopathies, even when the risk is adjusted to the same degree of cardiac dysfunction and remodeling. This suggests the restriction of the prophylaxis recommendations of thromboembolic events to groups at risk (defined in other cardiomyopathies) may not be able to prevent most events in CCC. The Brazilian Consensus suggests an increase in anticoagulation with a specific score, especially in the presence of ventricular aneurysms characteristic of CCC.[1]

Thromboembolic phenomena may occur in HF as a result of stasis, endocardial changes, and dilation of the cardiac chambers. The thromboembolism syndrome can compromise the lungs, brain, kidneys, spleen, and other sectors, leading to other immediate causes of death. For the person with Chagas disease, stroke presents an added burden for mortality and disabling sequelae. CCC is usually progressive, and its main clinical consequences (arrhythmias, heart failure, and thromboembolism) may be associated with each other, making the therapeutic approaches difficult.

Cardiovascular Rehabilitation

Cardiovascular rehabilitation (CR) is an important multidisciplinary (exercise physiologists, physical therapists, occupational therapists, nutritionists, pharmacists, nurses, social workers, and others) approach extensively advocated as an adjunct strategy in an integrated treatment approach with other cardiovascular diseases, which include Chagas cardiomyopathy.[14,19] It includes not only physical exercise but also nutritional orientation, psychosocial support, and the control of major risk factors.[20,21] CR in Chagas disease is indicated and should be encouraged both for people with the chronic indeterminate form as well as for those with clinical evidence of cardiac involvement.[14,15]

The exercise prescription for CR programs should include aerobic, strength, stretch, and balance exercises. Some of the important health-related benefits of exercise therapy are the control of comorbidities, improvement in cardiovascular and musculoskeletal function, and improvement in mental health. In addition, improvements on functional capacity and stamina to do activities of daily living (ADL) such as bathing, dressing, walking to visit a neighbor, and walking to participate in work, leisure time, and social activities are also achieved.[22] Experiencing benefits of cardiac rehabilitation improves adherence to treatment and improves quality of life of people affected by Chagas disease.[14,15]

The exercise recommendations for people in the chronic indeterminate form are identical to those for the general population, e.g., control of cardiovascular comorbidities such as arterial hypertension, diabetes mellitus, dyslipidemia, and overweight.[14,15] Lifestyle interventions increase physical activity levels to a minimum of 150 minutes of moderate-intensity activities and/or 75 minutes of vigorous activities per week (see Figure 5.4).[20,21] Education strategies for smoking cessation and reduction in alcohol consumption are also important.

Figure 5.4. Examples of Activities and Energy Used by the Body per Minute of Activity

Moderate-intensity examples	Vigorous-intensity examples
• Walking briskly (3 miles per hour or faster but not race walking) • Water aerobics • Bicycling slower than 10 miles per hour • Tennis (doubles) • Ballroom dancing • General gardening	• Race walking, jogging, or running • Swimming laps • Tennis (singles) • Aerobic dancing • Bicycling 10 miles per hour or faster • Jumping rope • Heavy gardening (continuous digging or hoeing) • Hiking uphill or with a heavy backpack

Adapted from https://www.cdc.gov/physicalactivity/basics/measuring/index.html

For individuals already diagnosed as having heart disease, with altered but still asymptomatic ECG, the recommendations are the same as previously described. In addition to physical activity, the initiation of neurohumoral blockade (ACE inhibitors or beta-blockers) may be needed for persons with evidence of ventricular dysfunction (increased CTI on chest X-ray or altered ECHO). In this case, pharmacists and doctors are needed for secondary prevention.[1,14,15]

In cases with HF or arrhythmia symptoms, the specific treatment of heart disease and the indication of physical activity should be combined with energy conservation techniques during activities of daily living and modifications of ADL that involve the arms to be held up against gravity (shampooing hair, brushing hair, shaving, lifting plates up off of a high shelf, etc.). The exercise prescription should consider the necessities of each individual and his or her clinical condition.

The control of water and alcohol intake and smoking are also very important approaches in the management of people with chronic Chagas heart failure.

