

**WORLD HEALTH ORGANIZATION  
GLOBAL PROGRAMME TO ELIMINATE  
LYMPHATIC FILARIASIS**

**LYMPHATIC FILARIASIS:  
MANAGING MORBIDITY AND  
PREVENTING DISABILITY**

# **LYMPHATIC FILARIASIS**

**AN AIDE-MÉMOIRE  
FOR NATIONAL PROGRAMME MANAGERS**



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Organization**



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# Glossary

The definitions given below apply to the terms used in this manual. They may have different meanings in other contexts.

**abscess:** localized collection of pus surrounded by inflamed tissue

**acute attack:** acute onset of fever with localized pain and warmth, with or without swelling or redness, in a limb or genital area; also used as a synonym for acute dermatolymphangioadenitis

**acute dermatolymphangioadenitis (ADLA):** acute inflammation of the skin, lymph vessels and lymph glands

**adenopathy:** any disease or enlargement of a lymph gland

**acute filarial lymphangitis:** inflammation caused by the death of adult worms, which usually produces a palpable ‘cord’ along the lymph vessel and progresses distally

**analgesic:** medicine used to relieve pain

**antibacterial cream:** a cream that kills bacteria or stops their growth; used to treat infected entry lesions and wounds and prevent infections in deep folds

**antibiotic:** medicine used to kill bacteria or stop their growth

**antifilarial medicine:** medicines used to kill filarial parasites; most primarily decrease microfilaria in the blood and may or may not kill adult worms in lymphatic vessels

**antifungal cream:** a cream that kills fungi or stops them from growing; used to treat entry lesions between the toes. For patients with advanced-stage lymphoedema (elephantiasis), antifungal creams can help prevent fungal infections in deep folds and in the interdigital spaces.

**antipyretic:** medicine used to treat fever

**antiseptic:** any medicine that stops or delays bacteria from growing; used on the skin

**chronic manifestation:** clinical sign present over a long period

**chyluria:** presence of chyle in the urine as a result of organic disease (as of the kidney) or obstruction of lymph flow from ruptured lymph vessels

**clinical case of lymphatic filariasis:** case in a resident of or long-term visitor to an endemic area, with hydrocoele, chylocoele, lymphoedema (elephantiasis), chyluria, haematochyluria, haematuria, hypereosinophilia or tropical pulmonary eosinophilia syndrome for which other causes have been excluded

**community home-based care:** care to ensure that patients maintain the best possible quality of life in their activities with the help of informal caregivers in the community, health staff or volunteers.

**disability:** inability to adequately or independently perform routine daily activities such as walking, bathing and toileting; the negative aspects of the interaction between a person with a health condition and his or her context (environmental and personal factors)

**elephantiasis:** severe or advanced lymphoedema

**endemic area:** area in which the average resident population or any subunit of population has a positivity rate of filarial antigenaemia or microfilaraemia equal to or greater than 1%

**entry lesion:** any break in the skin that allows bacteria to enter the body; can occur between the toes or in deep folds, through wounds on the skin surface, such as cuts, scrapes or scratches; visible in almost all patients with ADLA or acute attacks

**evaluation unit:** study area selected for assessing transmission; can comprise multiple implementation units or be part of an implementation unit

**family home-based care:** care to ensure that patients maintain the best possible quality of life by carrying out activities at home, with or without the help of a family member

**filarial infection:** presence of adult filarial worms in lymphatic vessels or of microfilaria in blood

**geographical coverage:** proportion of administrative units in which morbidity management and disability prevention activities are being implemented out of all those that require such activities

**haematoma:** mass of usually clotted blood that forms in a tissue, organ or body space as a result of a broken blood vessel

**haematuria:** blood in urine

**hydrocoele:** collection of excess fluid inside the scrotal sac that causes the scrotum to swell or enlarge

**hygiene:** conditions or practices conducive to maintaining health and preventing disability. In the context of managing morbidity from lymphatic filariasis, hygiene involves washing the affected limbs with soap and water until the rinse water is clean and then carefully drying.

**implementation unit:** administrative unit in a country that is used as the basis for making a decision about mass drug administration

**informal caregiver:** any person, such as a member of the family or community, who provides regular, continuous assistance to another person without payment

**interdigital lesion:** lesion between the toes or fingers

**long-term care and management:** various services to ensure that patients who are not fully capable of long-term self-care can maintain the best possible quality of life

**lymph scrotum:** disease in which the scrotal sac is thick, usually enlarged and has vesicles on the surface filled with (and frequently leaking) lymph

**lymphatic system:** network of nodes and vessels that maintain the delicate balance of fluid between the tissues and blood; an essential component of the body's immune defence system

**lymphoedema:** swelling caused by the collection of fluid in tissue

**mass drug administration:** a modality of preventive chemotherapy in which anthelmintic medicines are administered to the entire population of an area (e.g. state, region, province, district, sub-district, village) at regular intervals, irrespective of the individual infection status

**mass drug administration round:** distribution of antifilarial medicines to a target population during a defined period. As mass drug administration cannot be conducted simultaneously throughout a country, a round may take 1 week or more before completion at national level

**microfilaria:** microscopic larval stage of filarial parasites that circulate in the blood and are transmitted by mosquitoes

**microfilaraemia:** presence of microfilariae in blood

**morbidity:** clinical consequences of infections and diseases that adversely affect the health of individuals. Lymphatic filariasis causes chronic morbidity by damaging the lymphatic system, kidneys, arms, legs or genitals (especially in men).

**neglected tropical diseases:** primarily infectious diseases that thrive in impoverished settings, especially in the heat and humidity of tropical climates. They have been largely eliminated elsewhere and thus are often forgotten. WHO focuses on the eradication, elimination, prevention and control of 17 neglected tropical diseases: dengue, rabies, trachoma, Buruli ulcer, endemic treponematoses, leprosy, Chagas disease, human African trypanosomiasis, leishmaniasis, cysticercosis, dracunculiasis, echinococcosis, foodborne trematodiasis, lymphatic filariasis, onchocerciasis, schistosomiasis and soil-transmitted helminthiasis.

**neurological disorder:** disorder that affects the brain, spinal cord or nerves

**preventive chemotherapy:** the use of anthelmintic drugs, either alone or in combination, as a public health tool against helminth infections. Mass drug administration is one modality of preventive chemotherapy

**primary prevention:** prevention of disease; strategies applied to the general population to improve general well-being and provide specific protection against selected diseases

**prophylactic antibiotic:** antibiotic used to prevent bacterial infections

**reporting unit:** implementation unit or district health centre responsible for reporting morbidity management and disability prevention activities

**secondary prevention:** strategies and activities for the earliest possible identification of disease in at-risk populations to ensure prompt treatment and to prevent adverse sequelae

**social mobilization:** broad-scale movement to engage participation in achieving a specific development goal and effective behavioural and social change; involves reaching, influencing and involving all relevant segments of society

**target population:** population in an implementation unit that is targeted for treatment. In the context of lymphatic filariasis, the target population for mass drug administration is the same as the population eligible to receive the medicines, according to the criteria for drug safety, which is usually 85–90% of the total population. The target population for morbidity and disability activities are those with ADLA, lymphoedema (elephantiasis) or hydrocoele.

**tertiary prevention:** strategies and activities to promote independent function and prevent further disease-related deterioration



# Summary

The Global Programme to Eliminate Lymphatic Filariasis (GPELF) was launched by the World Health Organization (WHO) in 2000. In April 2012, lymphatic filariasis was endemic in 73 countries and territories; an estimated 1.39 billion people were at risk for infection, and approximately 120 million were already infected (1). More than 40 million people were incapacitated and disfigured by lymphatic filariasis-related disease, predominantly lymphoedema and its advanced form, elephantiasis, and hydrocoele.

The Programme has two main components:

- interrupting transmission of lymphatic filariasis through mass drug administration and
- managing morbidity and preventing disability.

Good progress was made with mass drug administration between 2000 and 2010, with over 3.9 billion doses of medicine delivered to a cumulative targeted population of 952 million people (1). Interventions to prevent and manage lymphatic filariasis-related disabilities in endemic communities were, however, limited.

In 2010, WHO published the GPELF progress report and strategic plan for the first 10 years of the Programme, with an outline of the approach and milestones for the second 10 years (2). One of the milestones is to disseminate revised.

## **Aim of this document**

In 2010, 33% of endemic countries had active morbidity management components and reported to regional programme review groups and WHO (2). The GPELF strategic plan stipulates that, by 2014, all endemic countries should be collecting and reporting data on morbidity management to WHO.

WHO published training modules on community home-based prevention of disability due to lymphatic filariasis in 2003 (3,4). A comprehensive booklet for programme managers on building a programme for managing morbidity and preventing disability was planned. The first draft benefited from valuable input from a WHO informal consultation held in Geneva, Switzerland, on 23–24 August 2006 (5). The draft was pre-tested in the field, updated and combined with a draft framework on disability prevention for national lymphatic filariasis programme; and the new draft was reviewed in 2011 by experts, who made several changes. The revised manuscript was reviewed again and aligned with other manuals and the WHO position statement on managing morbidity and preventing disability in the GPELF.

This document provides guidance on planning, implementing and monitoring activities at national level. It provides the best available information on managing morbidity and preventing disability after acute dermatolymphangioadenitis (ADLA; acute attacks), lymphoedema or elephantiasis, and hydrocoele. It also provides general operational and managerial guidance for reducing the number of cases of lymphatic filariasis and providing care for those affected.

## **Target readers**

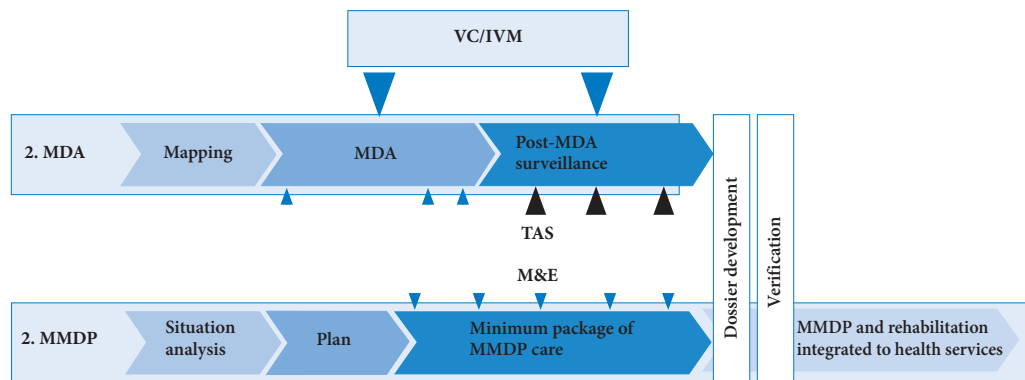
This document is intended for managers of national lymphatic filariasis programmes, national staff members involved in managing morbidity and preventing disability, district public health managers and medical or non-medical staff responsible for designing and implementing such activities.

## **Organization**

Section 1 provides background information, including a general description of the GPELF and the concepts of interruption of transmission, management of morbidity and prevention of disability (MMDP) associated with lymphatic filariasis within the wider framework of neglected tropical diseases. It also gives a scientific overview of the associated morbidity, including epidemiology, signs and symptoms and disability, and the methods available for managing and preventing them. Section 2 describes the building of a morbidity management and disability prevention component within the GPELF, with its goals and aims. Part 3 provides guidance for national programmes on preparing this component. The annexes give additional tools and resources for activities in hospitals, health clinics and communities.

*Figure 1* illustrates the twin pillars of the GPELF: interrupting transmission and preventing and managing disability among people who have the disease. Vector control, when appropriately used, can supplement activities to interrupt transmission (6). A strong monitoring and evaluation component is essential.

Figure 1. Twin pillars of the Global Programme to Eliminate Lymphatic Filariasis: interrupting transmission and preventing morbidity and managing disability among people with the disease



\*MDA, mass drug administration; M&E, monitoring and evaluation; MMDP, morbidity management and disability prevention; TAS, transmission assessment survey; VC/IVM, vector control/integrated vector management





# Section 1

## *Introduction*

### **1.1. Eliminating lymphatic filariasis**

#### **1.1.1 Background**

Approximately 15 million people globally are affected by lymphatic filariasis-related lymphoedema (or elephantiasis), which includes swelling of the limbs, breasts or genitals, and almost 25 million men are affected by urogenital swelling, primarily scrotal hydrocoele (7). Although these clinical manifestations are not often fatal, they lead to the ranking of lymphatic filariasis as one of the world's leading causes of permanent and long-term disability (8).

