

Basic Psychological Support for Persons Affected by Neglected Tropical Diseases (BPS-N)



COALITION FOR
OPERATIONAL
RESEARCH ON
NEGLECTED
TROPICAL
DISEASES



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Basic Psychological Support for Neglected Tropical Diseases

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The Basic Psychological Support for neglected tropical diseases (NTDs) guide (BPS-N) has been adapted from the Psychological First Aid: Guide for field workers (World Health Organization, War Trauma Foundation, World Vision International, 2011). Authorisation to adapt and translate into Hindi the 'Psychological First Aid: Guide for field workers' document was granted by the Translation & Licensing Department of the WHO.

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Disclaimer

The Basic Psychological Support for NTDs guide has been prepared for use by health workers, volunteers and others involved in supporting persons living with physical and/or psychosocial consequences of NTDs. It is not intended to be a substitute for professional medical or psychological advice or treatment for specific medical or psychological conditions. The advice of a physician/psychologist/psychiatrist may need to be taken when the advice offered in this guide is not sufficient or does not lead to improvement.

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FOREWORD

Neglected tropical diseases (NTDs) have a significant impact on the wellbeing of those affected, their family, community members and the health workers treating people with NTD-related disabilities.

This guide focuses on Basic Psychological Support, which involves humane, supportive and practical help for persons suffering from the chronic effects of NTDs. It is written for people who can help others.

This guide, the Basic Psychological Support for persons affected by NTDs (BPS-N) is an adaptation of the Psychological First Aid: Guide for field workers (World Health Organization, War Trauma Foundation, World Vision International, 2011). It has been adapted to better respond to the challenges associated with the mental health consequences of NTDs. NTDs pose specific problems for affected people (e.g., disabilities, stigmatisation, isolation, fear, and possible abandonment), their caregivers and responders (e.g., access to updated information).

Psychological First Aid has been recommended by many expert groups, including the Inter-Agency Standing Committee (IASC) and the Sphere Project. In 2009, the World Health Organization's (WHO) mental health Gap Action Programme (mhGAP) Guideline Development Group evaluated the evidence for Psychological First Aid and psychological debriefing. It concluded that Psychological First Aid, rather than psychological debriefing, should be offered to people in severe distress following recent exposure to a traumatic event.

Internationally, the interest in promoting the mental wellbeing of persons with chronic diseases is increasing. The BPS-N guide fits into this with a focus on persons living the chronic consequences of NTDs.

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INTRODUCTION

UNDERSTANDING NEGLECTED TROPICAL DISEASES



IN THIS CHAPTER WE DISCUSS:

- What are neglected tropical diseases (NTDs)?
- What is mental health?
- What is leprosy?
- What is lymphatic filariasis?
- What is COVID-19 and how is it relevant to the care of persons affected by NTDs?



WHAT ARE NEGLECTED TROPICAL DISEASES (NTDs)?

NTDs are a group of 20 different diseases that occur in many countries around the world. They are called neglected diseases because despite the high burden they cause to affected people and society, the different stakeholders have not given much priority to fighting these diseases. As many as one out of every 7 persons in the world may be suffering from one or more NTDs. NTDs mainly affect the world's poorest people, who live in hard-to-reach areas or rural and urban areas where access to safe water, sanitation, and essential medicines is lacking.

NTDs can cause severe pain and long-term disability. The stigma and social exclusion faced by people affected by NTDs makes it difficult for children to learn and develop to their full potential, and for adults to work and support their families. Consequently, NTDs can have a negative effect on their mental wellbeing. This guide explains how to help persons whose mental wellbeing is affected as a consequence of having (had) an NTD.

WHO ARE AT RISK OF CONTRACTING NTDs?

- ▶ All people in endemic areas are poor and/or disadvantaged but particularly women or people with certain ethnic backgrounds
- ▶ Highly marginalised groups of individuals who have little or no opportunity to speak up for themselves
- ▶ People who live in crowded and poor hygienic circumstances, especially those with no or poor access to clean water, sanitation and hygiene facilities
- ▶ Most (though not all) people get infected by NTDs through direct contact with an untreated patient (e.g., leprosy), through an insect, such as a mosquito bite (e.g. lymphatic filariasis), or through parasites, like worms in the soil, in polluted water or in food that has not been sufficiently cooked. Therefore, people who have been in close contact with untreated patients, who live in areas where mosquitos, other insects or animals are infected, or who do not have access to clean water and properly prepared food and/or who walk barefoot in fields are most at risk

WHAT IS MENTAL HEALTH?

Mental health is the aspect of health that concerns our mind. If you have good mental health, you are able to do what you need to do, you can cope with the normal stresses of life, you can work well and you can contribute to your family and community as fits with your role and position. People affected by NTDs often have poorer mental health than healthy people .



WHAT IS LEPROSY?

Leprosy is a disease caused by a bacterium called *Mycobacterium leprae*. Leprosy affects the nerves of the face, arms and legs, the skin, and the inside of the nose and throat. It may therefore cause long-term consequences such as disabilities of eyes, hands and feet. Leprosy is also known as Hansen's disease.



HOW DOES LEPROSY SPREAD?

The leprosy bacterium spreads through droplets in the air that come from the nose or throat of a person with the infection who has not yet started treatment. This usually happens when a person with leprosy sneezes or coughs. The disease is contagious, but only very few of the infected contacts will develop leprosy. Others have a natural ability to get rid of the bacteria from the body without illness. The time between when someone is infected and the appearance of the first symptoms is very long: around 5 years.

SIGNS, SYMPTOMS AND COURSE OF ILLNESS

You should think of the possibility of leprosy if a person shows the following signs and symptoms:

- ▶▶ Loss or decrease of the feeling of touch on a skin patch; such a patch is often light coloured.
- ▶▶ Numbness or tingling of the hands or feet
- ▶▶ Weakness of the hands, feet or eyelids
- ▶▶ Painful or tender nerves
- ▶▶ Swelling or lumps in the face or earlobes
- ▶▶ Painless wounds or burns on the hands or feet

If you notice any of the above signs or symptoms in a person, please refer them to a Primary Health Centre (PHC) or appropriate health facility to get a Medical Officer or health worker with leprosy training to check whether they may have leprosy.

Leprosy causes damage to the nerves, which leads to loss of sensation in patches and hands and feet and to muscle weakness. If it is not treated, it may lead to severe disfigurement and significant disability.

DIAGNOSIS

Leprosy is diagnosed through a physical examination carried out by a trained health worker. If available, a lab examination called a skin smear may also be conducted. This may help to confirm the diagnosis.

PHYSICAL EXAMINATION INCLUDES THE FOLLOWING STEPS

- »» A thorough inspection of the body surface (skin)
- »» Testing the sensation in one or more skin lesions
- »» Palpation (touching with hands to feel) of the nerves that are often damaged by leprosy
- »» Testing sensation and muscle strength in the face, hands and feet

TREATMENT

Leprosy is curable. Until now, more than 16 million leprosy patients have been cured. The World Health Organization (WHO) provides free treatment for all patients with leprosy. The treatment contains several antibiotics given together and is called multi-drug therapy (MDT). The type of treatment given to patients depends on the type of leprosy they have.

There are two types of leprosy: paucibacillary (PB) and multibacillary (MB). MB leprosy is more severe and therefore needs longer treatment.

- »» Patients with PB leprosy are treated with multidrug therapy (MDT) blisterpacks including 2 antibiotic drugs namely rifampicin and dapsone, both of which are antibiotics. Treatment usually lasts for about 6 months
- »» Patients with MB leprosy are treated with MDT blisterpacks including 3 antibiotic drugs namely rifampicin, dapsone and clofazimine. Treatment usually lasts for about 12 months

COMPLICATIONS

Before, during or after treatment with MDT, leprosy patients may get a so-called 'Lepra reaction': a sudden worsening of symptoms and signs in the eyes, skin or arms and legs. New skin lesions can also appear. The following are possible signs and symptoms of a leprosy reaction:

- »» Redness and/or pain in the eyes; inability to close the eyes properly
- »» Loss of feeling and or muscle weakness in hands or feet
- »» Pain or tenderness on touch in one or more nerves
- »» A red, swollen skin patch
- »» Skin lesions with wounds
- »» Pain and/or swelling of the face, hands or feet
- »» Pain and swelling of testes/scrotum

Reactions and nerve damage can lead to severe damage and disfigurements of eyes, hands and feet if not treated quickly and looked after with care.

WHAT IS SELF-CARE FOR LEPROSY AND WHY IS IT IMPORTANT?