KEY POINTS TO REMEMBER

1. The cardiac form of Chagas disease accounts for a greater morbidity and mortality burden.
2. The management of the cardiac form varies from clinical management to surgical interventions.
3. Cardiac rehabilitation is a multidisciplinary approach recommended to improve health among individuals with Chagas disease. It includes physical activity, nutritional orientation, and psychosocial support.
4. Exercise recommendations for individuals with the indeterminate form of Chagas disease are the same as those for the general population (150 minutes of moderate-intensity activities and/or 75 minutes of vigorous activities per week).
5. Exercise therapy for patients with Chagas heart failure should be supervised by a specialized team in order to maximize the benefits and minimize the risks of this intervention.
6. Nutritional orientation should focus on low-caloric diets, reduced consumption of foods high in saturated fat, low carbohydrate intake, and decreased sodium intake. The control of water and alcohol intake should also be a target in patients with chronic Chagas heart failure.
7. Affected individuals are encouraged to adopt a healthy lifestyle, control smoking and alcohol intake, increase physical activity levels, and improve eating habits.

Digestive Form of Chagas Disease

Each year 2% to 5% of people with Chagas disease can progress to the digestive form of the disease.[1,2,3,4,5,6] The digestive form of Chagas disease can range from impairments of the esophagus to the rectum, with a diverse clinical presentation.[1,6,17,23] All cases of megaesophagus and/or megacolon should be screened for *T. cruzi* infection and interventions initiated to preserve quality of life with chronic digestive complications. An association of digestive forms with heart disease occurs in up to 30% of cases, a fact that should be considered in the case evaluation. Annual follow-up in primary care is mandatory.[1,6,17,23]

The infection by *T. cruzi* destroys nerve cells of the enteric nervous system that coordinate different visceral functions from the esophagus to the anus. This can result in motor dyskinesia,

achalasia of sphincters, and secretory disorders, provoking dilatation and elongation of the affected segments.[6,17,23,24]

Achalasia

Achalasia is a disorder of the gullet (esophagus or throat) where it loses the ability to move food along. The valve at the end of the gullet also fails to open and allow food to pass into the stomach. Chagas disease is one of the most frequent causes of esophageal dysphagia (difficulty swallowing).[1,2,6,17,23,24] Dysphagia varies with the degree of esophageal impairment, from occasional and mild to an inability to ingest foods (consistencies and volumes). The affected person, the family, and health care team need to know about these changes in swallowing, so interventions can be started early to prevent complications.[23,24]

Swallowing changes, in any degree, can result in malnutrition and dehydration. In addition, the person presents a risk of oropharyngeal aspiration (part of the food swallowed goes to the lungs).[23,24]

The diagnosis is essentially clinical and radiological, and can be supplemented with manometry, pharmacological tests, and upper digestive endoscopy. The treatment of the early stages is preferably conservative. People with esophageal manifestations should be advised to chew food well; ingest liquid and semi-solid food if necessary; and avoid dry, hard, spicy, and very hot or cold foods, as well as food consumption or ingestion of tablets before sleep.[1,2,6,23,24]

The diagnosis is usually made by a speech pathologist through a functional evaluation of swallowing. The diagnostic process and proposed treatment include anamnesis, functional evaluation of swallowing, and cervical auscultation. Additional exams and treatment approaches may include speech-language pathology rehabilitation programs and professionals such as physiotherapists, nutritionists, gastroenterologists, or otorhinolaryngologists, among others.[23,24]

Signs and Symptoms of Dysphagia (difficulty swallowing)

The health team and people with Chagas disease should know the signs and symptoms of dysphagia and start interventions early. Below are some of the signs and symptoms:

- Complaint of a sore throat
- Wet or gurgly voice (aspiration)
- Excess production of saliva
- Increased secretion in the upper airways
- Anxiety preceding meals
- Increased time taken to eat
- Loss or change in food pleasure
- Food refusal
- Change in eating habits
- Need to change the consistency of food and/or drink water during meals
- Difficulty initiating a swallow
- Feeling of food stuck in the throat
- Frequent choking with liquids
- Coughing or choking during or after swallowing
- Regurgitation of part of the food after swallowing
- Difficulty swallowing solid, dry foods, larger pieces and volumes
- Coughing or choking with food or saliva
- Fatigue and difficulty in eating a full meal
- Difficulty in swallowing pills
- "Flu" and/or recurring pneumonia
- Fever without apparent cause
- Weight loss
- Gastroesophageal reflux
- Bad breath
- Dyspnea (difficulty breathing) during eating
- Chest tightness and shortness of breath immediately following swallowing