In 1997, the World Health Assembly resolved to eliminate lymphatic filariasis as a public health problem (9). The World Health Organization (WHO) subsequently launched the Global Programme to Eliminate Lymphatic Filariasis (GPELF) and proposed a comprehensive strategy based on two main components: (i) interrupting transmission of lymphatic filariasis through mass drug administration and (ii) managing morbidity and preventing disability.

#### **Interrupting transmission**

The approach to interrupting transmission comprises annual mass administration of a combination of two drugs to entire populations at risk. The treatment consists of albendazole (400 mg) plus either diethylcarbamazine (6 mg/kg) in areas without onchocerciasis or loiasis, or ivermectin (150–200 µg/kg) in areas where onchocerciasis and lymphatic filariasis are co-endemic (10).

Drugs are usually given by mass administration for 4–6 years, until adult worms have reached the end of their reproductive lifespan. In programmes where

coverage is poor or where transmission is particularly intense, annual campaigns may have to be longer in order to ensure interruption of transmission (11). Details of the use of mass drug administration to interrupt lymphatic filariasis transmission can be found in national programme managers' guidelines (2,12,13).

This pillar of the GPELF strategy also plays a role in primary prevention, by decreasing and reducing transmission rates in populations at risk. In addition, mass drug administration can prevent progression from subclinical to clinical disease and worsening morbidity. The benefit can also be quantified in terms of economic savings and increased productivity by healthier individuals (*Table 1*).

**Table 1. Estimated impacts of the Global Programme to Eliminate Lymphatic Filariasis, 2000–2008<sup>a</sup>**

Impact on health	No. of people protected (million)	Cost savings (billion US\$)
Prevention of infections in newborns	8.7	2.3
Prevention of progression from subclinical to clinical disease	10.7	16.5
Prevention of worsening morbidity or reversal	2.2	5.4
Total	22	24.2

<sup>a</sup> Source: The economic benefits resulting from the first 8 years of the Global Programme to Eliminate Lymphatic Filariasis (2000–2007) (14)

### Managing morbidity and preventing disability




A significant proportion of the public health problem represented by lymphatic filariasis is due to impairment and disability related to lymphoedema (elephantiasis) and hydrocoele. Therefore, national programmes must focus on managing morbidity and preventing disability. These activities will not only help lymphatic filariasis patients but can improve coverage with drugs (15).

Management of morbidity and disability in lymphatic filariasis require a broad strategy involving both secondary and tertiary prevention. Secondary prevention includes simple hygiene measures, such as basic skin care, to prevent ADLA and progression of lymphoedema to elephantiasis (16,17). For management of hydrocoele, surgery may be appropriate (18) (*Table 2*). Tertiary prevention includes 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. Activities beyond medical care and rehabilitation include 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 (19). The activities can also include education of families and communities, to help patients with lymphatic filariasis to fulfil their roles in society. Thus, vocational training and appropriate psychological support may be necessary for overcoming the depression and economic loss associated with the disease (20).

MMDP must be continued in endemic communities after mass drug administration has stopped and after surveillance and verification of interruption of transmission, as chronically affected patients are likely to remain in these communities.

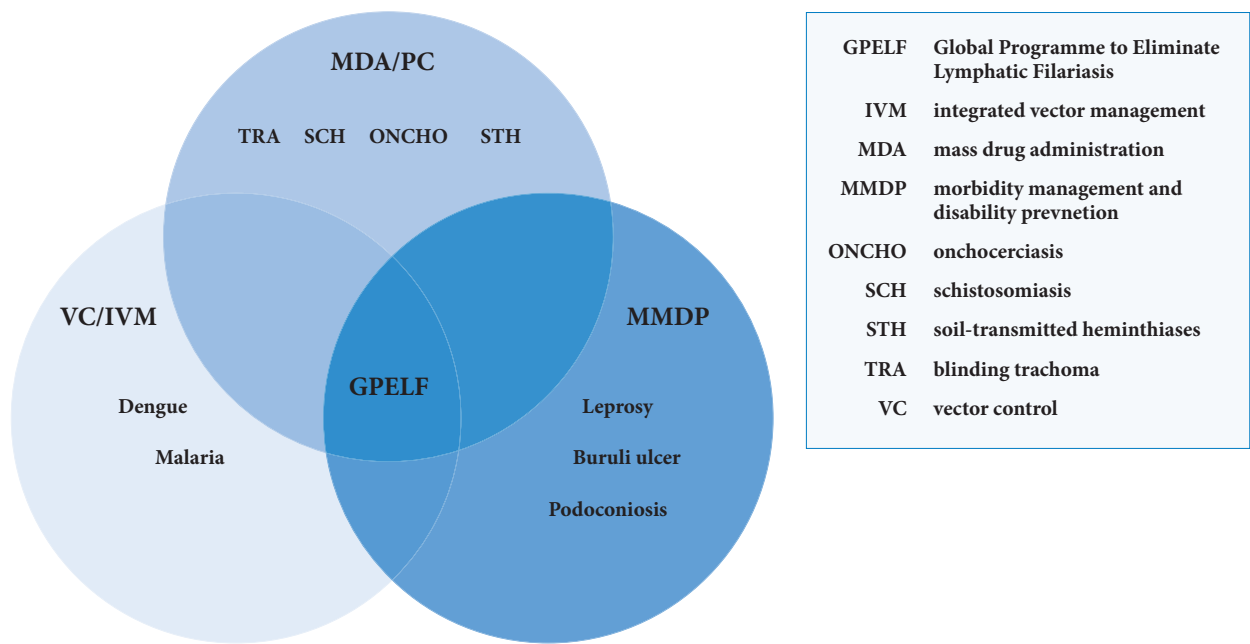
Table 2. Clinical manifestations and treatment of lymphatic filariasis

Clinical manifestation		Treatment	References
Acute dermatolymphangioadenitis		Antibiotics, antipyretics, analgesics	3,4,16
Lymphoedema and elephantiasis		Hygiene, antibacterial creams, antifungal creams	3,4,16
Hydrocoele		Surgery	18 and general surgical manuals

### 1.1.2 Integrating elimination of lymphatic filariasis into the control of other neglected tropical diseases

The GPELF is now part of integrated efforts to prevent and treat neglected tropical diseases (*Figure 2*). Transmission is being interrupted by mass drug administration, other forms of preventive chemotherapy and vector control, in collaboration with programmes for other neglected tropical and vector-borne diseases. For example, national lymphatic filariasis programmes are increasingly being integrated with preventive chemotherapy programmes to control or eliminate soil-transmitted helminthiases, onchocerciasis, schistosomiasis and trachoma. Strategic planning, training, drug distribution and monitoring are often common across these programmes. Integrated preventive chemotherapy and transmission control result in savings, due to optimal use of the resources of several programmes.

Figure 2. Opportunities for integrating lymphatic filariasis activities into programmes for other diseases



The minimal package of activities for lymphoedema described in this document can be used to manage not only lymphatic filariasis but all types of lymphoedema detected in areas endemic for lymphatic filariasis, irrespective of the etiology. Therefore, management of lymphoedema could be integrated with that of other chronic diseases that require long-term care with activities such as skin care, elevation and hygiene. Likewise, MMDP for lymphatic filariasis could be integrated into programmes for chronic diseases such as leprosy, diabetes, podoconiosis and Buruli ulcer. These programmes also involve training of health care workers and

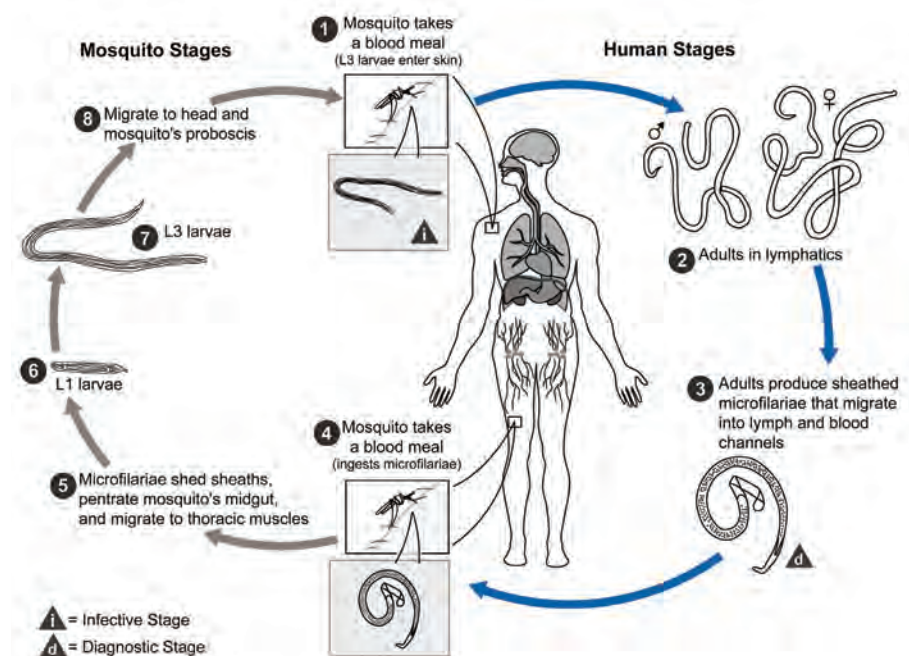
community and family members to care for people with chronic disabling diseases. Lymphatic filariasis morbidity and disability activities could also be integrated into programmes for chronic skin diseases, neurological diseases (acquired at birth or resulting from poliomyelitis, encephalitis, cerebral haemorrhage or stroke), consequences of trauma or burns, obesity, venous insufficiency and Madura foot. Integration of activities for hydrocoele would help improve general hospital surgery both qualitatively and quantitatively.

## 1.2 Morbidity associated with lymphatic filariasis

### 1.2.1 Background and epidemiology

Lymphatic filariasis is caused by three thread-like parasitic worms, called filariae. The species *Wuchereria bancrofti* is the most prevalent worldwide, *Brugia malayi* is found mostly in eastern Asia, and *B. timori* is confined to East Timor and adjacent islands. Filarial parasites in their adult stage live in the lymphatic system. The worms have an estimated active reproductive span of 4–6 years, producing millions of small immature larvae, microfilariae, which circulate in the peripheral blood. They are transmitted from person to person by several species of mosquito (Figure 3).

Figure 3. Life-cycle of filarial parasites



Source: <http://www.dpd.cdc.gov/dpdx>

It is estimated that close to 120 million people are infected with filarial parasites in 73 countries in the tropics and sub-tropics, while 1.39 billion people live in areas where filariasis is endemic (1). One third of the people affected with the disease live in India, one third in Africa and most of the remainder in South Asia, the Pacific and the Americas. Microfilariae are associated with microscopic haematuria in otherwise asymptomatic infected persons; they are also central to the pathogenesis of the relatively rare tropical pulmonary eosinophilia.

Lymphatic filariasis infection can occur early in life. In some areas, about 30% of children are infected before the age of 4 years (21, 22), and, while the clinical disease usually appears later in life, subclinical damage starts at an early age (21). Lymphatic filariasis is unlikely to cause lymphoedema or hydrocoele in children under 10–15 years of age (23, 24).

Lymphatic filariasis causes a wide range of acute and chronic clinical signs and symptoms. Acute forms of the disease include ADLA, usually due to secondary bacterial infection, which requires antibiotic therapy, and acute filarial lymphangitis, due to death of adult worms, which are self-limiting. Chronic manifestations include lymphoedema, hydrocoele, chyluria and tropical pulmonary eosinophilia.

In the context of the GPELF, the term ‘lymphatic filariasis’ refers both to infection with human filarial parasites and to clinical disease, including ADLA, lymphoedema and hydrocoele.

### **1.2.2 Signs and symptoms**

#### **Acute dermatolymphangioadenitis or acute attacks**

The adult filarial worms cause inflammation of the lymphatic system, resulting in lymphangitis and lymphadenitis. These conditions lead to lymphatic vessel damage, even in asymptomatic people, and lymphatic dysfunction, which predispose the lower limbs in particular to recurrent bacterial infection. These secondary infections provoke ADLA, commonly called ‘acute attacks’, which are the commonest symptom of lymphatic filariasis and play an important role in the progression of lymphoedema (20). It has been suggested that bacteria commonly gain access to damaged lymphatic vessels through ‘entry lesions’, often between the toes. ADLA, which resembles erysipelas or cellulitis, is associated with local pain and swelling and with fever and chills.