Self-care is the care of affected body parts, such as eyes, hands or feet, by the affected person themselves to prevent further damage and disability. Self-care is needed when the patient loses feeling in hands, and/or feet, and/or experiences weakness in muscles of hands or feet, or when they develop ulceration of extremities, including earlobes. Some patients develop eye problems like inability to close the eyes, loss of blinking, early onset of cataract, and even loss of vision. Self-care carried out by persons affected by leprosy often consists of the following:

- ▶▶ Soaking of the hands and/or feet for 15-30 minutes in normal water
- ▶▶ Applying non-smelling oil or Vaseline to the skin of hands and feet while they are wet
- ▶▶ Protecting hands and feet against heat and friction
- ▶▶ Using special footwear with soft insoles and walking slowly with short steps if a person has a loss of feeling in the feet
- ▶▶ Cleaning of wounds with soap and water and dressing them with a clean cloth
- ▶▶ Checking eyes daily using a mirror for eye discharge, redness or incomplete closure of eyes
- ▶▶ Protecting eyes during sleep with a moist cloth if eyelids do not close completely
- ▶▶ Sunglasses should be worn outside during the day

Activities beyond medical care and prevention of disabilities include promoting positive attitudes towards people with disabilities, providing education and training and supporting income-generating schemes.



WHAT SHOULD THE COMMUNITY KNOW ABOUT LEPROSY?

It is important that the messages about leprosy are simple, clear, and positive to help dispel the fear of the disease, misconceptions and myths.

- ▶▶ Leprosy is caused by a germ (a bacterium called *Mycobacterium leprae*). It is neither hereditary nor a curse or caused by bad karma or fate
- ▶▶ Leprosy does not spread by touch
- ▶▶ Leprosy can be easily diagnosed from clinical features alone by a trained health worker
- ▶▶ A combination of antibiotics, called multi-drug therapy (MDT) kills the germs and stops the spread of bacilli after the first dose
- ▶▶ MDT is available free of cost at all health facilities
- ▶▶ Patients on MDT and who have completed MDT do not spread bacilli anymore, even if they still have skin patches or disabilities
- ▶▶ Early and regular treatment prevents impairment
- ▶▶ Patients can lead completely normal lives during and after their treatment



WHAT IS LYMPHATIC FILARIASIS?

Lymphatic filariasis, popularly known as elephantiasis or LF, is an infectious disease caused by parasitic worms (in India commonly by *Wuchereria bancrofti*; and *Brugia malayi* in certain pockets) and spread by mosquitos. Infection usually happens in childhood, but signs and symptoms only occur in late childhood and early adulthood. LF affects all age groups. If LF is left untreated or diagnosed late, LF can cause severe disabilities.



SIGNS, SYMPTOMS AND COURSE OF ILLNESS

Visible signs are enlargement of the limbs (arms and/or legs) and/or genitals (scrotum, breast and very rarely female genitals), which progress slowly. The adult worms live in the lymph vessels and cause dilatation of lymph vessels and dysfunction. This causes swelling of limbs and genitals known as lymphedema. In advanced stages this is called elephantiasis. The swelling of the scrotum is called hydrocele. Severe lymphoedema can cause several folds in the skin that can be shallow or deep. The skin also develops knobs and cracks and becomes hard in advanced stages. Disabling acute attacks often occur where increased swelling of the affected limb, swelling of glands and generally feeling ill can affect untreated patients for periods up to a week, and reoccur again.

HOW DOES LYMPHATIC FILARIASIS SPREAD?

LF is spread by mosquitos. When a mosquito bites a person who has LF, and who has not yet been treated with anthelmintic agents, microscopic worms (microfilariae) in the person's blood enter and infect the mosquito. When a mosquito with the infective worm bites another person, these worms enter the lymph system where they grow into adult worms. It cannot spread directly from person to person.

DIAGNOSIS

Most patients with LF are diagnosed only after the symptoms of the disease become visible, such as swollen limbs or body parts, by when the disease may be at an advanced stage.

TREATMENT AND PREVENTION

Three drugs are used to treat LF and prevent further spread: albendazole, ivermectin and DEC. Instead of only treating patients with symptoms, a combination of 2 or 3 drugs is given to all people in communities where cases of LF are found. This is called mass drug administration (MDA). MDA is effective to kill the microfilariae so that the person cannot infect mosquitos and thus cannot pass on the infection to others. MDA must be given annually until the adult worms die naturally (this may take 5 to 6 years). Hydrocele can be treated and cured with a surgical operation.

COMPLICATIONS

Persons with LF who have swollen limbs (or other parts of the body) often develop skin damage in the form of small wounds, blisters, minor cuts, scratches, etc. These breaks in the skin are like open doors through which dirt and germs can enter, causing an infection that can be very serious. This can cause a so-called 'acute attack'. These 'acute attacks' are the most frequent signs of LF and play an essential role in the progression of lymphoedema. An acute attack usually causes local pain and swelling and also fever and chills. Many people cannot work during an acute attack.

WHAT IS SELF-CARE FOR LYMPHATIC FILARIASIS AND WHY IS IT IMPORTANT?

Self-care in LF is often called morbidity management and disability prevention (MMDP). This includes simple hygiene measures, such as washing the swollen leg with water and soap, exercises, massage and elevation of the limb. This prevents acute attacks and progression of lymphoedema to elephantiasis. Additionally, more severe stages of hydrocele are managed through surgery. Activities beyond medical care and MMDP include promoting positive attitudes towards people with disabilities, preventing the causes of disabilities, providing education and training and supporting income-generating schemes.

WHAT SHOULD THE COMMUNITY KNOW ABOUT LYMPHATIC FILARIASIS?

It is important that the messages to the community are simple, clear, and positive to help dispel the fear of the disease, misconceptions and myths.

- ▶▶ LF is caused by a parasitic worm. It is neither hereditary nor a curse and caused by bad karma or fate
- ▶▶ LF does not spread by touch, but through the bite of an infected mosquito. Mosquitos become infected by biting someone with untreated LF
- ▶▶ Advanced LF can be diagnosed based on clinical signs by a trained health worker or at an early stage with a simple blood test
- ▶▶ A combination of anthelmintic drugs often given to all members of the community where LF is prevalent as mass drug administration (MDA) kills the baby worms and stops the spread of the worms

- ▶▶ MDA is provided free of charge by the government and is usually given once a year during a campaign
- ▶▶ Early treatment prevents impairment
- ▶▶ Persons with lymphoedema can lead completely normal lives



WHAT IS COVID-19 AND HOW IS IT RELEVANT TO THE CARE OF PERSONS AFFECTED BY NTDs?

COVID-19 means coronavirus disease 2019. It was first detected in China in late 2019 and has since spread all over the world.

SYMPTOMS

A person who becomes infected, within 2-14 days may get some of the following symptoms: 1] fever or chills, 2] cough, 3] shortness of breath or difficulty breathing, 4] feeling tired, 5] muscle or body aches, 6] headache, 7] loss of taste or smell, 8] sore throat, 9] blocked or runny nose, 10] nausea or vomiting, and 11] diarrhoea.

METHODS OF TRANSMISSION

It mainly spreads from person-to-person between people who are in close contact with one another (within about 6 feet). The virus is spread mostly through droplets produced when an infected person coughs, sneezes, or talks. These droplets can enter the mouth or nose of the nearby people and can enter the lungs. COVID-19 can also be spread by people who are not showing symptoms. Sometimes it may spread by touching a surface or object that has the virus on it and then touching your mouth, nose, or eyes.

METHODS OF PREVENTION

Everyone should fully follow these preventive methods:

1. Wash hands (frequently) with soap and water, or sanitiser (with minimum 60% alcohol); soap and water is better. Some common times for washing hands should be: before eating or preparing food; before touching face; after using the restroom; after leaving a public place; after blowing nose, coughing, or sneezing; after handling your face mask; after changing a diaper; after caring for someone sick; and after touching animals or pets
2. Do not touch eyes, nose, and mouth with unwashed hands
3. When you need to cough or sneeze, cover your mouth and nose with your elbow, not with your hand
4. Avoid close contact and maintain a physical distance of at least 6 feet from a sick person at the home and outside home, from all persons
5. Use a mask covering mouth and nose; always when outside home; the physical distance is still to be maintained along with wearing a face mask

RELEVANCE TO THE CARE OF PERSONS AFFECTED BY NTDs

1. A person with a NTD may also be exposed to a symptomatic or asymptomatic COVID-19 case
2. S/he may have a disability which prevents him/her from practising hygiene and care for wounds
3. S/he may be on medication for the NTD, and the stock of medicines may have run out
4. S/he may have poor health and immunity
5. S/he is often stigmatised and, as a result, has poor access to sources of information and health care
6. S/he may be further marginalised and neglected by the family and community because of COVID-induced financial or other problems
7. S/he may be even more mentally stressed and depressed

ADVICE FOR INDIVIDUALS AND FAMILIES IN COVID-19 AFFECTED AREAS

Early detection increases the chance of survival for the person and prevents the spread of disease to others.