Megacolon

Megacolon is a clinical impairment of chronic Chagas disease that occurs later, usually in the fourth decade of life.[1,2,6,17] It can occur exclusively or overlap with heart disease and/or esophagopathy. A complaint of constipation for more than five days strongly indicates an individual with positive serology, but there are cases

without this complaint. The prominent symptoms of megacolon include meteorism and dyskinesia (difficult or painful defecation), increased interval between bowel movements, and intestinal constipation.[1,2,6] Increased abdominal volume and palpation of fecaloma are important findings in larger megacolons. After long constipation, a fecaloma, a hard and painful mass usually located in the left iliac fossa, can be visible and palpable, reaching the homolateral abdominal flank. In up to 20% of cases, colonic dilation coexists with normal bowel habits.[1,2,6,17]

The abdominal evaluation should investigate bloating and abdominal distension. In advanced cases of megacolon there may be abdominal asymmetry, and the organ may be palpable. In rectal touches, the presence of fecalomas can be perceived.[6,17]

The management of megacolon is preferably clinical in the early stages. Anti-constipation diet, good hydration, use of mineral oil or mild cathartics (milk of magnesia), and intestinal washes are useful measures to prevent or reduce the fecaloma.[1,2,6,17]

Persons with colonic manifestations require dietary management that includes restriction of constipating foods (banana, guava, jabuticaba), abundant ingestion of water (at least 2 L/day), and increased ingestion of food that favors intestinal transit (pawpaw, plum, orange, high-fiber food). Affected persons should have set times to evacuate and respond without delay. To aid evacuation, administer osmotic laxatives or mineral oil (avoid administration at night, due to risk of aspiration) and enema with glycerinate solution twice a week. Avoid constipating medications (opiates, diuretics, antidepressants, antihistamines, anticonvulsants, or antacids with aluminum hydroxide).

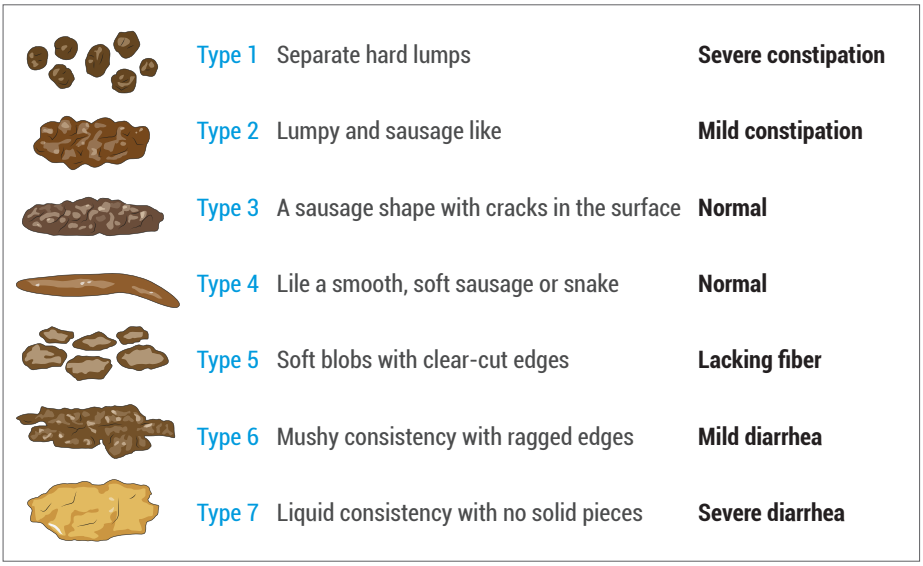
Although most cases do not present this condition, annual visits should be made to the health service. The body mass index (BMI) or Quetelet index (person's weight divided by the square of the body height [kg/m2]) is important to determine if the person is at a healthy weight, obese, or severely underweight.

Table 5.3. Body Mass Index (BMI) Classification

Category	BMI (kg/m^2)	
	From	To
Very severely underweight	>	15
Severely underweight	15	16
Underweight	16	18.5
Normal (healthy weight)	18.5	25
Overweight	25	30
Obese Class I (Moderately obese)	30	35
Obese Class II (Severely obese)	35	40
Obese Class III (Very severely obese)	>	40

The Bristol Stool Scale (Figure 5.5) can be used to evaluate and describe the shape of the fecal content. The images represent seven types of feces, according to their shape and consistency.[25] The Bristol Stool Scale can also help monitor changes in intestinal transit time caused by medications.[25]

Figure 5.5. Bristol Stool Chart



Adapted from https://en.wikipedia.org/wiki/Bristol_stool_scale#/media/File:BristolStoolChart.png

A summary of the signs and symptoms of gastrointestinal tract involvement and suggested interventions are listed in Table 5.4.

