



# TB HIV Training for Community Leaders



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**The Global Fund**  
To Fight AIDS, Tuberculosis and Malaria



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# INTRODUCTION

- TB is a burden in the whole world as well as South Sudan
- Sudan is 17th among the 22 countries in the Eastern Mediterranean Region (EMR)
- There has been an increase from 45,221 TB cases in 1990 to 93,808 in 2007
- TB affects all ages but it is worse between 15 to 49 years
- 15 - 20% of all TB patients in Southern Sudan have HIV
- TB is the commonest cause of death among People Living With HIV AIDS (PLWHAs)
- TB is preventable and curable if medicines are taken correctly.
- Your support and contribution is necessary for community sensitization to help in TB control

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# WHO ARE COMMUNITY LEADERS?

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# COMMUNITY LEADERS ARE PEOPLE WHOSE OPINIONS ARE HONoured E.G.

- Business people (employers)
- Religious leaders
- Executive chiefs - Bomas
- Sub chiefs - villages
- Goal leaders – assistant to sub chief
- Payam administrators - payam
- Commissioners - county
- Executive Directors – administrator in county
- Governor - State
- Women group leaders
- Youth group leaders
- Chief for fishermen
- Cattle camp leaders
- School teachers

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## ADVISE TO THE LEADERS

- Information alone is not usually enough to lead a person to change his or her behavior – but it is an important first step.
- Share correct information so as to:
  - ~ encouraging people to discuss issues related to TB and TB–HIV co-infection
  - ~ allow people to share their thoughts, worries, and experiences
  - ~ encourage people to adopt healthy behaviors.

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**WHY IS IT IMPORTANT  
FOR LEADERS TO TALK  
ABOUT TB AND TB HIV?**

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- Community leaders are the key people and they are respected and honoured when they pass any information to their community members.
- Leaders have a responsibility to share correct information
- Help people change their beliefs and adopt changes for better health seeking behaviour.
- Increase peoples awareness on the TB and TB HIV situation in their areas and the effects of these diseases

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# **WHY DO PEOPLE WITH TB NEED SUPPORT?**

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- TB drugs are taken for a long time-boring
- The tablets are many and have serious side effects-discouraging
- There is stigma and discrimination associated with TB and TB HIV

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## **SOME INFORMATION COMMUNITY LEADERS CAN GIVE TO PEOPLE WITH TB SHOULD AIM TO:**

- Inform them that TB drugs are available free in all the panakim of the GoSS and NGOs.
- Raise awareness of the benefits of completing treatment, as well as the risks of not completing treatment.
- Provide general support.
- Address issues of stigma and discrimination.
- Help them to remember to take their medicine.
- Ask them to practice cough hygiene to prevent the spread of TB

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# **FACTS ABOUT TB AND TB HIV**

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# KNOW ABOUT TB

- What is Tuberculosis?
- What is TB infection?
- What is TB disease?

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## KNOW ABOUT TB

- Tuberculosis (TB) is a bacterial disease caused by a germ. TB disease can affect any part of the body.
- TB of the lungs is the most common
  - It is also called pulmonary tuberculosis (PTB)

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**THERE IS A DIFFERENCE  
BETWEEN TB INFECTION  
AND TB DISEASE**

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# TB INFECTION

- People can be infected with TB germs but not feel sick because their immune system is able to fight the germs.
- TB infection means that someone has TB germs in his or her body.
- People who are infected with TB germs but are not sick cannot spread the disease to other people.
- Some people who have a TB infection are healthy. Most people with a TB infection who have a healthy immune system will never become sick with TB.
- This does not usually require treatment

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# TB DISEASE

- The disease develops when the immune system can no longer fight the TB germs, and the germs begin to multiply.
  - ~ Examples of causes of low immunity include:
    - Infection with HIV
    - Chronic diseases like diabetes and cancer
    - Malnutrition
    - Very young babies and old people
- When this happens, people start to feel sick.
- The most common reason why people develop TB disease is a weak immune system, especially when they are infected with HIV.