- ▶▶ If you suspect a family member or someone in the community of having COVID-19, encourage and support them in seeking appropriate medical attention at the nearest health centre
- ▶▶ If you have contact with a person suspected of or confirmed to have COVID-19, immediately contact the hospital/health worker in the area
- ▶▶ If you have travelled to a place known to have COVID-19 patients and if you develop any of the symptoms described above, you should immediately contact the hospital/health worker in the area
- ▶▶ Please do not go to crowded places and also do not crowd together with people especially for snacks, coffee and lunch
- ▶▶ Peer supporters¹ and health care workers should use personal protective equipment and observe infection prevention and control measures. Personal protective equipment includes face masks, face shields, gloves and anything else prescribed by your government
- ▶▶ Guide/counsel the family in the practice of COVID-19 prevention measures, and not panic
- ▶▶ Find out about the supply of basic needs and medicines and mobilise support
- ▶▶ If someone in your community has recovered from COVID-19, ask this person to help. It is not sure to what extent persons who have recovered from COVID-19 remain susceptible to COVID-19. You should not assume that someone who has been sick with COVID-19 cannot be reinfected



¹ Peer supporters would typically be people who are themselves affected by NTDs who will use the BPS-N guide to support others who show signs of mental distress.

CHAPTER 1

UNDERSTANDING BASIC PSYCHOLOGICAL SUPPORT



1 UNDERSTANDING BASIC PSYCHOLOGICAL SUPPORT

In this chapter we discuss:

- 1.1 How do chronic consequences of NTDs affect people?
- 1.2 What is Basic Psychological Support?
- 1.3 BPS-N: who, when and where?



1.1 HOW DO CHRONIC CONSEQUENCES OF NTDs AFFECT PEOPLE?

Persons affected by NTDs often face difficulties in their day-to-day life that are related to being poor or not having access to safe water, health care, etc. In addition, there are three things that can have a major negative effect on someone’s mental wellbeing, the way they function in their families and communities and on their happiness. These three things are complications of the disease, disfigurements and disabilities, and social stigma.

DISEASE COMPLICATIONS

For example, persons affected by leprosy may experience pain and damage to their nerves during so-called ‘reactions’. Persons who have swollen legs due to LF often experience acute attacks if they have

not yet learned how to care for themselves well. Such complications can be very stressful especially because they may be unpredictable and affect a person's ability to function in their daily work and roles. More details can be found in the NTD-specific sections of this document.

DISFIGUREMENTS AND DISABILITIES

Many people affected by NTDs develop long-term physical and functional disabilities. These may be visible and lead to embarrassment, shame and stigma. Examples are the severe swelling of limbs, scrotum or breasts in LF, and contractures and/or shortening of fingers and toes in leprosy. These physical problems often lead to problems in functioning such as difficulties in carrying out activities of daily life and/or in fulfilling one's role in the family or in society.

SOCIAL STIGMA

Persons affected by NTDs may experience negative attitudes or may be treated badly because of cultural or religious beliefs surrounding the disease. This may also be as people fear infection. And, those affected have difficulty doing their work due to disabilities. People fear social rejection too as stigma often reduces quality of life and poor mental health. If people are disfigured, have problems carrying out their tasks or work or face stigma because of their condition, this may lead to embarrassment, shame, fear, stress, low self-esteem and feelings of hopelessness. If people in the community act on their negative attitudes, this is called 'discrimination'. Common ways in which discrimination manifests are gossiping, name-calling, avoidance, rejection, loss of work, or problems in relationships. Children may be refused in or expelled from school.

All the above consequences of NTDs may have a negative effect on people's mental health, their ability and willingness to participate in their family and community and on their happiness. They cause mental distress and, if this is not recognised and dealt with at an early stage, it may lead to more severe mental health problems, such as anxiety and depression. Poor mental wellbeing along with social exclusion may further increase social disadvantages that people experience and may increase poverty.

“I am Arun Kumar, currently working with NLR India as the lead fundraiser. I am living happily with my wife and two adult daughters. Earlier we used to live with my father in a leprosy colony in Delhi. He was disabled due to amputation of both his legs and his right hand resulting from severe infection due to leprosy. At the age of 7, I was diagnosed with leprosy and treated with dapson. I was again put on treatment, this time MDT, at the age of 13. Children like me undergo a lot of mental stress due to their leprosy background, trying to cope with internal fear and adjustment to society. Life as a leprosy-affected person and as a child of a person affected by leprosy both have been a curse for me. All my life I have been feeling lonely and abandoned. At times, mainly during my teenage days, I have been stressed to the extent of wanting to end my life.

In fact, until today it is a challenge. Recently my family had to change the church we were attending for almost 15 years, as people came to know about my leprosy background and would taunt and tease my family. This is one example out of many of bad treatment by the community in which people like me live. I have been ill-treated in nearby villages where I studied, by employees in places where I worked and by the community where I have lived just because of stigma due to leprosy. Even today, I and many people like me are hesitant to talk openly about their connection with leprosy with others. The fear is so much that even if we hear the word 'leprosy' we become cautious.

Today, besides my job in NLR India, I work in my community as a volunteer, counselling teenagers and helping the elderly to obtain compulsory documents so that they can get their pension and other provision from the government. I do this as I want my dream to come true that people affected by leprosy and their children can live a dignified life with no fear and stress due to leprosy.”

Individuals and communities can be affected by NTDs in many ways. Some people may be mildly affected, whereas others may be severely affected. Some may face other disadvantages or stigma due to other causes, e.g. caste or ethnic background or poverty. In general, how someone reacts depends on many factors, including:

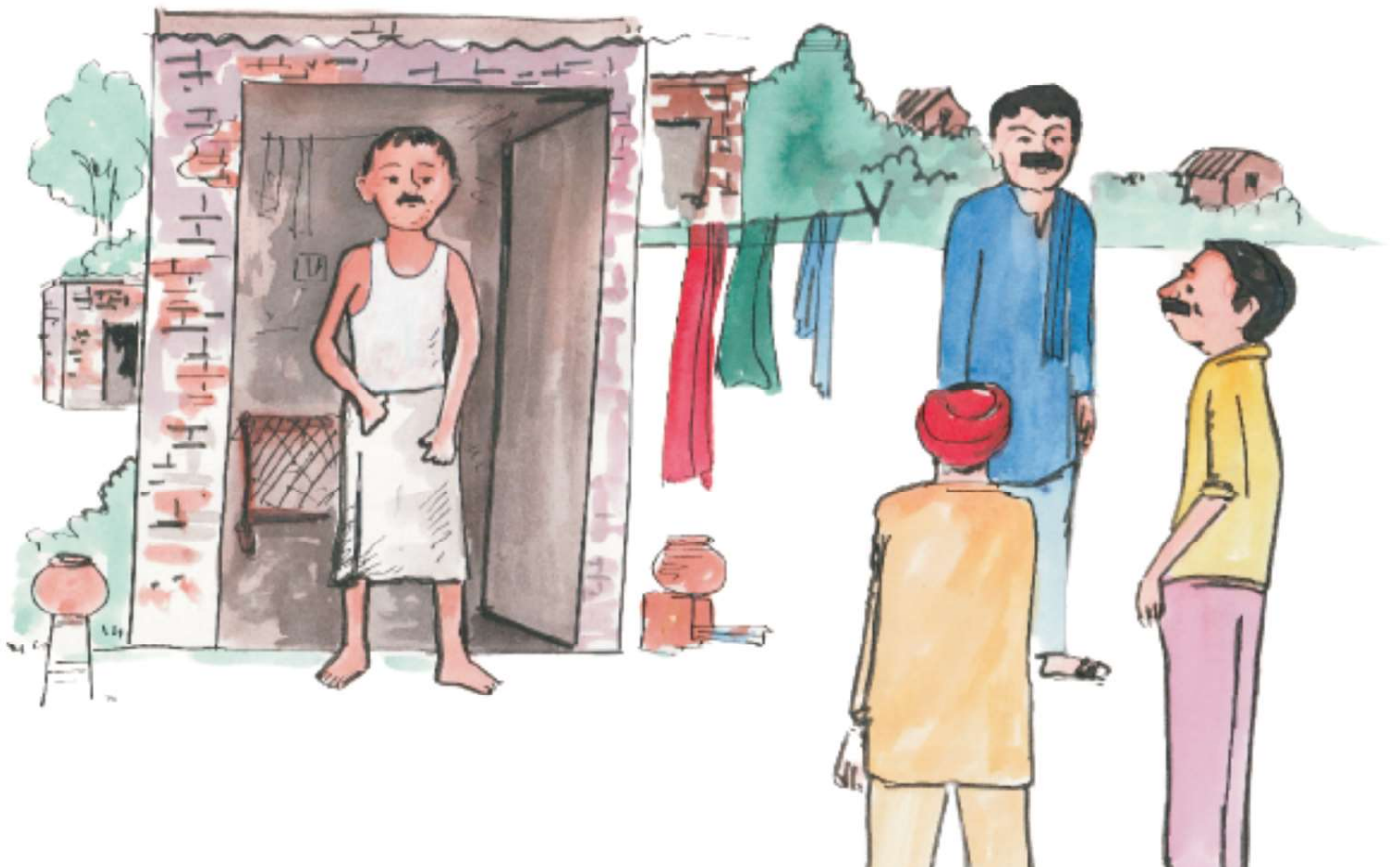
- » The nature and severity of the consequences
- » Their experience with other distressing circumstances
- » The support they have in their life from others
- » Their physical health and any disabilities they have
- » Their personal and family history of mental health problems
- » Their cultural background and traditions
- » Their spirituality and religious faith
- » Their age (for example, children of different age groups react differently)

Every person has strengths and abilities to help them cope with life’s challenges.