#### **Lymphoedema and elephantiasis**

Lymphoedema and its more advanced form, elephantiasis, occur primarily in the lower limbs and are commoner in women. Several factors have been implicated in the progression of lymphoedema, including repeated episodes of ADLA. Although lymphoedema due to filariasis should be distinguished from conditions such as heart failure, malnutrition, venous disease, podoconiosis and HIV/AIDS-associated Kaposi sarcoma, there is no agreement on its classification. (*Annex 1* presents a widely used classification and management scheme.) In its most advanced form, elephantiasis may prevent people from carrying out their normal daily activities.

## Hydrocoele

Scrotal hydrocoele is due to accumulation of fluid in the cavity of the tunica vaginalis. It has been suggested that true filarial hydrocoele occurs after the death of adult filarial worms, while a chylocoele is due to accumulation of fluid after the rupture of lymphatic vessels in the scrotal cavity (20). A system for classifying hydrocoele has been proposed (25) that may allow international comparisons.

### 1.2.3 Socioeconomic burden of lymphatic filariasis

Lymphoedema and hydrocoele lead to permanent, long-term disability; they also often cause disfigurement, with serious psychosocial and economic consequences. The direct economic costs of managing acute and chronic manifestations are a burden on patients and health systems alike. The cost to patients of treating ADLA episodes ranges from US\$ 0.25–1.62, almost 2 days' wages in some countries, while the cost of hydrocoele surgery, depending on the country and source of care, is US\$ 5–60 (20).

Indirect losses due to diminished productivity are also a severe drain on local and national economies. ADLA was estimated to be responsible for losses of US\$ 60–85 million per year in India (26,27) and US\$ 38 million per year in the Philippines (28). Furthermore, disability and disfigurement due to chronic manifestations often mean that patients have to stop working or change to less productive jobs (21–31). Lymphatic filariasis also exerts a heavy social burden on patients, as chronic complications are often considered shameful and prevent patients from playing their role in society and from leading a fulfilling emotional life (17,18,20,32–35). For men, genital damage is a severe disability, leading to physical limitations and social stigmatization (17,36). For women, shame and taboo are associated with lymphoedema and especially elephantiasis. When their lower limbs and genital parts are enlarged, they are severely stigmatized; marriage, in many situations an essential source of security, is often impossible. These individuals may be prone to depression and poor mental health (16). Lymphatic filariasis often affects not only the patient but also the family, especially if the patient is the major income earner.

### 1.2.4 Associated disability

The WHO International Classification of Functioning, Disability and Health (37) provides a coherent view of the intersections of the biological, individual and social perspectives of health, balancing both the medical and social perspectives of disability. In the context of lymphatic filariasis, the following terms are relevant (see Box 1):

- *Functioning* includes body functions, body structures, activities and participation. It denotes the positive aspects of the interaction between an individual with a health condition and the individual's environmental and personal factors.
- *Impairment* is loss or abnormality of psychological, physiological or anatomical structure or function.

## Box 1. How the International Classification of Functioning, Disability and Health (37) relates to patients with lymphatic filariasis

Patients with small hydrocoeles may have no difficulty in riding a bicycle, but large hydrocoeles may impede such activities.

Depending on existing services and social stigmatization, people with lymphoedema (elephantiasis) may have difficulty in having an acceptable social life, such as getting married or finding suitable employment.

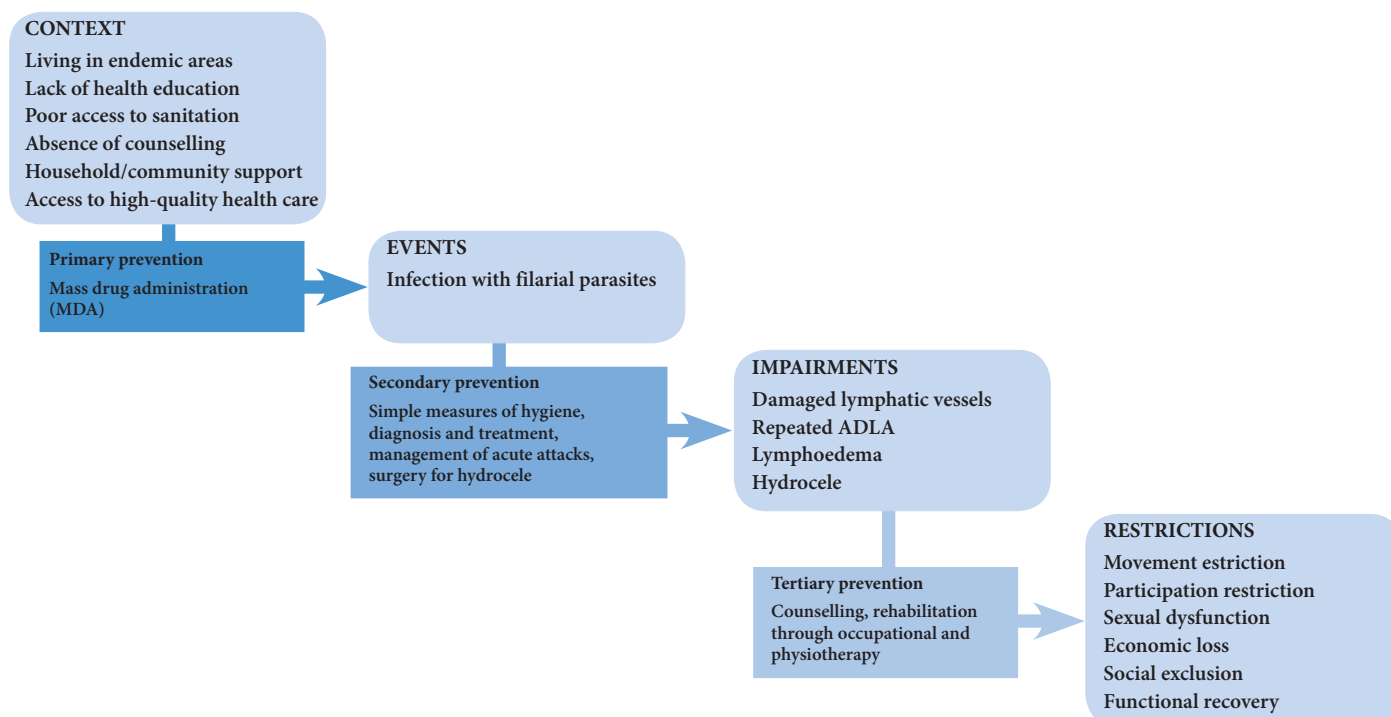
Anyone infected with adult worms or microfilariae may be considered to have impairment, as they have lymphatic damage and their skin defences may be impaired.

People with clinical manifestations related to lymphatic filariasis have a disability when the manifestations interfere with their daily life or professional activities, such as walking normal distances or regular attendance at work or school.

- *Disability* refers to impairment, activity limitation and restriction on participation. It denotes the negative aspects of the interaction between an individual with a health condition and the individual's environmental and personal factors. Disability can be altered by changes in environmental and personal factors.

The development of disability and restrictions on participation that result from impairment are illustrated in *Figure 4*. Infection is directly linked to living in an endemic area, poverty, social habits, ecological and other environmental variables. Infections lead to morbidity and may generate impairment.

Figure 4. Relations between impairment in lymphatic filariasis and participation in activities





The activities for MMDP describes in this document address restrictions on participation in primary, secondary and tertiary prevention. Primary prevention involves mass drug administration to the population at risk in order to reduce transmission of lymphatic filariasis and the development of new infections. Secondary and tertiary prevention involve providing care for people who are infected, with or without disabilities, in all areas, regardless of whether lymphatic filariasis transmission is present.

## 1.3 Tools for managing morbidity and preventing disability

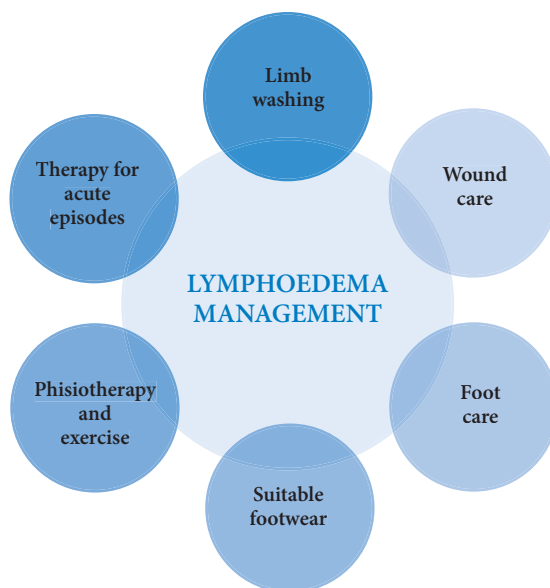
### 1.3.1 Managing acute dermatolymphangioadenitis

For the purposes of this document, the definition of ‘ADLA’ is ‘acute onset fever and localized pain and warmth, with or without swelling or redness in the limb and/or genital area’. As the clinical picture of ADLA is similar to that of cellulitis, the same recommended first-line antibiotic treatment—usually penicillin—should be used (20). National authorities may modify the antibiotic in accordance with the accepted norm for the use of antibiotics. Antifilarial treatment should not be given during acute attacks. The protocol for treating ADLA is described in *Annex 2*.

### 1.3.2 Managing lymphoedema and elephantiasis

Basic management for lymphoedema and elephantiasis involves simple measures, which can usually be carried out by the patient. The complete set of measures is more complex but usually cannot be implemented in resource-poor settings. Where there is a comprehensive health system, health workers could promote use of the complete package, including compression or pressure bandages, lymphatic massage and other recognized methods. Traditional health workers should be involved in these activities whenever possible. The basic measures include (*Figure 5*) (3,4,16,17):

Figure 5. Measures for managing lymphoedema



- **Washing:** The affected parts should be washed twice daily with soap and clean water at room temperature and dried carefully with a clean cotton cloth or gauze. The importance of hygiene in the management of lymphoedema cannot be overstated; diligent washing may reduce the requirement for antibiotics and prevent progression of lymphoedema.
- **Skin care:** An intact skin provides an effective barrier against infection.
- **Elevation and exercise:** The affected limb should be raised at night and when possible during the day and exercised regularly with low-intensity movement of the joints. As immobility significantly worsens the condition, patients should be encouraged to keep moving.
- **Foot care:** The nails and spaces between the toes must be kept clean.
- **Suitable footwear:** Comfortable shoes should be worn to protect the skin.
- **Wound care:** Medicated creams or antibiotics (e.g. antiseptics, antifungal and antibiotic creams) should be used to treat small wounds or abrasions. For patients with elephantiasis, antifungal creams can help prevent fungal infections in deep folds and in the interdigital spaces.
- **Therapy for acute episodes:** Episodes of ADLA should be treated with antibiotics and other measures.
- **Scarification** should never be used.

Patients should use these measures more vigilantly during the rainy season because of the increased risk for developing interdigital lesions and ADLA. In areas where *Brugia* are present, patients should be taught to dress abscesses properly, as patients infected with these species are at higher risk for abscesses on the proximal limbs. To start basic management, the programme, supporting agencies or the patient should provide a washing kit, consisting of a basin, soap and clean cotton cloth or gauze. All these measures are described in detail in WHO guides on community home-based prevention of disability due to lymphatic filariasis (3,4,16).

### 1.3.3 Managing hydrocoele

Early hydrocoele changes can often be reduced by lymphatic drainage (21). The treatment of choice for more extensive hydrocoele is hydrocoelelectomy, which generally does not require high-level facilities.<sup>1</sup> Hydrocoelelectomy is performed in most peripheral health institutions in areas endemic for *Wuchereria bancrofti*. In areas where the prevalence of this condition is much lower, surgery is usually done by specialists in central health institutions. Complicated hydrocoele, including very large, disfiguring forms, should be operated on only by experienced surgeons.

In 2002, a WHO informal consultation on surgical approaches to the urogenital manifestations of lymphatic filariasis discussed the management of hydrocoeles from a public health perspective (16,18,34). It concluded that three levels of health care management should be involved in hydrocoele surgery:

<sup>1</sup> This recommendation is based on expert opinion formulated at a WHO informal consultation on preventing and managing disability related to lymphatic filariasis at implementation unit level, WHO headquarters, Geneva, Switzerland, 23–24 August 2006. It is not based on a systematic review or a synthesis of the evidence.