Table 5.4. Summary of Gastrointestinal Tract Involvement in Chagas Disease and Suggested Interventions

Affected organs	Signs/ symptoms	General approaches for diagnosis	Interventions
Oral cavity	Sialorrhea (drooling or hypersalivation)	• Check if person has increased salivation. • Salivary gland hypertrophy, especially of the parotid gland, may be present in esophageal involvement.	• Oral cavity care and hygiene are mandatory. • Fewer than 5% of cases of halitosis are related to the digestive tract; they are more prevalent in patients with megaesophagus grade II and IV. • Stimulate water intake and healthy eating.
	Halitosis	• Ask the person and close relatives about bad breath, even with adequate oral hygiene. Does it worsen with the intake of foods rich in protein, especially red meats?	
Esophagus	Dysphagia	• This is the most typical but not always the most prevalent symptom. It should always be researched in detail. Check when the symptoms appeared. Relate to weight loss. Note that the affected persons often become accustomed to dysphagia and deny the symptoms. Some questions are very useful such as: "Do you need water to push the food down?" "Does food get stuck?" "Have you not been able to eat meat and prefer pasty foods?" "Do you eat slowly?" "Do other people finish eating before you?" • Locate the type of dysphagia, if high or low oropharyngeal or esophageal. • Check whether the dysphagia is for liquids and/or solids, or cold and/or hot foods.	• There is no drug that can restore esophageal motility. If there is hypertonia of the cardia (lower esophageal sphincter) and the person is symptomatic (dysphagia or chest pain) use nitrate 2.5 to 5 mg, 5 minutes before meals or nifedipine 10 mg, 45 minutes before meals. • Previous cardiological evaluation is mandatory. The effect of these drugs may be transient (tachyphylaxis). • In case of persistent symptoms, the person should be referred to secondary and/or tertiary care. • Dilation with pneumatic balloon may be indicated, although it is available in few services. • Botox injection can be used, but is usually inaccessible. • Myomectomy is indicated in young and symptomatic people. • In case of pyrosis, omeprazole 20 mg, taken about 30 minutes or an hour before meals, or pantoprazole 40 mg taken with or without food. Avoid continued use of these medications. • In case of clinical refractoriness (not responding to treatment) refer to a specialist. The use of antacids should be avoided due to the rebound effect.
	Odynophagia (pain with swallowing)	• Check if it occurs and with what type of food? How often?	
	Regurgitation	• Check if food or liquids rise toward the mouth. If yes, does this return occur spontaneously or post induction of vomiting? • Check if the person has had aspiration pneumonia or recurrent pneumonia. • Check if the person has a cough that is not related to breathing problems and if the cough gets worse at bedtime or at night, or after eating food.	
	Pyrosis (burning sensation)	• Check if burning is in the location of the esophagus and improves or worsens with fasting or if the person is using proton pump inhibitors or H2 blockers.	

Table 5.4. (Continued)

Affected organs	Signs/ symptoms	General approaches for diagnosis	Interventions
Stomach / duodenum	Dyspepsia (indigestion)	• Check if the symptoms are related to the epigastric region. Verify the relation of symptoms with a meal, if evolution is better or worse and if person is using proton pump inhibitors or H2 blockers.	• In case of pyrosis or dyspepsia, omeprazole 20 mg, taken about 30 minutes or an hour before meals, or pantoprazole 40 mg taken with or without food. Avoid continued use of these medications. • In case of clinical refractoriness (not responding to treatment), refer to a specialist. The use of antacids should be avoided due to the rebound effect.
	Precocious satiation (feeling full quickly)	• Check if the person is no longer hungry soon after they start eating.	
Colon	Constipation	• This symptom should be investigated most carefully, especially in elderly and debilitated people (often they do not know how to inform). Check how many times the person evacuates per week and the appearance and shape of the feces (Classification by the Bristol Stool Scale - see Figure 5.5).	• A therapeutic approach to megacolon depends on the degree of dilatation. • Stimulate water intake and healthy diet, rich in fiber. • Take advantage of the gastrocolic movement, post alimentary, to evacuate. • Establish defecation times and do not delay the trip to the bathroom. • Perform physical exercises and minimize inactivity. • The use of laxatives should be avoided but, if necessary, for as short a period as possible. • Add fiber to diet. • Cases with severe constipation should be referred and colectomy evaluated.
	Diarrhea	• Check how many times the person evacuates in a day and the appearance and shape of the feces (Classification by the Bristol Stool Scale - see Figure 5.5).	
Rectum	Feeling of incomplete evacuation	• Check if fecal impaction is present or absent and if there is a need for manual stool removal.	
	Dyschezia (difficulty in defecating)	• Check if people have pain when defecating.	