Some people may be especially vulnerable because of their age (children and the elderly), because they have a mental or physical disability, or because they belong to marginalised groups (including migrants).

See section 3.4 for guidance in helping vulnerable people.

More information on NTD-related stigma and its effects on mental wellbeing can be found in the ILEP/NNN Guides on Stigma and Mental Wellbeing (www.stigmaguides.org).



1.2 WHAT IS BASIC PSYCHOLOGICAL SUPPORT?

Basic Psychological Support (BPS) describes a humane, supportive response to someone who is suffering and may need support. BPS involves:

- » Providing non-intrusive, practical care and support
- » Assessing needs and concerns
- » Helping people to address basic needs (food and water, information)
- » Listening to people, but not pressuring them to talk
- » Comforting people and helping them to feel calm
- » Helping people connect to information, services and social supports
- » In the case of persons affected by NTDs, information is vital: those providing BPS can help to dispel myths, share clear messages about healthy behaviour and improve people's understanding of the disease

IT IS ALSO IMPORTANT TO UNDERSTAND WHAT BPS IS NOT:

- » It is not something that only professionals can do
- » It is not professional counselling
- » It does not necessarily involve a detailed discussion of the circumstances that caused the distress (as in “psychological debriefing/debriefing psychology”)²
- » It is not asking someone to analyse what happened to them or to put time and events in order
- » People should not be pressurised to tell you their feelings and reactions to their situation, but the peer supporter should rather be available to listen to people

OVERALL, BPS INVOLVES HELPING PEOPLE TO:

- » Feel safe, connected to others, calm and hopeful
- » Have access to social, physical and emotional support
- » Feel able to help themselves, as individuals and communities

1.3 BASIC PSYCHOLOGICAL SUPPORT FOR NTDs (BPS-N): WHO, WHEN AND WHERE?

1.3.1 WHO CAN BENEFIT FROM BPS-N?

BPS-N is for mentally distressed people who are exposed to stressful circumstances. You can help both children and adults, although not everyone will need or want BPS. Do not force help onto people but make yourself easily available to those who may want support.

There may be situations when someone needs much more advanced mental health support. When providing BPS-N to people who have a disease or disease complications, it is especially important to consider whether they may need access to medical attention. Know your limits and get help from others, such as health personnel (including, where relevant and available, mental health nurses and clinicians in district hospitals), your colleagues, local authorities, or community and religious leaders. An inventory of such potential sources of help and referral options should be made beforehand.

² Debriefing psychology is concerned with attempting to lessen or prevent psychological damage in crisis victims by utilizing specialized debriefing methods

PEOPLE WHO NEED MORE THAN BPS-N IN TERMS OF MENTAL HEALTH SUPPORT INCLUDE:

- ▶▶ People who are so upset that they cannot care for themselves or their children
- ▶▶ People with moderately severe or severe depression
- ▶▶ People at risk of hurting themselves or considering suicide
- ▶▶ People at risk of hurting others

People in any of these categories must be referred for further evaluation by a mental health care-trained health professional.

You may also encounter people suffering in other ways as a consequence of NTDs. You can offer BPS-N and determine if they may need further support. This may include livelihood support, learning how to care for their disabilities, education, etc. BPS-N may also be useful for people who may be stigmatised by their communities, such as:

- ▶▶ People who have recovered from NTDs
- ▶▶ Health care providers working with persons affected by NTDs



1.3.2 WHEN IS BPS-N PROVIDED?

Although many people affected by an NTD may need access to help and support, BPS-N is aimed at helping people who show signs of mental distress (see p.21). You can provide BPS-N when you first have contact with distressed people, but it can also be done in the context of, for example, self-care or self-help groups. The consequences of NTD-related disabilities and stigma are often chronic and interact with other distressing events in people’s lives. So the need for such support may occur months or years after diagnosis.

BPS-N CAN BE OFFERED:

- ▶▶ During home visits, e.g. in the context of contact tracing
- ▶▶ During group meetings



1.3.3 WHERE IS BPS-N PROVIDED?

You can offer BPS-N wherever the person who is being helped feels safe and comfortable. This is often in community settings; preferably home-based.

When providing BPS-N, it is essential to respect a person's confidentiality and dignity. Ideally, try to provide BPS-N where you can have some privacy to talk with the person, when appropriate and possible, while still adhering to COVID-19 safety precautions. This is important not only for confidentiality, but also to avoid the spread of rumours in the community.

Be gentle as you talk with people and acknowledge their fears or concerns.



³ See also "Adapting PFA for COVID-19" chapter on IASC Operational Considerations: <https://bit.ly/3nYvneE>

1.4 WHO IS A PEER SUPPORTER?

This BPS guide is meant to provide guidance to peer supporters in providing simple psychological support to peers – other persons also living with the consequences of a neglected tropical disease such as leprosy or lymphatic filariasis.

This PS is a person who is:

- » Above 18 years of age
- » Preferably educated at the level of class 8 or above
- » Knows the community well
- » Well accepted by the community
- » Has good communication skill
- » Willing to volunteer time without remuneration

The implementing agency of the BPS guide needs to select the peer supporters in discussion with the local community leaders e.g., village head, youth or women’s leader or local frontline health worker. The implementing agency will then train the peer supporter in the content of the BPS guide; it should ensure that the peer supporter(s) are monitored and mentored by a qualified person with professional mental health training e.g., a sociologist with social psychology as specialisation, social worker, nurse or a psychologist. The implementing agency may be an NGO working in collaboration with the local government health facilities or institutes; or the government may implement it directly with the peer supporters reporting to the frontline workers with adequate mental health training.

CHAPTER 2

HOW TO HELP RESPONSIBLY



2 HOW TO HELP RESPONSIBLY

Helping responsibly involves three main points:

- 2.1 Respect safety, dignity and rights
- 2.2 Be aware of other NTD-related support measures
- 2.3 Look after yourself

2.1 RESPECT SAFETY, DIGNITY AND RIGHTS

When you take on the responsibility of helping people affected by distressing circumstances, it is important to respect their safety, dignity and rights. The following principles apply to any person or agency involved in NTD services, including those providing BPS-N to persons affected and their families.

RESPECT PEOPLE'S:

SAFETY:

- »» Avoid putting people at risk of harm as a result of your actions; for example, avoid putting them at risk of COVID-19 infection by taking all necessary safety precautions
- »» Make sure, to the best of your ability, that the adults and children you help are safe and protect them from physical or psychological harm; for example, be careful not to trigger stigma or discrimination by your actions, e.g. by disclosing the NTD status of the person
- »» Do not expose them to further stigma. Instead, encourage them to think about how they can help others if they can and are willing, by perhaps taking care of others

DIGNITY

- »» Every human being deserves to be treated with dignity. Dignity is not the same as respect. People earn respect through one's actions, personality, knowledge, wisdom, etc. However, we should also show respect to persons we do not know, because of their dignity as a person
- »» Recognising the dignity and rights of every person is the foundation of freedom, equality, justice and peace in the world
- »» Every person is unique and they should therefore be treated as someone of value. In areas where NTDs are common, life may be difficult for many people due to poverty, difficulties in accessing health care, low literacy rates, inequality between women and men, etc. In such circumstances, it is essential to treat every person with respect and promote dignity for all
- »» Discrimination against any person on the basis of disability is a violation of the inherent dignity of the person
- »» What can we do? We should help the people we support to (re)discover their dignity and worth as a person. We should be respectful ourselves and treat people with dignity

RIGHTS

- »» Rights are the basis of freedom, equality, dignity and social justice. Rights are widely regarded as the basis of law. The rights of people with disabilities include equality before the law, freedom of speech, respect for privacy, the right to both marriage and family, the right to education, the right to health and many more
- »» People with disabilities due to NTDs continuously face social, political, physical and cultural problems that challenge or violate their rights

As a peer supporter, you should:

- ▶▶ Show that you respect people's individual autonomy and independence, including the freedom to make their own decision
- ▶▶ Act only in the best interest of any person you encounter
- ▶▶ Explain what rights are and that these are the same for all people
- ▶▶ Explain the different rights that exist and the potential implications of these for the person who is being helped (e.g. the right to life, right to freedom of discrimination, freedom of speech, right to work, right to family, right to health); for example people affected by leprosy/NTDs have rights to get married and have a family (rights to marriage and family); and the rights of education and work
- ▶▶ Explain that there are many services and facilities that persons are entitled to. For example, encourage your clients to ask the health worker about their disease and access to available care and services (rights to freedom of expression); people with severe disability due to leprosy have a right to have health insurance and social benefits (rights to health, freedom and livelihood)
- ▶▶ Make sure people can access help fairly and without discrimination
- ▶▶ Help people to use their rights and access available services, support and entitlements. Gather, become familiar with and share accurate information on how to access such services and facilities. For example, for the rights of health, give information on the available health service, such as name and address of primary health centre, available service, name and contact of person in charge. You can also give information on the available health insurance or social benefits for persons with disabilities, and how to obtain those
- ▶▶ You can also accompany them during advocacy to policy makers or decision makers to obtain their rights



Keep these principles in mind in all of your actions and with all people you encounter, whatever their age, gender or ethnic background. Consider how you would like to be treated in that situation and treat people in the same way.