- Level I: community screening of patients with scrotal swelling. Either the patient himself or a community health worker identifies scrotal swelling, and the patient is referred or reports to a level II facility.
- Level II: a centre at which surgery for uncomplicated hydrocoele can be performed. Depending on the country, this would be a peripheral health structure such as a district hospital with basic surgical facilities. The facility should have a clean room in which surgical procedures can be performed with appropriate asepsis of the surgical field and facilities for basic resuscitation. There should also be a facility for observing patients for a minimum of 24–48 h. A qualified general physician, trained to perform surgery on patients with simple hydrocoele by a standard operating procedure and using local anaesthesia, should be present in the facility.
- Level III: a regional or provincial referral hospital, where patients with more serious problems or complicated hydrocoeles can be referred for surgery. This should be equipped with an operating theatre that allows surgery under general anaesthesia and should be staffed by qualified, experienced surgeons or urologists.

The consultation also noted that hydrocoelelectomy ‘camps’ have been useful in Africa, where a concerted effort can result in treatment of a large number of hydrocoele patients relatively quickly. These events can also serve for advocacy for MMDP.

The choice of method depends mainly on the practice of the surgical service in the district. A list of items to be included in a surgery kit for use at level II facilities and the physical facilities required is available in Surgical approaches to the urogenital manifestations of lymphatic filariasis (18).

Care should always be taken to ensure that patients have adequate pre- and post-surgical preparation and support, as these significantly improve the success of this intervention.

### Individual antifilarial treatment

All people with filariasis who are positive in the immunochromatographic test or have microfilaraemia should receive anti-filarial 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 µg/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 (12,13,38).<sup>2</sup>

<sup>2</sup> This recommendation is based on expert opinion formulated at a meeting of the Monitoring and Evaluation Subgroup on Disease-specific Indicators of the Strategic and Technical Advisory Group for Neglected Tropical Diseases, Task Force for Global Health, Atlanta, Georgia, USA, 1 October 2012, and not on a systematic review or a synthesis of the evidence.



# Section 2

## *MMDP within the Global Programme to Eliminate Lymphatic Filariasis*

This section is summarized from two GPELF documents recently published by WHO (2,39).

### **2.1. Why manage morbidity and prevent disability?**

Lymphatic filariasis is a public health problem because the infection damages the lymphatic system, increasing the risk for secondary infections and complications. An estimated 40 million people globally have clinically significant manifestations of lymphatic filariasis—predominantly lymphoedema and hydrocoele—accounting for 5.9 million disability-adjusted life years (8), with a concomitant loss of productivity and social stigmatization. As the goal of the GPELF is to eliminate the disease, managing morbidity and preventing disability are integral to elimination programmes (40).

Access to management of lymphoedema and surgery for hydrocoele may increase community cooperation in mass drug administration (15) and thereby contribute to interrupting transmission of the parasite and preventing new infections. The main reason for managing morbidity, however, is to relieve suffering. This component of the programme is therefore rooted in compassion. All national programmes must manage morbidity and prevent disability in order to eliminate lymphatic filariasis, including care for those affected, even after interruption of transmission. Patients with clinical and social consequences have a right to health care, and this is the responsibility of national elimination programmes (39).

The GPELF is part of integrated efforts to prevent and treat a number of neglected tropical diseases, and collaboration is already established with other programmes in terms of preventive chemotherapy and integrated vector management to interrupt transmission. Combined approaches to MMDP should also be explored with other programmes, such as those for chronic diseases (see section 1.1.2).

## 2.2. What is MMDP?

The public health priorities are ADLA, lymphoedema and hydrocoele, the main manifestations of the disease. Management of other clinical forms of filarial disease, such as chyluria, lymphocoele, scrotal lymphoedema, tropical pulmonary eosinophilia, adenopathy and haematuria, should follow standard clinical and referral practices, as public health approaches have not yet been established.

Almost 15 million people, mainly women, have lymphoedema or its more advanced form, elephantiasis, primarily of a lower limb (1,2). Lymphoedema and elephantiasis can be managed by simple measures that include hygiene and skin care to prevent ADLA, proper wound care, exercise, elevation of the affected limb and proper footwear. These simple measures are effective in reducing episodes of adenolymphangitis, improve the quality of life of patients and can be maintained for several years by home-based care. About 25 million men have urogenital disease related to lymphatic filariasis, most commonly hydrocoele. Hydrocoele is effectively cured by surgery, and this has been shown to improve men's economic situation, community participation and quality of life.

To prevent disability, people with disease related to lymphatic filariasis should also have access to psychological and social support to assist their reintegration into society and economic life (see section 1.2.3) (39).

## 2.3. Goals and aim of MMDP

The goals of this component of the GPELF are to alleviate suffering in people with ADLA, lymphoedema and hydrocoele and to improve their quality of life (39). The aim is to provide access to the recommended basic care for every person with these manifestations in all areas where lymphatic filariasis is endemic.

The recommended minimum package of care includes:

- treating episodes of ADLA among people with lymphoedema or elephantiasis;
- preventing debilitating, painful episodes of ADLA and progression of lymphoedema;
- providing access to hydrocoele surgery; and
- providing antifilarial medicines to destroy any remaining worms and microfilariae by mass drug administration or individual treatment.

People with lymphoedema must have access to continuing care throughout their lives, both to manage the disease and to prevent progression to more advanced stages. Thus, MMDP should be part of the primary health care system to ensure sustainability (40).

## 2.4. Strategic planning

In 2010, WHO published a strategic plan for 2010–2020 in which it defined the strategic aim and goals for managing morbidity and preventing disability (2). During the next decade, such programmes will be a priority in all countries endemic for lymphatic filariasis, with the aim of providing access to care for all people with manifestations of the disease. Starting programmes and scaling them up to achieve full coverage both geographically and in terms of the clinical conditions managed will be a challenge. The new emphasis on integrated management of neglected tropical diseases will facilitate inclusion of care for lymphoedema with care for related disabilities and inclusion of hydrocoele surgery into other surgical programmes. The ultimate aim is to integrate services for the management of morbidity and the prevention of disability due to lymphatic filariasis fully into national health systems by training health staff to care for these patients, strengthening referral mechanisms from community to health worker to specialist and back and finding subsidies for the cost of treatment.

### Global milestones:

- 2013: Metrics for annual reporting on morbidity management programmes developed by WHO and disseminated
- 2020: Full geographical coverage and access to basic care for lymphoedema (and hydrocoele in areas of Bancroftian filariasis) offered in all countries.

### Global indicators:

- proportion of countries that have implemented morbidity management programmes
- proportion of countries with full coverage of morbidity management services and access to basic care.

## 2.5. What will success look like?

The aims of the Global Programme by 2020 are to achieve (*Table 3*):

- full geographical coverage with MMDP in national programmes to eliminate lymphatic filariasis in all endemic areas;
- access to basic recommended care for all people with hydrocoele, lymphoedema or elephantiasis in areas where lymphatic filariasis is endemic;
- a reduction in the frequency and intensity of episodes of adenolymphangitis for people with lymphoedema; and
- a reduction in the number of new cases of lymphoedema and hydrocoele to background levels when transmission of the parasite has been interrupted, i.e. no new cases due to lymphatic filariasis.

Table 3. Targets for morbidity management services in endemic countries in the GPELF, by year

Year	Objective <sup>a</sup>		
	Morbidity- management programme implemented	Collecting and reporting data to WHO using specified metrics	Full geographical coverage and access to basic care
2012	40	0	20
2014	80	80	40
2016	100	100	60
2018	100	100	80
2020	100	100	100

<sup>a</sup> Values are the proportion of country-based programmes that should achieve specified indicators for morbidity-management services.



# Section 3

## *Planning MMDP in a national programme*

Each endemic country is encouraged to prepare a plan for this component of the national programme to eliminate lymphatic filariasis. Countries should ensure that their plan is aligned with the goals and aims of the global plan (and regional plans if any), even if they adopt innovative approaches and use opportunities to integrate their programme with those that provide similar care.

### **3.1 Policy and guiding principles**

The aim at all levels is to give every patient with lymphatic filariasis a better, more productive life and allow them to participate equally in the community, both socially and economically. By 2020, every national programme should have achieved full geographical coverage of access to basic recommended care in all endemic areas.

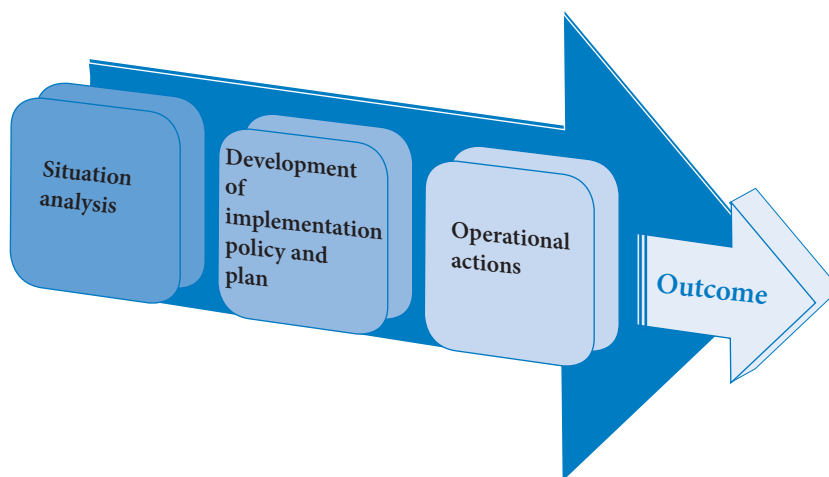
The guiding principles and policies for MMDP are:

- **Access:** Provide access to basic care for all patients with ADLA, lymphoedema and hydrocoele as part of the programme to eliminate lymphatic filariasis.
- **Flexibility:** Allow flexible approaches to strategies for preventing and alleviating disabilities associated with lymphatic filariasis.
- **Integration:** Whenever possible, integrate the activities into other disease control programmes.

## 3.2 Strategic planning and implementation

The steps involved in setting up an effective MMDP components are :  
(i) conducting a situation analysis, (ii) preparing an implementation policy and plan and (iii) operational activities (*Figure 6*).

Figure 6. Setting up effective morbidity management and disability prevention (MMDP)



### 3.2.1 Situation analysis

A national situation analysis can be helpful for determining the prevalence of disease, the efficiency of the health care and information system, the policy environment, the role of advocacy, the capacity of health staff and possibilities for integrating activities with those for other chronic diseases.

The comprehensiveness of the analysis will depend on the disease burden, the number of stakeholders and the available resources. The steps outlined below represent a detailed approach to the collection of data but can be modified by national programmes. This information can be collected at the level of the implementation unit, which often requires detailed information in order to adapt activities to local conditions and resources (*Annex 3*).

A national situation analysis usually covers epidemiology, the health and social environment and a strategic framework.

#### Epidemiology

The first step is to assess the numbers of cases of ADLA, lymphoedema and hydrocoele in all implementation units in the country. Although the exact number of cases of lymphatic filariasis is not required at national level, a fair assessment of the burden will help in planning and setting priorities for activities. This information

may already be available in the health information system, or it may have to be collected in special surveys, during baseline surveys, when enumerating households during mass drug administration or in collaboration with nongovernmental organizations concerned with disability. This information is useful for designing activities and training packages for motivating patients and their families to practise regular hygiene or to seek surgery for hydrocoele.

### **Health and social environment**

With regard to health facilities and services, the information should include whether appropriate referral systems are in place for complicated cases of lymphoedema and hydrocoele surgery and whether appropriate rehabilitation services are available, either institutional or home-based.

Environmental barriers and facilitators should be investigated, such as:

- the availability of basic supplies and materials for care, e.g. clean water, soap, cloths, basins, antifungal cream or ointment;
- the availability of appropriate footwear;
- access to transport;
- access to information about the disease and its management;
- access to health services; and
- knowledge of general and personal hygiene measures for lymphatic filariasis.

A review could be made of the presence of appropriate health care workers, such as surgeons, doctors, nurses and public health staff, at regional, district, hospital and health centre levels and referral mechanisms. Ascertaining current knowledge, attitudes and prescribing practices of health providers will help in preparing appropriate training materials.

The basic characteristics of endemic communities in the country, e.g. culture, language, literacy and socioeconomic characteristics, should also be noted.

### **Strategic framework**

A strategic framework is based on analysis and identification of problems in relation to the policy environment, i.e. policies with an adverse or beneficial effect on managing morbidity and preventing disability due to lymphatic filariasis, and identifying gaps in existing policy frameworks (*Table 4*).

The activities include capacity-building, conducting applied research, ensuring within-sector coordination and intersectoral collaboration, decentralization, community empowerment and clinical treatment. Support is required at national level to enable the government, programme manager and the community to take decisions on these issues.