Specific Supportive Treatment of Dysphagia and Dysphonia

Chagas disease can cause dysphonia (voice impairments) and is one of the most frequent causes of esophageal dysphagia (difficulty swallowing). Early recognition and care can improve voice quality and prevent dehydration and malnutrition. Routine primary health care screening and evaluation by a speech/language specialist can identify factors that could lead to dysphagia and dysphonia, and interventions can be initiated early to address these issues.[23,24] In addition, the health care team can also promote good daily oral hygiene and dental care, which is important to reducing bacterial growth and risk of pneumonia.[6]

Dysphagia. Dysphagia is difficulty or discomfort in swallowing food. Early recognition of dysphagia by the health care team, affected person, his or her family, and caregivers permits interventions to be started early. Any degree of swallowing changes can result in malnutrition and dehydration. In addition, the person presents risk of oropharyngeal aspiration (food/liquid swallowed goes to the lungs).[23,24] The goal of dysphagia care is to maintain adequate nutritional intake and maximize airway protection. The management of dysphagia includes the following:

- Early recognition of dysphagia symptoms;
- Confirmation of dysphagia diagnosis;
- Dietary modifications;
- Postural changes (chin-tuck position) or swallow maneuvers (supraglottic swallow) during swallowing;
- Early care and rehabilitation.

Methods to improve deglutition (swallowing).[17,23,24] Dietary modifications are key to facilitating the swallowing of foods and liquids. Food viscosity (frictional resistance to shear) and texture

should be considered. Recommendations may include alternating bites of food with sips of water, reducing bite and sip size, and increasing the number of swallows. Using a chin-tuck position, in which the person holds their chin down to reduce the airway diameter, can decrease risks of aspiration. A supraglottic swallow involving a simultaneous swallow with breath-holding followed by an immediate cough after the swallow can also protect the trachea from aspiration. The size, viscosity, and type of food or liquid can be adapted to make swallowing easier.

Viscosity levels:

Level 1:
Pudding, mashed potato, and ground meat
Level 2:
Curd-type yogurt, cream soups, thickened juices and soups
Level 3:
Tomato juice, liquid yogurt
Level 4:
Water and orange juice

Food progression:

- Thin liquids (coffee, tea, juice)
- Nectar-thick liquids (cream soups)
- Honey-thick liquids (juices and soups are thickened)
- Pudding-thick liquids/foods (mashed bananas, mashed potatoes, cooked cereals)
- Mechanical soft foods (baked beans, meatloaf)
- Chewy foods (pizza, cheese)
- Foods that fall apart (rice, bread)
- Mixed textures

Facilitate deglutition:[17,23,24]

- Drink plenty of fluids, in small sips, keeping the chin down (chin-tuck) when swallowing. This facilitates swallowing, reduces the risk of orotracheal aspiration, and helps prevent dehydration.
- Choose by food size, viscosity (thickness), and hardness.
- Place small portions of food in the mouth, chew well and swallow with the head slightly down (chin-tuck) and after the food is swallowed, swallow again one or two times with no food.
- Make foods/liquids thicker. Thicken natural juices, soups, and broths.
- Modify food to make it softer, the consistency of mashed potatoes, mousses, or pudding. It is easier to swallow and more enjoyable. The nutritionist can assist in ensuring nutritionally balanced meals.

- Eat well-cooked food, in smaller pieces moistened with sauces and broths.
- Avoid hard and dry foods like fried foods, baked goods, breads, toast, and others.