Do's

- ▶▶ Be honest and trustworthy
- ▶▶ Respect people's right to make their own well-informed decisions
- ▶▶ Be aware of and set aside your own biases and prejudices
- ▶▶ Make it clear to people that even if they refuse help now, they can still access help in the future
- ▶▶ Respect privacy and keep personal details of the person's story confidential. In the unique cases in which it might not be possible, explain why you might need to share information
- ▶▶ Behave appropriately by considering the person's culture, age and gender

Don'ts

- ▶▶ Don't exploit your relationship as a helper
- ▶▶ Don't ask the person for any money or favour for helping
- ▶▶ Don't make false promises or give false information
- ▶▶ Don't exaggerate your skills, i.e. pretend that you are able to help when you don't know
- ▶▶ Don't force help on people, and don't be intrusive or pushy. Forcing people in any way can be harmful
- ▶▶ Don't pressure people to tell you their story
- ▶▶ Don't share personal details of the person's story with others (confidentiality)
- ▶▶ Don't judge the person for their actions or feelings

2.2 BE AWARE OF OTHER MENTAL HEALTH SERVICES AVAILABLE

This also involves dispelling the many myths that often arise regarding NTDs. Specifics regarding myths and beliefs around leprosy and LF can be found in the condition-specific information sections in Chapter-1.

When offering BPS-N, it is essential to be aware of what other agencies are doing regarding mental health services, and where and how people who may need this should seek help (e.g., know the contact information for key service providers).



2.3 LOOK AFTER YOURSELF

Helping responsibly means looking after your own physical and mental wellbeing.

As a peer supporter, you may be living with consequences of an NTD and may have family who are affected in one way or another. Helping other people and listening to their difficulties also puts a strain on you. It is essential to pay extra attention to your own wellbeing and be sure that you are physically and emotionally able to help others. This is also true for others than peer supporters who may be using the BPS-N. If working in a team, also be aware of the wellbeing of your fellow helpers and find ways to support each other.

See Chapter 4 for more information on looking after yourself and your colleagues.



CHAPTER 3

PROVIDING BASIC PSYCHOLOGICAL SUPPORT FOR NTDs



3 PROVIDING BASIC PSYCHOLOGICAL SUPPORT FOR NTDs

In providing BPS-N, consider the following:

- 3.1 Good communication with people for behaviour change
- 3.2 Preparing to help
- 3.3 BPS-N action principles: Look, Listen and Link!
- 3.4 Helping people who are likely to need special attention

3.1 GOOD COMMUNICATION WITH PEOPLE FOR BEHAVIOUR CHANGE

The way you communicate with someone in distress is very important. People who are affected by disabilities and other chronic consequences of NTDs may be anxious or depressed. Some people may blame themselves for things that happened and others may be angry.

Being calm and showing understanding can help people in distress feel more safe and secure, understood, respected and cared for appropriately.

Someone who has lived with disabilities, stigma and other challenges may want to tell you their story. Listening to someone's story can be a great support.

However, it is important not to pressure anyone to tell you what they have been through. Some people may not want to speak about what has happened or their circumstances. Nevertheless, they may value having you stay with them quietly, knowing you are there if they want to talk, or being offered practical support like a meal or a glass of water.

Don't talk too much and don't worry about silence or having to know what to say. Keeping silent for a while may give the person space and encourage them to share with you if they wish.

To communicate well, be aware of both your words and body language, such as facial expressions, eye contact, gestures, and the way you sit or stand in relation to the other person. Speak and behave in ways that take into account the person's culture, age, gender, customs and religion.

Culture determines how we relate to people, and what is all right and not all right to say and do. For example, some people may not be used to sharing their feelings with someone outside of their family, or it may be appropriate for women to speak only with other women. You may be helping people from a different cultural background, or from a minority group, or someone who may be marginalised. As a helper, it is important to be aware of your own cultural and religious background and beliefs, so you can set aside your biases, or know when to engage another helper. Offer help in ways that are most appropriate and comfortable to the people you are supporting.

Below are suggestions for things to say and do, and what not to say and do. Most importantly, be yourself, be genuine and be sincere in offering your help and care.

THINGS TO SAY AND DO

- ▶▶ Try to find a quiet place to talk and minimize outside distractions
- ▶▶ Respect privacy and keep personal details of the person's story confidential, if this is appropriate
- ▶▶ Keep an appropriate distance from the person, depending on their age, gender and culture
- ▶▶ Let them know you are listening; for example, nod your head or say "hmmmm...." "I understand"
- ▶▶ Be patient and calm
- ▶▶ Provide factual information, if you have it
- ▶▶ Be honest about what you know and don't know. "I don't know, but I will try to find out about that for you"
- ▶▶ Give information in a way that any person can understand – keep it simple
- ▶▶ Acknowledge the person's strengths and how they have helped themselves
- ▶▶ Allow for silence

THINGS NOT TO SAY AND DO

- ▶▶ Don't pressure someone to tell their story
- ▶▶ Don't look distracted or inattentive (for example, don't look at your watch or speak too rapidly)
- ▶▶ Don't judge what they have or haven't done, or how they are feeling
- ▶▶ Don't say: "You shouldn't feel that way," or "You should feel lucky with your current situation"
- ▶▶ Don't make up things you don't know
- ▶▶ Don't use terms that are too technical
- ▶▶ Don't tell them someone else's story
- ▶▶ Don't talk about your own troubles
- ▶▶ Don't give false promises or false reassurances
- ▶▶ Don't think and act as if you must solve all the person's problems for them
- ▶▶ Don't take away the person's strength and sense of being able to care for themselves
- ▶▶ Don't talk about people in negative terms (for example, don't call them "crazy" or "mad")



3.2 PREPARING TO HELP

Learn about NTDs like leprosy and LF from reliable resources – how they are transmitted, signs and symptoms, the way they are treated, the risk of developing disabilities and how to manage these. (See Introduction Chapter 1)

Know what other agencies in the area are doing and where people can go to obtain more information about NTDs, or to talk to someone. Be aware of the procedures for referring people for medical attention, and where and how people can access other support services.

For people who need extra help in coping emotionally and socially with the situation, know the contact information for relevant mental health and psychosocial resources in your area.



3.3 THE ACTION PRINCIPLES OF BPS-N: LOOK, LISTEN AND LINK!

3.3.1 LOOK

- »» Check for safety
- »» Check for people with obvious urgent basic needs
- »» Check for people with serious distress reactions

Take time - even a few moments - to “look” around you before offering help. These moments will give you a chance to be calm, be safe and think before you act. See the following table for questions to consider and important messages as you “look” around you.

Look

People with obvious urgent basic needs

Question

- ▶▶ Does anyone appear to have symptoms of Covid-19?
- ▶▶ Does anybody have obvious urgent basic needs, such as clothing or food?
- ▶▶ Who may need help to be protected from discrimination and violence?

Important message

Know your role and try to get help for people who need special assistance, such as those with obvious urgent basic needs. If the person has been exposed to the disease and/or has symptoms, encourage them to go to a local health centre. If they cannot go to a health facility, speak with your community leader or seek help from appropriately trained health care workers

People in serious distress

- ▶▶ Are there people who are very anxious or depressed?
- ▶▶ Where and who are the most distressed people?