The feasibility of integrating lymphoedema management with that of other chronic diseases that require long-term care should be investigated. Activities such as

**Table 4. Proposed framework for analysing the policy environment in relation to managing morbidity and preventing disability due to lymphatic filariasis**

Activities (examples)	Existing policies, guidelines or programmes	Gaps to be addressed
Treatment of acute dermatolymphangioadenitis		
Use of antibiotics		
Integrated control of neglected tropical diseases		
Water supply and sanitation improvement		
Hygiene legislation		
Hydrocoele surgery		
Primary health care		
Medical and clinical guidelines		
Medical and clinical education		
Community education and social mobilization		
Psychosocial support		
Socioeconomic rehabilitation		
Collaboration with nongovernmental organizations		

skin care, limb elevation, exercise and use of appropriate footwear are often similar in the programmes shown in *Figure 2*. Assessing the feasibility of integration with other chronic disease programmes may involve:

- determining whether there is a national policy for integrating chronic diseases;
- discussing the feasibility of integration with the departments responsible for these chronic diseases;
- sharing epidemiological data, the strategy and planned activities with focal persons for such diseases;
- collecting any missing epidemiological data through surveys and from community informants;
- establishing common activities for patients with lymphoedema and those with other chronic diseases;
- making decisions jointly with the departments involved in the integrated disease programme;
- adapting process indicators for each disease programme, e.g. programme coverage, frequency of referral to a health facility for monitoring integration; and
- training health staff and informal caregivers in hygiene, exercises and technical follow-up of patients in the same way for all the diseases.

### 3.2.2 Implementation policy and plan

The implementation plan for MMDP should be part of the national lymphatic filariasis plan. The situation analysis will identify the policies that govern management of lymphatic filariasis, including the criteria for diagnosis, treatment policies and rehabilitation methods. If there is no policy, it should be defined before the MMDP component is launched.

*Box 2* lists the possible content of the plan. It should be discussed with all stakeholders, and roles and responsibilities should be clearly established. Advocacy and social mobilization should be included, and the plan should be adapted to local circumstances. In all plans, however, primary health centres will provide referral care for all types of lymphoedema management, especially for complicated ADLA. Nevertheless, the various morbidity management systems should be adapted to each community, even in the same country. For example, if a family home-based care system is chosen, staff at the health centre could supervise informal caregivers, if operationally feasible. If there are few chronic cases and access to a health facility is easy, lymphoedema patients could be monitored at the primary health care centre. For patients who are unable to walk, staff from the health centre could make home visits or the family could provide care in consultation with health centre staff. Alternatively, patients might care for themselves at home or go daily to the health facility.

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#### Box 2. Example of content of a MMDP implementation plan

##### Country profile

- Geography and climate
- Political situation and administration
- Demographic and socioeconomic information
- Health status
- Health system

##### Endemic situation and mass drug administration programme

- Mapping
- Microfilariae or antigenaemia baseline prevalence by implementation unit
- Mass drug administration coverage
- Clinical cases

##### Operational activities and responsibilities

- Management and organization
- Advocacy and social mobilization
- Capacity building and training
- Minimum packages of care for ADLA, lymphoedema and hydrocoele surgery
- Psychological support and socioeconomic rehabilitation

##### Monitoring and evaluation

- Data collection and analysis
- Reporting

##### Time frame

##### Budget

---

### 3.2.3 Operational activities

#### National level

##### Management

As a first step, the national lymphatic filariasis programme must decide how it will organize its activities. The national programme and district authorities are responsible for providing services and should decide which of the activities described in this document are to be included in the national lymphatic filariasis elimination programme. The roles of the programme manager therefore include:

- harmonizing the institutional arrangements for mass drug administration and for MMDP at national, subnational and peripheral levels (e.g. determining whether the implementation units are the same); and
- integrating the MMDP component with that of other chronic diseases in order to optimize use of resources and improve programme efficiency.

It is suggested that one staff member be appointed as the focal point for MMDP in lymphatic filariasis. If an integrated approach is chosen, the focal point could also be responsible for this aspect of other disabling diseases. The focal point could outline the responsibilities of the national programme, the primary health care system, nongovernmental organizations, faith-based organizations and the private sector in these activities.

Health care staff in implementation units are often routinely involved in MMDP for lymphatic filariasis patients. District health facilities serve as technical referral centres, provide treatment for complicated cases and provide expertise to communities. Even where most lymphoedema patients are cared for by their families or the community at home, the implementation unit often trains and supervises caregivers and conducts monitoring and evaluation. In areas with a high burden of disease or many stakeholders, a 'lymphatic filariasis team' of health staff could be formed, as they may work in different parts of the health sector, e.g. surgeons, public health officers and nurses in health clinics.

In countries with a large burden of lymphatic filariasis-related disease or where many stakeholders are involved in MMDP, a national committee might be established. The responsibilities of this committee could include sharing information, identifying common goals and objectives and assigning responsibilities for meeting programme objectives. As these activities include medical, psychological, social, economic and managerial issues, the committee should represent various sectors, including government ministries (health, education, social development), industry, donors, nongovernmental organizations and United Nations agencies. The national committees for mass drug administration and for morbidity management may be combined or separate entities, as the expertise and input are not necessarily the same. The two committees should, however, communicate to ensure coordination of elimination efforts.

A lymphatic filariasis committee might also be formed at peripheral level to help government staff to involve the community and implement activities. This would be particularly appropriate in areas where the management system is community-based home care.

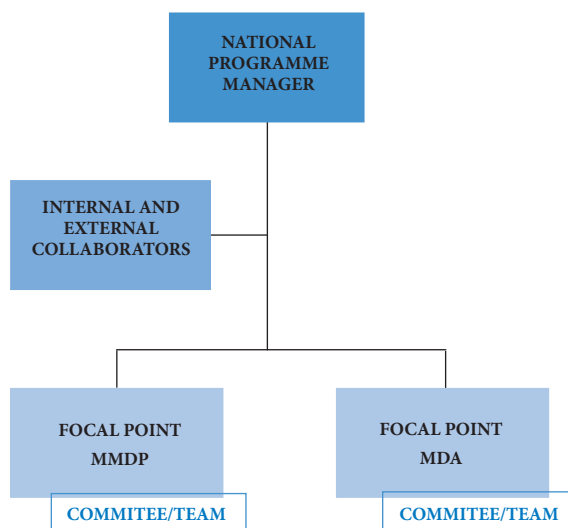
The stakeholders involved in implementing and supervising MMDP include:

- community-based care organizations such as health workers, women's groups and youth groups, whose involvement should be supervised;
- nongovernmental organizations, whose involvement should be coordinated and supervised;
- individuals with or without expertise in community-based care to ensure organization and coordination;
- religious and community leaders; and
- traditional healers and members of faith-based organizations.

Programmes could also establish a team consisting of people interested in improving the status of lymphatic filariasis patients in their community. It could include representatives of local nongovernmental organizations, community-based care organizations or volunteers from women's groups, support groups, self-help groups, youth groups or corporative groups. The membership should broadly represent the community.

An example of team organization for MMDP in national programmes to eliminate lymphatic filariasis is shown in *Figure 7*.

Figure 7. Example of team organization for morbidity management and disability prevention (MMDP) in national programmes to eliminate lymphatic filariasis



MMDP, Morbidity management and disability prevention  
MDA, mass drug administration

### Advocacy and social mobilization

Advocacy and social mobilization to encourage MMDP activities should be implemented at different levels in order to ensure smooth running as well as the involvement of all different actors. An outline of advocacy and communication activities is presented in *Table 5*.

**Table 5. Planning advocacy and social mobilization activities for managing morbidity and preventing disability due to lymphatic filariasis**

Level	Target audience	Method	Expected outcome
Policy	Health sector decision-makers, donors, policy-makers, community leaders, religious leaders, opinion leaders, teachers	Policy briefs, messages, success stories	Increase knowledge and awareness and change attitudes to become advocates for prevention activities, budget allocation, coordination
Programme	Managers of disease-specific programmes, doctors, nurses, public health workers	Messages, success stories	Collaboration in operation, monitoring and evaluation
Research	Medical laboratories, research scientists	Forum discussion	Research
Community	Community health workers and volunteers	Training sessions	Awareness, commitment
	Community at large, including young people (schoolchildren)	Information, education and communication materials and activities	Awareness, behavioural change

Educating patients and their families as well as school-children about health is of primary importance in managing morbidity and preventing disability. National programmes might also conduct broader social mobilization campaigns, depending on, for instance, the disease burden in communities, hygiene practices, levels of stigma and available resources.

Where there are few cases of chronic lymphatic filariasis, social mobilization for disability prevention can be incorporated into a mass drug administration campaign or with similar activities for other disabling diseases. Social mobilization is used to inform the population about the disease and its consequences; modify their attitudes, particularly when the patients experience stigmatization; sensitize people to the importance of early screening, and encourage active participation in case identification. Social mobilization can also encourage modification of hygiene practices to prevent initial ADLA episodes, particularly in people who do not realize that they are infected, and also to increase compliance and participation in mass drug administration.



Developing a social mobilization strategy requires special skills, and it is recommended that the programme work with specialists in this domain. Campaigns and advocacy targeted at stakeholders such as local leaders should create a sense of ownership and empowerment in the community in order that MMDP activities are sustainable, with limited input from the health system.

#### Capacity-building and training

Reinforcing the capacities of health staff at various levels and of communities will ensure the success of MMDP. *Table 6* gives examples of capacity-building activities.

Table 6. Capacity-building activities for different target groups

Target group	Required competences	Capacity to be built	
		Human resources	Infrastructure
Technical staff	Advocacy, communication, curriculum development	Training, study visits	Not applicable
Programme managers	Planning, targeting of interventions	Training	Databank and reporting systems
Programme staff	Basic techniques, monitoring and evaluation	Training	Forms, networking
Nurses and doctors	Disease and treatment techniques, monitoring and evaluation	Medical and nursing schools	Medicine and treatment guidelines
Community-based workers, volunteers	Techniques, health promotion	Training, supervision of training facilities	Networking, use

In general, standard operating procedures and training procedures for treatment of ADLA, management of lymphoedema and hydrocoele surgery should be established at national level. National programme staff can adapt training materials for management of lymphoedema from general guidance (3,4,16). Training materials also might have to be adapted for implementation units, depending on the available knowledge, language and literacy. Health care staff and caregivers should be trained to give patients with lymphoedema or hydrocoele correct information on whom to contact, what to do and not do for self-care, and indications for hydrocoelelectomy (*Box 3*).

The steps in preparing a training programme for the management of ADLA and lymphoedema are:

- Define standard operating procedures for identifying and managing ADLA and lymphoedema for physicians in primary health care, health workers and lay workers.

### **Box 3. Training procedures for community home-based care (3,4)**

The aim of training or capacity-building of targeted groups (health care workers, informal caregivers, individuals and families) should be to develop four competences:

- recognize the disease burden and its complications,
- understand home-based and long-term care,
- provide adequate management of lymphoedema and elephantiasis and
- establish appropriate follow-up, monitoring and referral systems.

The materials used in training courses consist of four parts:

- a two-part training module: a tutor's guide and a learner's guide for training-trainers workshops,
- a flipchart for use by informal caregivers and
- a poster for patients with lymphoedema or elephantiasis.

- Prepare training curricula on the basis of the situational analysis of the competences and needs of health staff for managing morbidity and disability due to lymphatic filariasis and identify how the training will be structured, perhaps by identifying training facilities at national and subnational levels.
- Include modules on morbidity and disability due to lymphatic filariasis in medical and nursing school curricula.

Trained staff should be used to organize training courses for health staff at implementation units and for informal caregivers. Training programmes for hydrocoele surgery should be organized at level II (peripheral health facility) by surgeons with experience in the procedure who work in endemic areas or surgeons attached to teaching or training institutions with continued experience in hydrocoele surgery. Level II medical officers should be trained in diagnosis, evaluation for surgery and all aspects of surgery, including local anaesthesia, postoperative care and follow-up at an implementation unit.

Training courses also can include modules on strategies for lymphatic filariasis elimination, informed consent and patient hygiene pre- and post-surgery. Case demonstration and actual surgery need not be performed during training but are useful when possible.

#### Minimum package of care

The recommended minimal care comprises:

- treating episodes of ADLA in patients with lymphoedema;
- preventing debilitating, painful episodes of ADLA and progression of lymphoedema to elephantiasis;
- ensuring access to hydrocoele surgery; and
- providing antifilarial medicines to destroy any remaining worms and microfilariae by mass drug administration or individual treatment.

The delivery strategies, the people involved, their responsibilities, the action and the activities and skills required are summarized in *Table 7*.