Dysphonia. Dysphonia is any difficulty in vocal emission that prevents or hinders natural voice production. Dysphonia is not reported in most scientific studies but is observed in persons with Chagas disease. Generally, the signs and symptoms are related to changes in muscle strength, iatrogenic causes associated with other interventions and treatment, the general physical effects of the disease (like cardiac and gastrointestinal), their comorbidities, and other factors. Dysphonia changes may vary and be intermittent or permanent. The speech-language specialist has the knowledge and skills to evaluate, document, and rehabilitate vocal sequelae and myofunctional disorders as part of an integrated care plan for persons with Chagas disease.

Dysphonia can be diagnosed early when the first voice changes are identified. The specialist, usually a speech therapist, takes a history and evaluates the auditory-perceptual aspects of the voice. The diagnostic process and treatment proposal may also include evaluations from otorhinolaryngology and other specialties for better definition of the situation and needed treatment.

Identifying Dysphonia

- Voice impairments impact quality of life and communications. Voice changes may be intermittent or constant and vary in degrees of change ranging from mild to severe. Some of the most common signs and symptoms are:
- Difficulty maintaining voice
- Tiredness or fatigue when talking
- Variations in the usual tone
- Hoarseness
- Loss of volume and projection (weak voice)
- Loss of vocal efficiency
- Loss of strength and endurance in speaking
- Needs effort to speak
- Constantly needs to clear the throat
- Feels a foreign body is in the throat

Methods to care for voice impairments. The primary health care service promotes good voice health and confirms that the person understands and knows how to take care of their voice or if they need referral to a specialist. The following are important care tips:

- Develop habits of regular sleep and adequate physical activities and exercise to contribute to overall health and better vocal production.
- Do aerobic activities such as walking, swimming, etc. as instructed by your cardiologist and cardiac physical therapist.
- Maintain a balanced diet and chew food well.
- Sit upright with good relaxed posture. This facilitates adequate diaphragmatic breathing needed to produce a good voice.
- Keep well hydrated by drinking plenty of water in small sips. The ideal is to drink 7 to 8 cups a day. The color of the urine is clear if you are well hydrated.
- Choose environments that are quieter, so you do not have to increase the volume of your voice to overcome the ambient noise.
- Avoid shouting, but always speak firmly and strong.

Environments and behaviors that can be harmful to the voice:

- Smoke, dust, cigarettes, chemicals (cleaning materials), and some kinds of medications can irritate the mucosa of the vocal tract.
- Alcoholic beverages can irritate the mucosa of the vocal tract, and the anesthetic effect makes it difficult to perceive the vocal force being used to speak. Distilled beverages are more harmful than fermented beverages.
- Home remedies may irritate the mucosa of the vocal tract. Use treatments indicated by a qualified health professional.
- Sudden changes in temperature can be damaging to the voice. The temperature shock of very cold or hot beverages affects the voice.
- Caffeine, soft drinks, fried foods, and heavy, fatty, or spicy foods can make digestion difficult, leading to gastroesophageal reflux, especially in people who already have esophageal changes.

- Chocolate, milk, and milk derivatives can cause thicker mucus secretions in the vocal tract that lead to harmful throat clearing.
- Very dry air environments dry the mucosa of the vocal tract, damaging the voice. In such cases, the humidity needs to be restored with saline, nebulizer, etc.
- Some medications interfere with vocal production. Talk with your doctor if you notice that some medications are interfering with your voice. Avoid self-medication.
- Screaming and talking loudly are among the most aggressive behaviors for the larynx. Try to always talk in a calm and natural way.
- Speaking during exercise and physical activity overloads the musculature of the larynx. It is essential to have good coordination between breathing and speech so the voice is produced naturally.

KEY POINTS TO REMEMBER ABOUT CHAGAS DISEASE

1. Carry out the etiological diagnosis through clinical-epidemiological data and parasitological or serological tests.
2. Stage clinical forms of Chagas disease impairment to help determine the frequency of follow-up.
3. Establish the therapeutic plan and the prognosis according to the degree of cardiac and digestive involvement.
4. Systematically monitor persons with Chagas disease to evaluate progression.
5. Identify associated digestive compromise and, when present, guide or refer to gastroenterology.
6. Treat identified comorbidities or refer the person to a specialist.
7. Stimulate adherence to pharmacological and nonpharmacological treatment, optimizing the cost/effectiveness ratio.
8. Provide educational actions to affected people, family, and caregivers about the disease, self-management, and early identification of signs and symptoms of cardiac or digestive involvement.
9. Clarify that there should be no donating of blood, organs, or tissues.
10. Provide nutritional guidance.
11. Provide psychosocial support to the person affected, his or her family, and community with a view to reducing stigma, self-prejudice, taboos, and misconceptions related to Chagas disease.
12. Provide guidance on medical aspects, work, social security, gestation, family planning, physical exercise, and sexual activity.
13. Clarify with the affected person, family, and caregiver when there is a need for pacemaker implantation or ICD, as well as cardiac computed tomography (CT).
14. Stress the importance of prevention of aggravating environmental and behavior factors that affect function (alcohol, smoking, licit and illicit drugs).
15. Promote care support in special situations (people with pacemaker and ICD).
16. Identify *T. cruzi* infection in other family members or people in the social network promoting integrated approaches.
17. Stimulate and support the creation of associations of persons affected by Chagas disease, aiming to improve care, reduce stigma, advocate for social benefits, and support as needed.