Consider who may benefit from BPS-N and how you can best help. It is important to realise that distress has multiple causes; not just leprosy or LF-related

EXAMPLES OF PSYCHOLOGICAL DISTRESS RESPONSES INCLUDE:

- » Physical symptoms (shaking, headaches, backache, stomach problems, tiredness, loss of appetite, aches and pains that do not seem to have a medical basis)
- » Crying, sadness, depression
- » Anxiety and fear
- » Being “on guard” or “jumpy”
- » Worrying that something bad is going to happen
- » Disturbance in sleep, not being able to sleep and nightmares
- » Irritation and anger
- » Guilt and shame (for having an NTD)
- » Confusion, emotional numbness, or feeling unreal or in a daze
- » Hallucinations
- » Appearing withdrawn or very still (not moving)
- » Not responding to others, or not speaking at all
- » Disorientation (not knowing their name, where they are from, or what happened)
- » Not being able to care for themselves or their children (not eating or drinking, not able to make simple decisions)

SOME PEOPLE MAY BE ONLY MILDLY DISTRESSED OR NOT SHOW SIGNS OF DISTRESS AT ALL.

Most people are able to recover emotionally, especially if they receive support from others and help in meeting their basic needs. However, people with severe and/or long-lasting distress, anxiety or depression may need more support than BPS-N, particularly if they cannot function in their daily life or if they are a danger to themselves or others. Ensure that severely distressed people are not left alone and try to keep them safe until you can contact the relevant mental health and psychosocial support resources in your area.

VULNERABLE PEOPLE

Remember to look for children, people with other health conditions or physical and mental disabilities, and people at risk of discrimination, as they are likely to need special attention for their care and safety.

3.3.2 LISTEN

- » Approach people who may need support
- » Ask about people’s needs and concerns
- » Listen to people and help them to feel calm

Listening carefully to a person you are helping is essential to understand their situation and needs, to help them feel calm, and to offer them appropriate help. Learn to listen with your:

- » Eyes » giving the person your undivided attention
- » Ears » truly hearing their concerns
- » Heart » with care and showing respect

Even if you must communicate from a distance because of safety precautions, you can still give the person your full attention and show that you are listening with care by using active listening skills:

- ▶▶ **Pay attention**
 - Focus and put aside distracting thoughts
- ▶▶ **Show that you are listening**
 - Nod occasionally and encourage a person to continue with small verbal comments like: yes, uh..uh, ...hmmm...and then...?
- ▶▶ **Provide feedback**
 - Reflect on what has been said
 - Repeat what a person has said in your own words
 - Ask questions to clarify certain points
 - Summarise what a person has said
- ▶▶ **Do not judge**
 - Allow a person to finish their statement before asking a clarification or question
 - Don't interrupt
 - Don't argue or counter the arguments
 - Don't show physical signs of disapproval, such as facial expressions
- ▶▶ **Respond appropriately**
 - Be honest
 - Deliver your comments respectfully



1. APPROACH PEOPLE WHO MAY NEED SUPPORT:

- ▶▶ Approach people respectfully
- ▶▶ Introduce yourself by name and organisation
- ▶▶ Explain that you will listen and care about how they are feeling. Ask the person how s/he is feeling and coping with the situation, and if you can provide help
- ▶▶ Be sure to ask about the person's physical condition and how they are feeling
- ▶▶ If possible, find a quiet place to talk that is as private as possible
- ▶▶ If the person is distressed, try to ensure they are not alone until further help can be found
- ▶▶ Ensure that the interview/support session is done in a gender-sensitive way. For example, a woman should be present when the participant is a woman

2. ASK ABOUT PEOPLE'S NEEDS AND CONCERNS:

- ▶▶ Although some needs may be obvious, always ask what people need and what their concerns are
- ▶▶ Find out what is most important to them at this moment, by asking 'How can I help you?' and help them work out what their priorities are

3. LISTEN TO PEOPLE AND HELP THEM TO FEEL CALM:

- ▶▶ Do not pressure the person to talk
- ▶▶ Listen in case they want to talk about what they have experienced
- ▶▶ Offer to sing, read, or tell stories to reassure them they are not alone and ease their fear
- ▶▶ If they are very depressed, help them to feel calm and understood and try to ensure they are not left alone

HELP PEOPLE TO FEEL CALM

Some people may be very anxious or depressed. They may feel hopeless and may have physical symptoms, like loss of appetite or difficulty sleeping. The following are some techniques to help very distressed people feel calm in their mind and body:

- ▶▶ Keep your tone of voice calm and soft
- ▶▶ Try to maintain some culturally adequate eye contact with the person as you talk with them
- ▶▶ Remind the person that you are there to help them
- ▶▶ If someone feels disconnected from their surroundings, it may help them to make contact with their current environment and themselves. You can do this by asking them to:
 - Place and feel their feet on the floor
 - Tap their fingers or hands on their lap
 - Notice some non-distressing things in their environment, such as things they can see, hear or feel. Have them tell you what they see and hear
 - Encourage the person to focus on their breathing, and to breathe slowly



3.3.3 LINK

- »» Help people address basic needs and access services
- »» Help people cope with problems
- »» Give information
- »» Connect people with loved ones and social support

1. HELP PEOPLE ADDRESS BASIC NEEDS AND ACCESS SERVICES

People affected may need help in addressing basic needs and accessing services, especially if they were excluded from their families. As you provide BPS-N, consider the following:

- »» Try to help the person in distress to meet the basic needs they request, such as food, water, shelter and information about medical and social services. It is important that you map and collect contact information of services in your area
- »» Learn what specific needs people have and try to link them to the help available, including any disability-specific services, for example for assistive devices
- »» Make sure that persons with NTD-related disabilities know how to do self-care
- »» Ensure vulnerable and marginalised people are not overlooked (see Section 3.4)
- »» Follow up with people if you promise to do so



2. HELP PEOPLE COPE WITH PROBLEMS

A person who is anxious or depressed can feel overwhelmed with worries and fears. Help them to consider their most urgent needs, and how to prioritise and address them. For example, you can ask them to think about what they need to address now, and what can wait for later. Being able to manage a few issues or do certain activities will give the person a greater sense of control and strengthen their ability to cope.



REMEMBER TO :

- »» Help people identify supports in their life, such as friends or family, who can help them. Think also of additional supports, such as religious leaders or other members of the community
- »» Ask the person to consider how they have coped with difficult situations in the past and affirm their ability to cope with the current situation
- »» Give practical suggestions for people to meet their own needs
- »» Ask the person what helps them to feel better. Encourage them to use positive coping strategies and avoid negative coping strategies (see the table under coping)

COPING

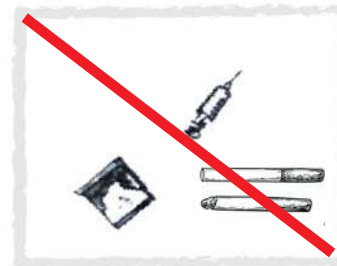
Everyone has natural ways of coping. Encourage people to use their own positive coping strategies, while avoiding negative strategies that seem to help in the short term but have negative consequences in the long run. This will help them to feel stronger and to regain a sense of control. You will need to adapt the following suggestions to take into account the person's culture and what is possible in the particular crisis situation.

Encourage positive coping strategies

- »» Get enough rest
- »» Eat as regularly as possible and drink water.
- »» Talk and spend time with family, friends or other community members
- »» Discuss problems with someone you trust.
- »» Do activities that help you relax (walk, sing, pray)
- »» Do physical exercise
- »» Find safe ways to help others in the crisis and get involved in community activities

Discourage negative coping strategies

- »» Don't take drugs, smoke or drink alcohol
- »» Don't sleep all day
- »» Don't work all the time without any rest or relaxation
- »» Don't isolate yourself from friends and loved ones
- »» Don't neglect basic personal hygiene



Use the following steps for helping people cope with specific problems:

i. CLARIFICATION:

- » Ask the person to clarify the information s/he has shared, if necessary
- » Repeat a person's statement/story in your own words
- » Ensure the information is clear and you have understood the situation properly
- » Stimulate the person to find solutions and make changes

ii. COMPROMISE:

- » Encourage the person to think about ways to manage their problems. You might ask:
 - What have you done in the past to overcome problems like this?
 - What have you already tried doing?
 - Is there someone who can help with managing this problem (e.g., friends, loved ones or organisations)?
 - Do other people you know have similar problems? How have they managed?
- » Help and encourage the person to see things from a different perspective

iii. COMMITMENT:

- » Support the person to commit to a potential solution – it is important that the person is helped to come with a solution, rather than you suggesting one
- » Help and encourage a person to take action

3. GIVE INFORMATION

People affected by a condition like leprosy or LF may want accurate information about:

- » Leprosy or LF as a disease
- » See facts about the NTDs in the introduction
- » Try to keep yourself informed of the latest updates on the situation regarding the NTDs and the situation regarding COVID-19 and other public health issues in the area where you work
- » Their disabilities and how they can prevent these from getting worse
- » Leprosy and LF-related stigma is common, but its negative effects can be prevented or reduced
- » Their rights and responsibilities
- » This includes their rights to treatment and care, legal rights, being treated with dignity, etc
- » This also includes their responsibility to follow the guidance of local authorities and health workers
- » Services and supports
- » This includes how to access services and other things they need

You may not have all the answers at any given moment, but wherever possible, try to get as much information as you can before you offer people support and information. It may be helpful to use official written information, such as posters and leaflets in the local language, or in pictorial form for people with low literacy, to complement the information you are giving. Try to ensure vulnerable people know about existing services and how to obtain information.