**Table 7. Activities and responsibilities in a minimum package of care for patients with lymphatic filariasis**

Disease manifestation	Delivery strategy	People involved	Responsibility	Action	Skills
ADLA	Hospital, primary health care centre	Doctors and nurses	Manage ADLA and its complications	Treat ADLA and its complications with appropriate antibiotics	Knowledge of basic principles of treatment and management of ADLA and complications
	Hospital, primary health care centre Community home-based care	Health care staff and community caregivers	Identify patients, manage ADLA and report activities	Visit patients regularly to identify attacks, treat ADLA with appropriate antibiotics, follow up patients*	Knowledge of basic principles of treatment and management of ADLA and complications
	Hospital, primary health care centre Community and family home-based care	Patients with ADLA	Prevent injuries and entry lesions that predispose to ADLA; recognize ADLA and seek appropriate treatment	Washing limbs, monitoring use of footwear, prompt treatment of injuries, ensuring rest during acute attacks	Knowledge of predisposing factors for ADLA and facilities available for treatment
Lymphoedema and elephantiasis	Hospital, primary health care centre	Doctors and nurses	Manage lymphoedema and its complications	Treat lymphoedema and its complications; consultation	Knowledge of basic principles of treatment and management of lymphoedema and complications
	Hospital, primary health care centre Community home-based care	Health care staff and community caregivers	Identify patients, manage lymphoedema and report activities	Visit patients regularly to identify lymphoedema, demonstrate basic principles of limb care to prevent progression, and supervise and follow up patients*	Knowledge of basic principles of prevention of progression of lymphoedema, communication skills
	Hospital, primary health care centre Community and family home-based care	Patients with lymphoedema	Introduce basic principles of hygiene, foot care, exercise and prevention of ADLA; ensure availability of clean water and soap	Washing limbs, monitoring use of footwear, prompt treatment of injuries, exercise, hygiene	Knowledge of basic principles of prevention of progression of lymphoedema, such as washing, foot care including use of footwear and simple exercises

Table 7. Activities and responsibilities in a minimum package of care for patients with lymphatic filariasis (Continued)

Disease manifestation	Delivery strategy	People involved	Responsibility	Action	Skills
Hydrocoele	Hospital, primary health care centre	Doctors and nurses	Perform safe hydrocoelelectomy	Treat ADLA and its complications with appropriate antibiotics	Knowledge of basic principles of treatment and management of ADLA and complications
		Health care staff	Identify patients, who require surgery, refer to hospital and report activities	Visit patients regularly to identify attacks, treat ADLA with appropriate antibiotics, follow up patients*	Knowledge of basic principles of treatment and management of ADLA and complications
		Hydrocoele patients	Accept hydrocoelelectomy	Visit hospital and undergo surgery	Awareness of signs and symptoms of hydrocoele, benefits of surgery, facilities available for treatment
		Informal caregivers	Identify patients who require hydrocoele surgery and refer them to hospital	Visit patients to motivate them to undergo surgery and for follow-up after surgery	Communicate features of the disease, benefits of surgery and facilities available

ADLA, acute dermatolymphangioadenitis

\*Individual recording and follow-up forms are provided in Annex 5.

Three types of delivery strategy can be used to manage ADLA and lymphedema: hospital- or primary health-based care, community home-based care and family home-based care. An algorithm to decide which delivery strategy to use for management of ADLA is shown in Annex 2, and an example of a home-based care delivery system for the management of lymphedema is given in Annex 4. Hydrocoele surgery can be performed only in a hospital.

#### Psychological support and socioeconomic rehabilitation

The psychological effects of lymphatic filariasis have been poorly recognized. Psychological support and socioeconomic rehabilitation are necessary to complement the medical and surgical care of patients so that they can achieve full integration into their community by overcoming the psychological consequences of stigma and shame. As the impairments and disability associated with lymphoedema and hydrocoele often lead to inability to work, these patients need assistance in finding suitable jobs. These activities are, however, often outside the remit of the staff of lymphatic filariasis programmes both nationally and in implementation units.

Setting up a psychological support and socioeconomic rehabilitation system also depends on the human and financial resources available. Even if such support is not available, other MMDP activities should not be delayed.

For psychological support, the following activities might be considered:

- Discuss the relevance of psychological support for patients with lymphoedema or hydrocoele and delivery strategies with health counsellors.
- Establish a referral system for patients to psychological support services.
- Decide which training materials are required for health care staff, community health workers and/or patients, and ensure that sufficient supplies are available.
- Organize training of health care staff and community health workers on providing appropriate psychological support, including how to refer patients to appropriate support services.
- Monitor and supervise health care staff and community health workers who are giving support.
- Decide how peer groups will be involved.
- Organize social mobilization on the potential psychological impact of the chronic complications of lymphatic filariasis.

For socioeconomic rehabilitation:

- Organize a social mobilization campaign to reduce the social stigma attached to lymphatic filariasis. Discuss social inclusion and income-generating activities with welfare or finance services.
- Assess the socioeconomic needs of patients.
- Provide preliminary social support to patients through the welfare service by integrating patients into existing income-generating activities.
- Assess the feasibility of introducing production of suitable footwear as an income-generating activity. The main aim is to achieve sustainability, in view of the high cost of footwear and the poverty of most patients.

### **District and community levels**

#### Management

District health facilities could serve as technical referral centres, provide access to treatment of complicated cases and provide expertise to communities; they may also give medical training and supervision to informal caregivers and conduct monitoring and evaluation activities. 'Lymphatic filariasis teams' of health staff could be formed in areas with a high burden of disease or many stakeholders.

A lymphatic filariasis committee could also be formed at the implementation unit or at peripheral level to strengthen the capacity of government staff to involve the community and implement activities. This would be particularly appropriate in areas where community home-based care is chosen as the management system. Programmes could also establish community teams with varied professional profiles interested in improving the status of lymphatic filariasis patients in their community. The stakeholders in the community involved in implementing and supervising MMDP activities are the same as those at national level.

If necessary, a situation analysis similar to that at national level could be completed at the implementation unit. The following steps could be taken:

- At the start of the programme, use the numbers of lymphoedema patients and patients with an enlarged scrotum estimated during the survey before mass drug administration.
- Refer patients with an enlarged scrotum to health workers for accurate diagnosis of hydrocoele or lymphoedema of the scrotum. Hydrocoele patients should be referred for surgery.
- Determine the geographical distribution of patients.
- Collect information on potential caregivers in order to form a managerial team, delivery strategy and referral system.
- Investigate the possibility of integrating some activities for the long-term management of lymphoedema with other home-based care activities.

### Training

In many implementation units, health care staff have been trained at national or subnational level and can organize training for other health staff and informal caregivers. The training cascade could be organized as follows:

- for trainers: training of district health and other government workers by professional trainers from national or subnational level;
- for informal caregivers: training of community health workers and informal caregivers by recently trained trainers; and
- for lymphoedema patients and their families: training by informal caregivers in the homes of patients.

For management of hydrocoele, national-level trainers can train level II physicians and surgeons identified by national and local health systems. Level II medical officers must be trained in diagnosis, evaluation of fitness for surgery and all aspects of surgery including local anaesthesia, postoperative care and follow-up.

### Implementation

This step involves setting up a follow-up system and other activities, such as social mobilization, lymphoedema management, hydrocoele surgery, psychological support and socioeconomic rehabilitation. The target populations for social

mobilization are selected in the implementation unit, which may use national materials and resources. The activities could be coordinated with similar activities of other programmes targeting behavioural change.

The choice of how lymphoedema management is to be delivered depends in part on the number and geographical spread of patients. The optimal number of patients that can be followed by an informal caregiver in a community home-based care programme has not been established. It can therefore be decided locally and reviewed later. In general, when there are more than five cases of chronic lymphoedema in a community or village, it is advisable to adopt community home-based care and follow-up by informal caregivers.

The steps in designing lymphoedema management by the lymphatic filariasis team are:

- Determine the number of patients with lymphoedema and their location in the community, and sensitize the community before preparing the work plan, taking care to estimate the required human resources, monitoring and drugs and supplies.
- Organize training in lymphoedema management, with emphasis on ADLA, for several government health and non-health workers at district level. Set up a referral system for managing clinical manifestations of different severity.
- Once training has been completed, people involved in follow-up will begin making monthly visits to lymphoedema patients, or the patients will begin coming to the health facilities for routine care.
- Organize monthly supervision until the health workers or informal caregivers can record data correctly on follow-up forms.
- Manage the supply of drugs for treatment of ADLA at the most peripheral health facilities. These include paracetamol, amoxicillin, penicillin G, erythromycin, penicillin V and antiseptic, antibacterial and antifungal creams.
- Collect reports from the informal caregivers and health centres, and summarize them on the forms in Annex 5 and Annex 7.
- Organize annual refresher courses for people involved in follow-up of lymphoedema management for optimal sustainability of activities.

Hydrocoelectomy should be made available at the most peripheral parts of the health care system and should be both easily accessible and affordable to the population:

- Determine the estimated numbers of hydrocoele patients from the mass drug administration team or the community. The lymphatic filariasis team could work with community leaders and informal caregivers to inform patients about the availability of hydrocoelectomy. Liaise with health authorities at the implementation unit to ascertain the most suitable treatment approach.

- Organize training of the hospital medical staff who will be in charge of hydrocoelelectomy, with a surgeon trainer and head of surgery. Also train informal caregivers if community home-based care is used for management or community leaders at the hospital, including follow-up of surgery for dressing and evaluation.
- Organize monitoring and reporting to the national programme manager according to national programme guidance.

Follow-up of hydrocoelelectomy can be included in follow-up of all surgical activities at the health facility. Hydrocoele patients can be followed up by completing the sample forms shown in Annex 5. For activities at community level (i.e. preparation of patients for surgery by teaching them hygiene measures), follow-up could be conducted by informal caregivers.

The national programme should prepare indicators to monitor and evaluate the progress of MMDP. At implementation unit level, informal caregivers could be asked to report to health centres, which would then report monthly to the implementation unit or the district lymphatic filariasis team reporting unit. This can be adapted to local capacity and needs.

### 3.3 Monitoring and evaluation

The GPELF *Progress report 2000–2010 and strategic plan 2011–2020* stated that the metrics for monitoring and evaluation were to be finalized by 2013 (2). This section provides the details of the metrics and the reporting mechanisms. The purpose of the plan is to measure objectively the success of the MMDP component of national programmes and of the GPELF.

#### 3.3.1 National monitoring and evaluation plan

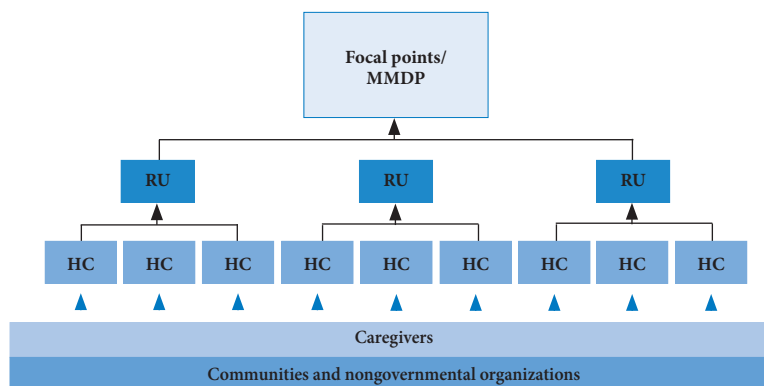
Monitoring involves routine collection of information on all aspects of a project. The monitoring indicators for lymphatic filariasis MMDP include the prevalence of lymphoedema and hydrocoele, programme coverage and health impact. Evaluation involves episodic assessment of changes in results. The national lymphatic filariasis programme should ensure that activities for MMDP are included in the monitoring and evaluation plan, including indicators, targets, reporting templates and systems and a plan for analysing and disseminating the results.



## Data collection and reporting

Each reporting unit (RU), either implementing unit or district health unit, is responsible for collecting all relevant data on forms designed for this purpose (Figures 8 and 9). Data that could be collected include the number of patients with ADLA or lymphoedema started on treatment and the number of patients who have undergone surgery for hydrocoele. Annex 5 gives examples of individual recording and follow-up forms for use by informal caregivers and a monitoring form to be used at health centre level. Care should be taken to ensure that the confidentiality of patient information is protected in accordance with prescribed national ethical guidelines.

Figure 8. Reporting by public health centres (HC) through reporting units (RU) to the focal point for morbidity management and disability prevention (MMDP) in a national programme to eliminate lymphatic filariasis



## Monitoring

Examples of indicators to measure programme coverage, lymphoedema and hydrocoele activities and impact are given below. If data are collected only once a year, '6-month period' can be changed to '12-month period'.