Final Considerations: Chagas Disease at the Primary Level[1,3,6,26]

1. Chagas disease is a chronic and neglected infectious condition, with a high burden of morbidity and mortality.
2. Epidemiological risk includes vector transmission (contact with triatomines), blood and tissue transmission (transfusion, transplantation, congenital,[27] and intravenous injecting drug use), oral transmission (contaminated food), work accident (laboratory, surgical practices), and existence of infected relatives (mother, siblings).
3. Chagas disease can be suspected by clinical manifestations and epidemiological risk, but can only be confirmed by routine laboratory testing; many with the disease go unnoticed and undetected.
4. Timely diagnosis and access to trypanocidal treatment with benznidazole or nifurtimox (at any stage of illness) are important to prevent disease progression and the occurrence of impairments, functional limitations, and participation restrictions (disability), as well as prevention and control in the locality of occurrence.
5. There is a consensus that most people affected should be treated in primary health care by trained health workers who have adequate technology and a referral and counter-referral system available.
6. Functional capacity, effectiveness of nonsurgical conservative treatment, and cardiac involvement are important factors for health-related quality of life in people affected by Chagas disease.
7. Clear and comprehensive communication about the diagnosis and its therapeutic interventions between health care workers and the active participation of people and families affected by Chagas disease are crucial.

8. The intervention of support professionals (social worker, psychologist, etc.) to optimize quality of care and feelings of control is desirable.
9. Self-care and participation in self-help groups are important strategies for enabling independence; improving self-esteem; addressing depression, anxiety, and fear of death; and overcoming stigma.
10. Any donor of blood or organs, or persons identified in population studies with positive serological screening, must be informed and advised of their probable diagnosis and referred for serological confirmation/exclusion of disease.
11. Emphasis is placed on eliminating Chagas disease in children and young people, generating new possible donors of blood or organs, and freeing pregnant women of infection, thereby preventing transmission.
12. Chagas disease should not limit the professional work and social life of affected persons. Routine follow-up by the health team is fundamental to ensure safety and improve quality of life.

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In 2016, PAHO's Directing Council, through Resolution CD55.R9, approved the "Plan of Action for Elimination of Neglected Infectious Diseases (NID) and Post-Elimination Actions, 2016-2022." This Resolution urges Member States to implement a set of interventions to reduce the burden of disease by NID in the Americas by 2022, including "...support promotion of treatment, rehabilitation, and related support services through an approach focused on integrated morbidity management and disability prevention for individuals and families afflicted by those neglected infectious diseases that cause disability and generate stigma."

NIDs can have devastating chronic sequelae for patients, such as disability, visible change or loss in body structure, loss of tissue, and impairment of proper tissue and organ function, among others. All of these can in turn lead to unjustified discrimination, stigmatization, mental health problems, and partial or total incapacity to work, perpetuating the vicious cycle of neglected diseases as both a consequence and a cause of poverty. Patients with chronic conditions caused by NIDs require proper health care in order to prevent further damage and improve their living and social conditions. This should be provided at the primary health care level, as patients suffering from NIDs are often unable to travel to or afford to pay for specialized care services. Care for patients suffering from chronic morbidity caused by NID should be integrated into care for other chronic conditions caused by non-communicable diseases.

This manual provides a framework for morbidity management and disability prevention of patients affected by NIDs and gives specific guidance for the proper care of patients suffering from chronic conditions caused by lymphatic filariasis, leprosy, trachoma, and Chagas disease. It is intended to be used mainly by health care workers at the primary health care level, but health workers at more complex and specialized levels may also find it useful.

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