WHEN PROVIDING INFORMATION

- » Explain the source of the information and how reliable it is
- » Say only what you know – do not make up information or give false reassurances
- » Keep messages simple and accurate, and repeat the information to be sure people hear and understand it

- ▶▶ It may be useful to give information to groups of affected people, so that everyone hears the same message
- ▶▶ Let people know if you will keep them updated on new developments, including where and when

When giving information, be aware that the peer supporter can become a target of the frustration and anger people may feel, especially when their expectations of help have not been met by you or others. In these situations, try to remain calm and be understanding.



4. CONNECT WITH LOVED ONES AND SOCIAL SUPPORT

It has been shown that people who feel they have good social support cope better than those who feel they are not well supported. Because of this, linking people with loved ones and social support is an important part of BPS-N.

This task may be very difficult, as people may have been rejected because of their disease or disabilities due to the stigma associated with the illness. Affected people can feel very isolated. Therefore, it will be very important to help people identify someone in the family or someone else within their community who could be of support. There may be existing self-care or self-help groups and community networks that can provide support.

Mental health and psychosocial workers can help those lacking social support by visiting or accompanying them. Social reintegration in the community for those who have been cured of the disease is also important. This can help to reduce stigma, decrease other people's fear of interacting with them, and to identify other sources of support if relatives are missing.

IN CONNECTING PEOPLE WITH LOVED ONES AND SOCIAL SUPPORT:

- ▶▶ Help keep families together and keep children with their parents and loved ones if possible, while also observing the safety measures to avoid COVID-19 transmission
- ▶▶ Refer to the information on people who likely need special attention in Section 3.4 regarding the specific needs of children and adolescents who are being rejected in their communities

- ▶▶ Help people to contact friends and relatives so they can get support; for example, provide a way for them to call loved ones, including admitted patients
- ▶▶ Use phones to give psychosocial support: a phone could be made available at the health centre for patients' use only, so relatives can talk to their loved ones
- ▶▶ If a person lets you know that prayer, religious practice or support from religious leaders might be helpful for them, try to connect them with their spiritual community, always observing safety measures
- ▶▶ Given the risk of spreading COVID-19 in public gatherings or through direct contact, it is important to find new ways of praying together. Religious leaders can also help by finding new ways to provide spiritual support and guidance that don't involve touching to protect people by preventing the spread of disease
- ▶▶ Help bring affected people together to support each other. For example, ask people to help care for the elderly, or link individuals without family support to other community members



ENDING YOUR HELP

What happens next? When and how you stop providing help to someone will depend on their situation, your role and circumstances, and the needs of the person you are helping. You may be working in the affected community for some time, but if you are ending your assistance with someone, explain why and also where they can find additional help in future, if needed. If you have linked the person with other services, let them know what to expect and be sure they have the details to follow up. No matter what your experience with the person, you can say goodbye in a positive way by wishing them well.



3.4 PEOPLE WHO LIKELY NEED SPECIAL ATTENTION

People who may be vulnerable and need special help in a crisis include:

1. Children, including adolescents
2. People with other health conditions or disabilities
3. People at risk of discrimination or violence
4. Elderly persons

Remember that all people have resources to cope, including those who are vulnerable. Help vulnerable people to use their coping resources and strategies.



3.4.1 CHILDREN, INCLUDING ADOLESCENTS

Many children – including adolescents – affected by NTDs are particularly vulnerable to stigma and exclusion. Even children of parents affected by NTDs may face discrimination and exclusion. NTDs may disrupt their familiar world, including the people, places and routines that make them feel secure. Stigma and discrimination may isolate them from protection and support. Young children are particularly vulnerable since they cannot meet their own basic needs or protect themselves. Girls usually face the greatest risk of sexual violence and exploitation, and those who have been abused may be stigmatised and further isolated.

How children react to a crisis depends on their age and developmental stage. It also depends on the ways their carers and other adults interact with them. For example, young children may not fully understand what is happening around them and are especially in need of support.

Children generally cope better when they have a stable, calm adult around them.



Children and young people may experience similar distress reactions as adults (see Section 3.3). They may also experience the following specific distress reactions:

- ▶▶ Young children may return to earlier behaviours (for example, bedwetting or thumb-sucking), cling to carers, and reduce their play or use repetitive play related to the distressing event
- ▶▶ School-age children may believe they caused bad things to happen, develop new fears, become less affectionate, feel alone and be preoccupied with protecting or rescuing people in the crisis
- ▶▶ Adolescents may feel “nothing”, feel different or isolated from their friends, or display risk-taking behaviour and negative attitudes

Family and other caregivers are important sources of protection and emotional support for children. Those who are discriminated against may be fearful and insecure, and may not be able to properly judge the risks and danger around them.

It is very important not to do this on your own, but rather to work through child protection agencies. If you make mistakes, it will make the child’s situation worse.

Children may experience horrific events, even if they are not directly affected.



REMEMBER THAT CHILDREN HAVE THEIR RESOURCES FOR COPING.

Learn what children's resources are for coping and support positive coping strategies, while helping them to avoid negative strategies. Older children and adolescents can often help in crisis situations, such as giving accurate information about the NTD. Finding safe ways for them to contribute may help them to feel more in control. Children, adolescents and youth may also have networks and associations that can provide social support.

HOW CARERS CAN HELP CHILDREN

- ▶▶ Give them extra time and attention
- ▶▶ Remind them often that they are safe
- ▶▶ Explain to them that they are not to blame for bad things that have happened
- ▶▶ Keep to regular routines and schedules as much as possible or help create new ones in a new environment
- ▶▶ Give simple explanations about their situation without too much detail
- ▶▶ Be patient with children who start demonstrating behaviours they had when they were younger, such as sucking their thumb or wetting the bed
- ▶▶ Provide a chance to play and relax, if possible

OLDER CHILDREN AND ADOLESCENTS

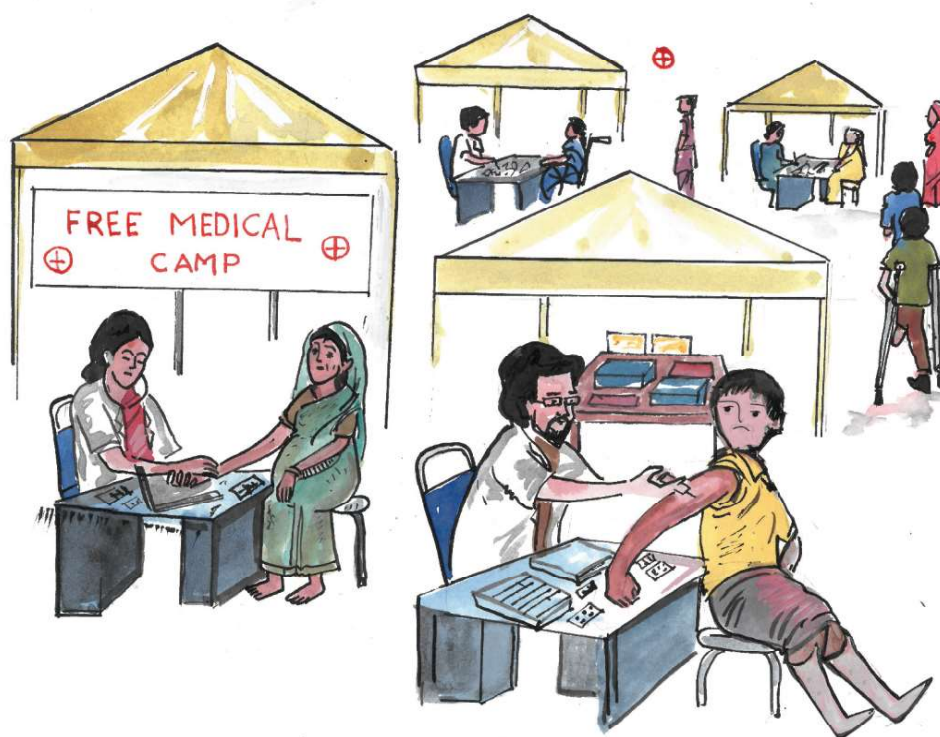
- ▶▶ Give them your time and attention
- ▶▶ Help them to keep regular routines, including school/ learning
- ▶▶ Provide facts about their situation, explain what is going on now
- ▶▶ Encourage and allow opportunities for them to be helpful in concrete, purposeful common interests
- ▶▶ Allow them to be sad. Don't expect them to be tough
- ▶▶ Listen to their thoughts and fears without being judgemental
- ▶▶ Set clear rules and expectations
- ▶▶ Ask them about the dangers they face, support them and discuss how they can best avoid being harmed
- ▶▶ Link them with existing networks of adolescents, youth and other community and social support groups

WHEN PROVIDING BPS-N TO CHILDREN, REMEMBER TO LISTEN, TALK AND PLAY:

- » Be calm, talk softly and be kind
- » Listen to children's views on their situation
- » Try to talk with them at their eye level (e.g. sit or kneel on the floor) and use words and explanations they can understand
- » Introduce yourself by name, let them know that you are there to help
- » If passing time with children, try to involve them in play activities or simple conversation about their interests, according to their age

3.4.2 PEOPLE WITH HEALTH CONDITIONS OR PHYSICAL OR MENTAL DISABILITIES

People with chronic (long-term) health conditions, physical or mental disabilities (including severe mental disorder), and the elderly may need special help. This may include help to get to a safe place, to connect with basic support and health care, or to take care of themselves. Pregnant and nursing women may experience additional stress that can affect their pregnancy, their health and their infant's health. People who cannot move on their own, or who have problems seeing or hearing, may have difficulty finding loved ones or accessing services.