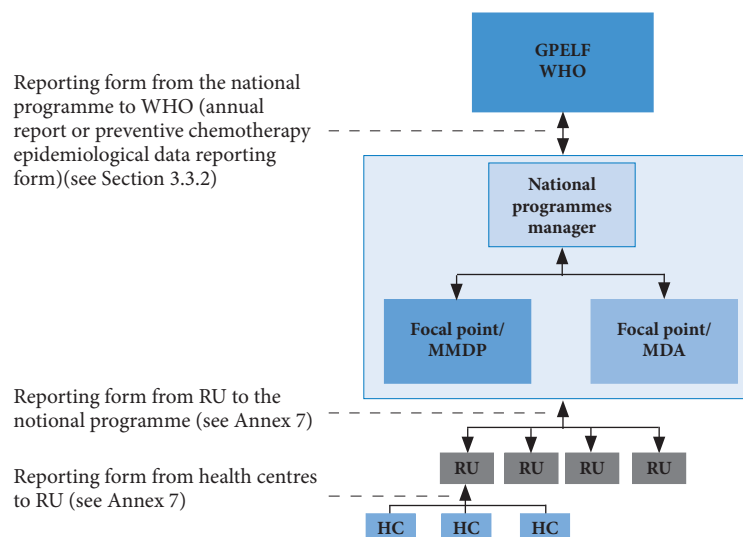
The indicators for monitoring effects on lymphoedema may include those for input and process, and impact.

### Input and process indicators

#### *Baseline data:*

- total number of patients with ADLA,
- total number of patients with lymphoedema and
- total number of patients with hydrocoele.

Figure 9. Reporting by reporting unit (RU) through the national focal point for morbidity management and disability prevention (MMDP) to the Global Programme to Eliminate Lymphatic Filariasis (GPELF)



HC, health centre; MDA, mass drug administration

*Input indicators:*

- total number of patients with ADLA who were treated,
- total number of patients with lymphoedema who were treated and
- total number of hydrocoele patients who were treated.

*Process indicators:*

- total number of visits by informal caregivers for the identification, treatment and follow-up of ADLA,
- total number of visits by patients to health centres for treatment and follow-up of ADLA and
- number of health workers trained.

The indicators\* for monitoring the quality of hydrocoelelectomies could include:

- number of patients with infection within 5 days of surgery,
- number of patients with haematoma within 5 days of surgery,
- number of patients who had a recurrence of hydrocoele after surgery and
- number of health facilities with a surgeon or medical doctor trained in hydrocoelelectomy.

\* When the actual number of patients (denominator) in an endemic area is known, percentages rather than numbers should be reported.

Coverage and outcome indicator: The aim of the programme is to manage morbidity and prevent disability in all patients living in all endemic areas of a country. The indicator is therefore the:

- geographical coverage, which is the proportion of endemic areas in which MMDP are implemented.

#### Impact indicators

Ideally, the programme would be assessed on the basis of an improvement of the quality of life of patients. As this is difficult to measure, the impact can be measured clinically and epidemiologically.

#### *Clinical indicators:*

- reduction in the number of cases of ADLA and
- reduction in the number of patients with hydrocoele who were treated.

Other benefits of the programme may be a reduction in the number of severe cases of lymphoedema or elephantiasis, a reduction in the size of the limbs, increased mobility, decreased disability or a general increase in the quality of life.

### **Evaluation**

Evaluation of these activities requires technical and financial resources. Therefore, the national programme might conduct evaluations in specific locations. For example, the national programme in coordination with staff in implementation units might prepare a sampling framework to evaluate hydrocoele patients throughout the country.

One measure of the success of a programme is the availability and accessibility of facilities staffed with trained health and community workers for the management of patients with ADLA, lymphoedema and hydrocoele. The availability of several facilities that can support patients with various forms of filariasis and various models of provision of care, with flexibility in the choice of facility and provider, would indicate that a programme has successfully expanded and been accepted. The extent to which programmes offer services based on the principles of management of lymphoedema to patients with other chronic diseases (diabetes, leprosy, podoconiosis and vascular insufficiency) in an integrated fashion would be another useful evaluation parameter.

National programmes could use these indicators to monitor and evaluate the progress of MMDP activities. Annex 6 provides an example of how an implementation unit might monitor and evaluate its activities at the level of the reporting unit. At this level, peripheral health centres send in reports, often monthly but more or less often, depending on local capacity and needs. The reporting unit then reports to the national programme semi-annually or annually. Examples of reporting forms from health centres to the reporting unit and from the reporting unit to the national programme are given in Annex 7.

The national programme compiles the reports on the impact of the MMDP component and combines the summary with reports on mass drug administration and post-mass drug administration surveillance in a dossier to be submitted for verification of the elimination of lymphatic filariasis.

### **3.3.2 Annual reporting to the Global Programme**

#### **Annual reporting**

National programmes should collect data on morbidity and disability regularly, once or twice a year, depending on the local disease burden and the available human resources. The Global Programme requires reporting of morbidity data either in the annual report or on the 'preventive chemotherapy epidemiological data reporting form' to WHO. Currently, the Programme captures the following information in the annual report and submits it to WHO through the regional programme review groups:

At national level:

- number of patients with lymphoedema,
- number of patients with lymphoedema included in activities in the previous 6 months,
- number of patients with lymphoedema treated,
- number of patients with hydrocoele,
- number of patients with hydrocoele treated and
- number of health workers trained.

At the level of implementation and reporting units:

- number of people examined for lymphoedema and the number and percentage with lymphoedema and
- number of people examined for hydrocoele and the number and percentage with hydrocoele.

#### **Verification of elimination of lymphatic filariasis**

National programmes should follow the procedures for verifying interruption of transmission outlined in the 2011 WHO manual *Monitoring and epidemiological assessment of mass drug administration in the global programme to eliminate lymphatic filariasis* (12). Even when lymphatic filariasis transmission has been interrupted and it is no longer a public health problem, with no new cases, national programmes should continue to MMDP in affected people by integrating these services into the public health system and strengthening rehabilitation.

Dossiers for verification of elimination should include the following information on filarial disease:

- a description of the filarial disease, including geographical distribution, prevalence and treatment for its various clinical manifestations;
- review of case management;
- review of any data on the impact of interventions; and
- review of case reports through routine disease surveillance or other systems for case detection.

Given that the aim of national programmes is to provide access to care for all cases of ADLA, lymphoedema and hydrocoele, evidence should be included to demonstrate that all patients have access to treatment for ADLA, to long-term care for lymphoedema and to surgery for hydrocoele.

As lymphoedema can also be caused by non-lymphatic filariasis factors, the number of new cases will be reduced to the background level when transmission is interrupted. However, there is no consensus on the background levels of lymphoedema in most countries endemic for lymphatic filariasis.

The MMDP component of a national programme to eliminate lymphatic filariasis will have attained its goal when full geographical coverage and access to the minimum package of care have been ensured. At the global level, this component will be considered complete only when 100% geographical coverage has been achieved in all previously endemic countries.





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# Annexes

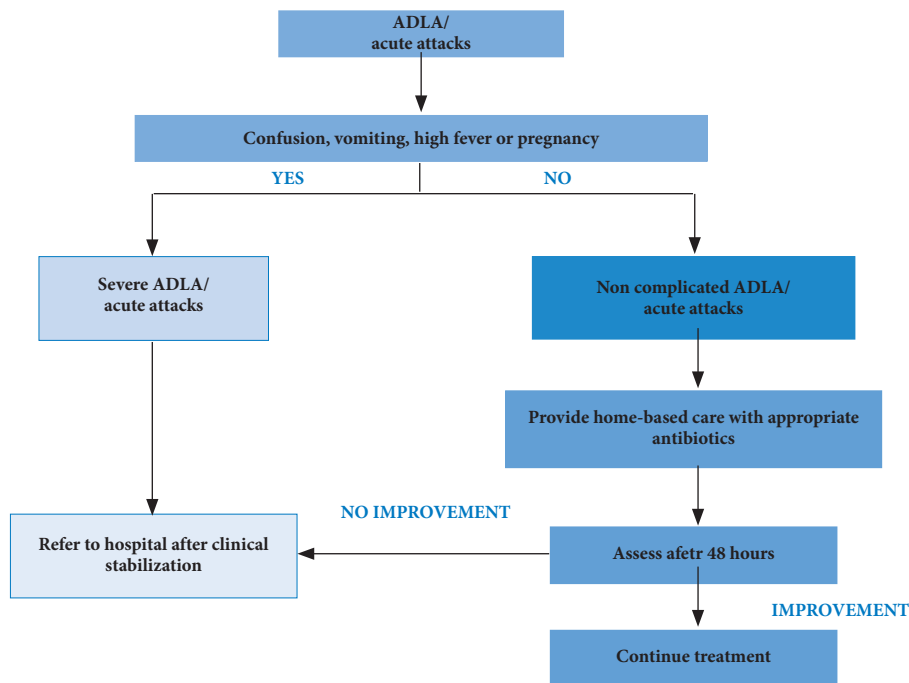
## Annex 1. Stages of lymphoedema and elephantiasis

Treatment	Stage 1	Stage 2	Stage 3	Stage 4	Stage 5	Stage 6	Stage 7
							
Hygiene (washing and drying)	Yes (ideally at night)	Yes (ideally at night)	Yes (ideally at night)	Yes (ideally at night)	Yes (twice a day if possible)	Yes (twice a day if possible)	Yes (twice a day if possible)
Care of entry lesions	If present	If present	If present	If present	If present	If present	If present
Exercise	Yes	Yes	Yes	Yes	If possible	If possible	If possible
Elevation	Usually not necessary	Day and night	Day and night	Day and night	Day and night	Day and night if possible	Day and night if possible
Compressive bandaging	Optional	Optional	Optional	Only when advised	Only when advised	Not advised in most cases	Not advised in most cases
Prophylactic creams	No	No	No	When necessary	Usually necessary	Always necessary	Always necessary
Prophylactic systemic antibiotics (send to doctor)	No	No	No	Usually not necessary	Usually necessary (if ADLA persists)	Always necessary	Always necessary
Plastic surgery	No	No	No	If medically indicated	If medically indicated	If medically indicated	If medically indicated

ADLA, acute dermatolymphangioadenitis

Source: *Lymphoedema staff manual: treatment and prevention of problems associated with lymphatic filariasis* [Part 1. Learner's guide]. Geneva, World Health Organization, 2001.

## Annex 2. Algorithm for deciding on the management of acute dermatolymphangioadenitis (ADLA)



Source: Modified from *Informal consultation on preventing disability from lymphatic filariasis*, WHO, Geneva, August 2006 (5). *Weekly Epidemiological Record*, 2006, 40:373-383.

### Annex 3. Information to be collected for a situation analysis

#### General demographic information

Information required	Purpose
When is the rainy season?	To decide when to intensify disability control because of increased risk of ADLA due to interdigital lesions in this period
What are the main religion and the culture? Are there indigenous populations or special groups in the community?	To adapt social mobilization messages and facilitate community mobilization To develop appropriate information, education and communication materials and messages
What languages are spoken?	To translate technical forms and training guidelines
How populated is the intervention unit?	To select an appropriate number of informal caregivers and assess transport needs
Is clean water readily available?	To ensure clean water for washing affected limbs or, if clean water is not available, to improve access to clean water
What means of communication are used by the population?	To use the most appropriate methods for getting messages to the community in a social mobilization campaign
What type of education system is in place?	To adapt the health education material
What is the economic status?	To assess whether families could buy a washing kit (soap and a cloth) To assess whether families could contribute to the cost of surgery To assess the ability of the community to support informal caregivers
What outside funding sources are available?	To initiate and support programme activities
Are there companies that employ local workers with clinical manifestations of lymphatic filariasis?	To set up partnerships to support programme activities

#### Community organization information

Information required	Purpose
Who are the most powerful and influential people in the community?	To include these people as focal points to advocate for support for MMDP
Which health and social welfare staff are working in the community?	To use these staff to answer questions and form part of the stakeholder group
Which are the most prominent social organizations in the community?	To take these into account in establishing workers' responsibilities
Are there taboos and stigma concerning patients with lymphoedema or hydrocoele?	To address such barriers in social mobilization messages
What disability prevention activities already exist in the community (under the ministry of health, local nongovernmental organizations, associations)?	To involve these organizations as stakeholders and in community-based home care as technical coordinators or supervisors
Is there an existing coordination or collaboration framework for disability prevention?	To adapt the framework for lymphatic filariasis programme activities

### Health and social welfare information

Information required	Purpose
How accessible are the health facilities in the implementation unit? What is their geographical distribution?	To set up a feasible referral system
How many health staff are there? How are they distributed? What are their competences and motivation?	To plan management of technical training and supervision
What and how much equipment and materials are available? What is the quality of the equipment?	To plan what resources are necessary to provide treatment for ADLA and surgery for hydrocoele
What are the locations and distribution of existing social welfare structures, systems and programmes?	To determine where in the broad health and social framework to best integrate or scale up activities
Where are the educational facilities?	To use these facilities in a network for social mobilization and health education
Are community-based services already available?	To potentially adapt these services for the lymphatic filariasis programme
How many potential informal caregivers (voluntary, non-health personnel) are there? Where are they?	To determine which lymphoedema management delivery strategy is most feasible
How many traditional practitioners are there? Where are they? Do they treat lymphoedema or hydrocoele? involve them in programme activities	To determine whether traditional healers are an important source of care for lymphoedema and hydrocoele patients, and, if so, how to

ADLA, acute dermatolymphangioadenitis

#### Annex 4. Example of steps for home-based management of lymphoedema and elephantiasis

Three types of home-based management of lymphoedema and elephantiasis have been recognized. These include: (i) family home-based care, which involves a family member in training, follow-up and monitoring of the lymphoedema patient; (ii) community home-based care, which can be integrated with services that include care of patients with other chronic diseases such as leprosy, diabetes and neurological disorders; and (iii) primary health care system, in which prevention of disability is an integral part of the primary health care system.