Here are some things you can do to help people with other health conditions or disabilities:

- » Help them to meet their basic needs, such as being able to eat, drink, get clean water and care for themselves
- » Ask people if they have health conditions other than their NTD, or if they regularly take medication for a health problem. Try to help people get their medication or access available medical services
- » Stay with the person if they are very anxious or depressed or try to ensure they have someone to help them if you need to leave. Consider linking the person with a protection agency or other relevant support, to help them in the longer term

3.4.3 PEOPLE AT RISK OF DISCRIMINATION OR VIOLENCE

People at particular risk of discrimination or violence may include women, people from certain ethnic or religious groups, and people with mental and physical disabilities. They are vulnerable because they may be:

- ▶▶ Left out when basic services are provided
- ▶▶ Left out of decisions about aid, services or where to go
- ▶▶ Targeted for violence, including sexual violence

People at risk of discrimination or violence may need special protection depending on their situation and may need extra help to address their basic needs and access available services. Be aware of these people and assist them by:

- ▶▶ Helping them to find safe places to stay
- ▶▶ Helping them to connect with their loved ones and other trusted people
- ▶▶ Providing them with information on available services and helping them to link directly with those services when necessary



CHAPTER 4

CARING FOR YOURSELF AND YOUR COLLEAGUES



4 CARING FOR YOURSELF AND YOUR COLLEAGUES

In this chapter, we will discuss:

- 4.1 Getting ready to help
- 4.2 Managing stress: healthy work and life habits
- 4.3 Rest and reflection

As a peer supporter, you or your family may be directly affected by an NTD. Even if you are not directly involved, you may be affected by what you see or hear while helping. As a helper, it is important to pay extra attention to your wellbeing. Take care of yourself, so you can best take care of others!

4.1 GETTING READY TO HELP

Consider how you can best get ready to be a helper in crisis settings. Whenever possible:

- » Learn about the NTD (s) in your area, and the roles and responsibilities of different kinds of helpers (e.g., health authorities and community workers)
- » Consider your health, and personal or family issues that may cause severe stress as you take on a helping role for others
- » Make an honest decision about whether you are ready to help in each particular situation and at this particular time
- » Be sure that you know and understand how to observe all the safety measures to avoid COVID-19 disease



4.2 MANAGING STRESS: HEALTHY WORK AND LIFE HABITS

A main source of stress for helpers is day-to-day job stress, particularly if you do this besides other daily work. Long working hours, many responsibilities, the lack of a clear job description, poor communication or management, and working in areas that are not secure are examples of common job-related stress that can affect helpers assisting in helping others.

As a helper, you may feel responsible for people's safety and care. You may hear or even directly experience things you have not heard or seen before, such as medical complications or the results of social exclusion. You may also hear stories of other people's pain and suffering. All of these experiences can affect you and your fellow helpers.

Consider how you can best manage your stress, to support and be supported by your fellow peer supporters. The following suggestions may help manage your stress:

- » Think about what has helped you cope in the past and what you can do to stay strong
- » Try to take time to eat, rest and relax, even for short periods
- » Try to keep reasonable working hours so you do not become too exhausted
- » You may feel inadequate or frustrated when you cannot help people with all of their problems. Remember that you are not responsible for solving all of a person's problems, and it is not realistic or possible for you to do so. Do what you can to help people help themselves
- » Minimise your intake of alcohol, caffeine or nicotine and avoid non-prescription drugs
- » Check in with fellow helpers to see how they are doing and have them check in with you. Find ways to support each other
- » Talk with friends, loved ones or other people you trust for support



4.3 REST AND REFLECTION

Taking time for rest and reflection is an important part of ending your helping role. The needs of people you have met may have been very challenging, and it can be difficult to bear their pain and suffering. After helping someone, take time to reflect on your experience and to rest. The following suggestions may help your recovery:

- » Talk about your experience of helping with a supervisor, colleague or someone else you trust
- » Join a peer support group of persons delivering BPS; it is important that you yourself receive sufficient support
- » Acknowledge what you were able to do to help others, even in small ways
- » Learn to reflect on and accept what you did well, what did not go very well, and the limits of what you could do in the circumstances
- » Take some time, if possible, to rest and relax before beginning your other work and life duties again

If you find yourself with upsetting thoughts or memories, feel very nervous or extremely sad, have trouble sleeping, or drink a lot of alcohol or take drugs, it is important to get support from someone you trust. Speak to a mental health specialist if these difficulties continue for more than one month.



BASIC PSYCHOLOGICAL SUPPORT FOR NTDs (BPS-N): POCKET GUIDE

WHAT IS BASIC PSYCHOLOGICAL SUPPORT?

Basic Psychological Support (BPS) describes a humane, supportive response to a person who is suffering and may need support.

PROVIDING BPS-N RESPONSIBLY MEANS:

1. Respecting people's safety, dignity and rights
2. Adapting what you do to take into account the person's **culture**
3. Being aware of other emergency response measures
4. Looking after yourself



IN PROVIDING BPS-N RESPONSIBLY IN THE CONTEXT OF COVID-19:

- » Ensure people know their rights (such as right to treatment and care, being treated with dignity, etc.) as well as their responsibilities in preventing Covid-19, such as their responsibility to follow the guidance of local health authorities and health workers
- » Look after your own physical and mental wellbeing! As a peer supporter, you may also be affected by the NTD or may have family, friends and colleagues who are affected. Pay extra attention to your own wellbeing

- PREPARE**
- » Learn about the NTD(s) in your area (see NTD-specific sections in the main BPS-N Guide)
 - » Learn about available services and supports
 - » Learn about safety and security concerns

BPS-N ACTION PRINCIPLES

- LOOK**
- » Check for safety
 - » Check for people with obvious urgent basic needs
 - » Check for people with serious distress reactions

- LISTEN**
- » Approach people who may need support
 - » Ask about people's needs and concerns
 - » Listen to people and help them to feel calm

Even if you must communicate from a distance because of safety precautions, you can still give the person your full attention and show that you are listening with care.

LINK

- »» Help people address basic needs and access services
- »» Help people cope with problems
- »» Give information
- »» Connect people with loved ones and social support

ETHICS

Ethical do's and don'ts are offered as guidance to avoid causing further harm to the person receiving BPS-N, to provide the best care possible, and to act only in their best interests. Offer help in ways that are most appropriate and comfortable to the people you are supporting. Consider what this ethical guidance means in terms of your cultural context.

Do's

- »» Be honest and trustworthy
- »» Respect people's right to make their own well-informed decisions
- »» Be aware of and set aside your own biases and prejudices
- »» Make it clear to people that even if they refuse help now, they can still access help in the future
- »» Respect privacy and keep personal details of the person's story confidential, if this is appropriate
- »» Behave appropriately by considering the person's culture, age and gender

Don'ts

- »» Don't exploit your relationship as a helper
- »» Don't ask the person for any money or favour for helping
- »» Don't make false promises or give false information
- »» Don't exaggerate your skills
- »» Don't force help on people, and don't be intrusive or pushy
- »» Don't pressure people to tell you their story
- »» Don't share personal details of the person's story with others
- »» Don't judge the person for their actions or feelings

PEOPLE WHO NEED MORE HELP THAN BPS-N ALONE:

Some people will need much more than BPS-N alone. Know your limits and ask for help from others who can provide more advanced mental health support, medical care or other assistance.

PEOPLE WHO NEED MORE ADVANCED MENTAL HEALTH SUPPORT IMMEDIATELY:

- »» People who are so upset they cannot care for themselves or their children
- »» People who may hurt themselves
- »» People who may hurt others

Further information may be found in the ILEP/NNN Guides on Stigma and Mental Wellbeing (www.stigmaguides.org).