The choice of system for managing lymphoedema and elephantiasis must ensure effective, efficient programme implementation and sustainability and follow-up of patients. The type of system is determined by the number and distribution of patients in the area, their social grouping and the awareness and support of the community, which depend on the setting.

The optimal number of patients who can be followed up by an informal caregiver in a community home-based care programme has not been established. The number suggested in this document is five patients; however, this number can be adapted to the local situation and reviewed over time. Thus, when there are more than five cases of chronic lymphoedema or elephantiasis per community, it is advisable to adopt community home-based care, follow-up and monitoring. When there are fewer than five cases, family home-based, community home-based or primary health centre-based care can be considered.

The steps in planning home-based management of lymphoedema under the responsibility of the lymphatic filariasis team are:

1. Determine the number of patients and their location in the community.
2. Sensitize the community and hold discussions with key figures to establish their tasks. While the lymphatic filariasis team coordinates, monitors and supervises the programme, the medical staff in the implementation unit runs the programme.
3. Set up the follow-up system (family or community home-based), and select the workers to be involved.
4. Hold monthly coordination meetings with medical staff and other caregivers, establish a quarterly reporting system, supervise technical and managerial issues and monitor.
5. Register the patients to be included with the help of the community.
6. Estimate the human resources and drugs and supplies required on the basis of the estimated number of patients and their geographical distribution:
  - Ascertain the number of patients to be followed by each caregiver.
  - Ascertain the distribution of patients per health facility.
  - Calculate the number of monitoring forms required per month and year and the number of training manuals.
  - Ascertain the means of transport required for supervision and monitoring
7. Organize meetings with people involved in supervision to discuss the screening of new patients.
8. Organize a training cascade in lymphoedema and elephantiasis management, with emphasis on acute dermatolymphangioadenitis (ADLA) management for several government health and non-health workers in the district. Set up a referral system for managing clinical manifestations of different severity. In areas where community-based management has been chosen, train informal caregivers in teaching the principles of home-based self-care to patients and their relatives, friends or neighbours. When management in primary health care centres has been chosen, government health and non-health workers will train the patients.

9. Once training has been completed, people involved in follow-up will begin monthly visits to patients to: disseminate messages on the prevention and alleviation of disability, involve patients' relatives, friends and neighbours, and maintain patients' commitment for maximum sustainability.
10. Organize monthly supervision until the health workers or informal caregivers can record data correctly on the follow-up forms. From then on, supervision can be conducted every 2 or 3 months by the community team in the case of community-based management or by the lymphatic filariasis team and health staff where family or primary health care management systems are used. This will ensure not only correct recording but also the commitment of those involved in follow-up for maximum sustainability.
11. Manage the supply of drugs for treating ADLA at the most peripheral health facilities, e.g. paracetamol and antiseptic, antibacterial and antifungal creams.
12. Collect reports from informal caregivers and health centres (Annex 5) and summarize them on a form such as that in Annex 7. Submit reports regularly to the national programme manager, usually every 6 or 12 months, as defined by the national programme.
13. Organize an annual refresher course for people involved in following up lymphoedema management for optimal sustainability of activities.




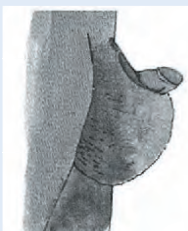


## Annex 5. Individual recording, follow-up and monitoring forms for informal caregivers

### Example of individual recording form for informal caregivers

Tick the box on the form that corresponds to the affected part of the body on the drawings, and, in the case of limbs and breasts, tick the box to indicate whether it is the right or left side that is affected. In the case of acute attack, hydrocoele, wounds and referral to a primary health care unit, tick 'Yes' or 'No'.

In the case of acute attack, the 'Yes' box refers to the current month and the 'No' box to a previous period. For example, if you are visiting a patient on 22 February and the patient had an acute attack on 10 February, you will tick 'Yes' because the attack occurred fewer than 30 days ago; if the patient had an acute attack in December, you will tick 'No' because the attack occurred more than 30 days ago.

Informal caregiver's name _____				Date (DD/MM/YYYY) _____
Village _____		Street _____		
Patient's name _____		Sex _____	Date of birth (DD/MM/YYYY) _____	
Please circle the affected part of the body below.				
Leg	Arm	Breast	Swelling of scrotum	ADLA in previous month
				Yes
				No

ADLA, acute dermatolymphangioadenitis

Source: Modified from *Training module on community home-based prevention of disability due to lymphatic filariasis. Tutor's guide*. Geneva, World Health Organization, 2003.

### Example of individual follow-up form to be used by informal caregivers to report to the health centre

This form charts patients' progress from the first visit and allows informal caregivers to advise and counsel them and their carers. The form covers visits over 1 year. Each patient must be followed up monthly to determine whether:

- any episodes of ADLA have occurred and how many within 1 month;
- there have been any wounds or skin damage;
- there has been any swelling;
- the condition has improved;
- the advice you gave on self-care to prevent pain and disability has been followed and was effective; and
- referral to a primary health care unit is necessary.

Date _____																								
	Visit1		Visit2		Visit3		Visit4		Visit5		Visit6		Visit7		Visit8		Visit9		Visit10		Visit11		Visit12	
	L	R	L	R	L	R	L	R	L	R	L	R	L	R	L	R	L	R	L	R	L	R	L	R
Leg																								
Arm																								
Breast																								
	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N
Acute attack																								
Hydrocoele																								
Wounds																								
Patients																								

L, left; R, right; Y, yes; N, no.

Source: Modified from *Training module on community home-based prevention of disability due to lymphatic filariasis. Learner's guide*. Geneva, World Health Organization, 2003.

### Example of monitoring form for health centre (every 6 months)

Name of health centre					
Name of informal caregiver					
Date of monitoring (dd/mm/yy)					
Number of lymphoedema patients in informal caregiver's area					
Number of lymphoedema patients included in the activities in the previous 6 months					
Number of hydrocoele patients in informal caregiver's area					
Number of hydrocoelectomies in the previous 6 months					
Name of patient	Number of visits made in previous 6 months	Number of ADLA in previous 6 months	Number of interdigital lesions in previous 6 months	Number of referrals by informal caregiver	Number of hydrocoelectomies in previous 6 months

## Annex 6. Example of monitoring and evaluation at reporting unit level

During the previous mass drug administration, 364 cases of lymphoedema or elephantiasis cases and 1050 cases of hydrocoele were found in the implementation unit.

### Lymphoedema and elephantiasis

The 364 patients with lymphoedema were included in MMDP activities. As there were more than five cases in each community, the team chose the community-based follow-up system. In January, the team trained 30 informal caregivers, who were each responsible for following up approximately 12 patients monthly. They were also asked to report on their activities every 6 months, using the forms in Annex 7.

In June, the activities were monitored for the first time by 28 informal caregivers. One asked permission to conduct the monitoring in July, for family reasons; the other had ceased acting as informal caregivers in April, and the district manager is recruiting a new informal caregiver for this village.

The data collected during monitoring by the 28 informal caregivers were as follows:

- 310 of the 340 patients followed-up by the 28 informal caregivers were visited.
- 1502 visits were made in the previous 6 months to the 310 patients, out of 1860 possible visits.
- 65 episodes of acute dermatolymphangioadenitis (ADLA) were reported in the previous 6 months.
- Data on interdigital lesions were not collected for 250 of the 310 patients.

Analysis of the data gave the following results:

#### *Programme coverage:*

The percentage of lymphoedema patients included in management activities:

$$\frac{364}{364} \times 100 = 100\%$$

#### *Monitoring coverage:*

The percentage of lymphoedema patients monitored:

$$\frac{310}{364} \times 100 = 84\%$$

Total number of visits per patient:

$$\frac{1052}{310} \times 100 = 4.84$$

Out of a maximum of six possible visits per patient:

$$\frac{4.84}{6.00} \times 100 = 80.7\%$$

#### *Frequency of ADLA episodes:*

Average number of episodes per patient:

$$\frac{65}{310} = 0.21$$

### **Hydrocoele**

During the previous 6 months, 90 hydrocoelelectomies were performed in the district hospital, with only one case of local infection.

#### *Programme coverage:*

The percentage of lymphoedema patients included in management activities:

$$\frac{90}{1050} \times 100 = 8.5\%$$

Quality of surgery (in infection rate):

$$\frac{1}{90} \times 100 = 1.1\%$$

### **Conclusions**

The programme and monitoring coverage for lymphoedema show that the activities were well conducted. No adaptation of the activities is required, except for training potential informal caregivers to replace those who have abandoned their work. The results with regard to the number of ADLA episodes per patient should be compared with the baseline number (before treatment) and with the results of future monitoring.

The programme coverage for hydrocoele patients was low, although the quality of surgery appears to be appropriate. The programme could investigate how to increase access to surgery, such as at special field sessions.

## Annex 7. Examples of reporting form from health centres to reporting units and from reporting units to national level

### From health centre to reporting unit (every 6 months)

Name of reporting unit			
Name of health centre			
Date of monitoring (dd/mm/yy)			
Number of lymphoedema patients in health centre			
Number of lymphoedema patients included in activities in previous 6 months			
Number of hydrocoele patients in health centre			
Number of hydrocoelelectomies in previous 6 months			
Name of informal caregiver	Number of visits to lymphoedema patients made in previous 6 months	Total number of acute attacks in lymphoedema patients in previous 6 months	Number of hydrocoelelectomies in previous 6 months

### From reporting unit to national level (every 6 months)

Name of reporting unit			
Date of reporting (dd/mm/yy)			
Number of lymphoedema patients in reporting unit			
Number of lymphoedema patients included in activities in previous 6 months			
Number of hydrocoele patients in reporting unit			
Number of hydrocoelelectomies conducted in reporting unit in previous 6 months			
Name of health centre	Total number of visits to lymphoedema patients made in previous 6 months	Total number of acute attacks in lymphoedema patients in previous 6 months	Number of hydrocoelelectomies in previous 6 months

A significant proportion of the public health problem represented by lymphatic filariasis is due to impairment and disability related to lymphoedema (elephantiasis) and hydrocoele. Therefore, national programmes must focus on managing morbidity and preventing disability. These activities will not only help lymphatic filariasis patients but can improve coverage with drugs.

Management of morbidity and disability in lymphatic filariasis require a broad strategy involving both secondary and tertiary prevention. Secondary prevention includes simple hygiene measures, such as basic skin care, to prevent acute dermatolymphangioadenitis and progression of lymphoedema to elephantiasis. For management of hydrocoele, surgery may be appropriate. Tertiary prevention includes 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. Activities beyond medical care and rehabilitation include 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. The activities can also include education of families and communities, to help patients with lymphatic filariasis to fulfil their roles in society. Thus, vocational training and appropriate psychological support may be necessary for overcoming the depression and economic loss associated with the disease.

Morbidity management and disability prevention must be continued in endemic communities after mass drug administration has stopped and after surveillance and verification of interruption of transmission, as chronically affected patients are likely to remain in these communities.