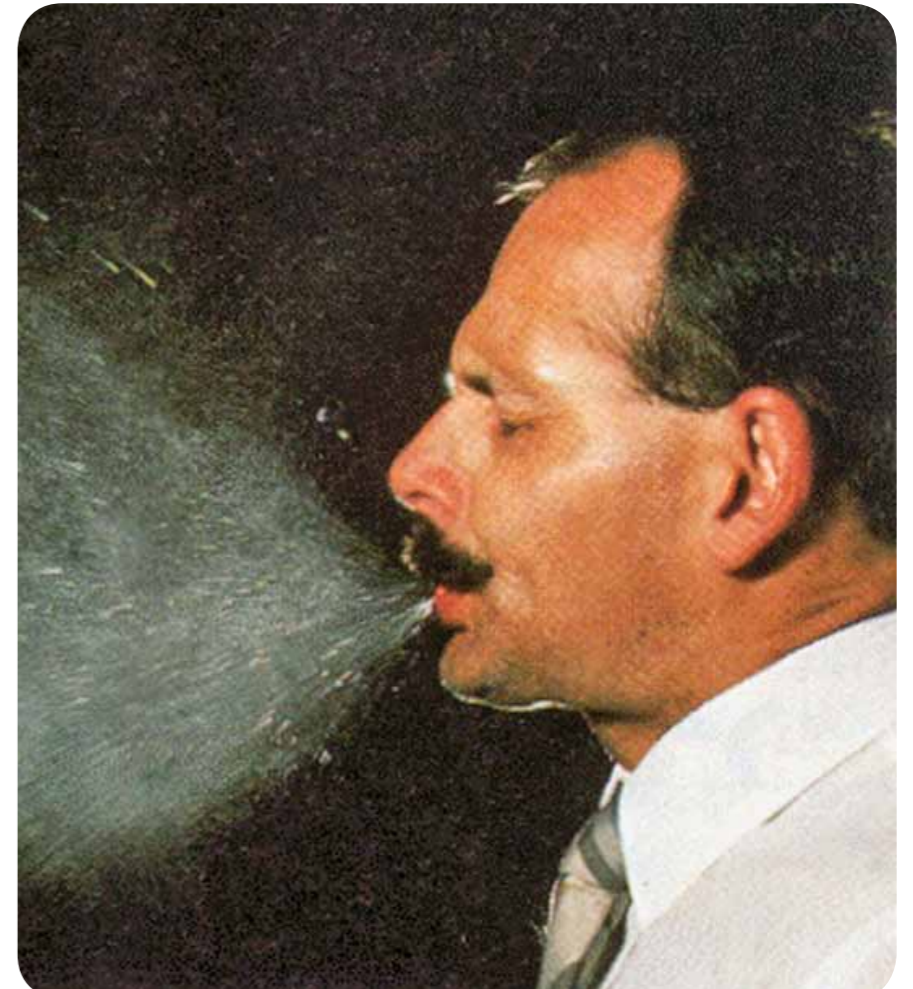
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# TB DISEASE SPREAD AND RISK FACTORS

- How do people acquire TB?
- How does TB spread?
- How is TB NOT spread?
- Who is at risk of getting TB disease?

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- TB spreads easily from one person with TB disease to another without TB disease.
- When a person with TB disease coughs, spits, laughs or sneezes without covering his or her mouth, people nearby can breathe in the air that contain the germs.
- The germs can remain in the air for long periods of time.
- The TB germs can survive in the dark for a long time. Direct sunlight kills TB germs in five minutes
- Overcrowding and poor ventilation are particularly risky.



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## HOW TB IS NOT SPREAD

- ***You cannot get TB germs from:***
  - ~ Inheriting from your parents
  - ~ shaking hands with people suffering TB disease
  - ~ sharing drinking containers or utensils, cigarettes with people suffering TB disease
  - ~ sexual contact
  - ~ food and water
  - ~ blood transfusion
  - ~ from mosquito bites.



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# PEOPLE AT RISK OF GETTING TB DISEASE

- People of all ages can develop TB disease
- People with TB infection who have a weak immune system are most at risk of
  - ~ becoming sick with TB (developing TB disease)
  - ~ people with HIV and AIDS,
  - ~ Chronic diseases like diabetes and cancer,
  - ~ malnutrition,
  - ~ Heavy smoking and alcoholism
  - ~ Children under five years old and elderly people have a much higher chance of becoming sick with TB disease

NB: Their bodily defenses are not strong enough to resist TB infection becoming TB disease

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**WHAT PARTS OF  
THE BODY ARE AFFECTED BY TB?**

**WHAT ARE THE  
SIGNS AND SYMPTOMS OF TB?**

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## PARTS OF THE BODY AFFECTED BY TB

- Commonly the Lungs
- But ANY part of the body can be affected except:
  - ~ Hair
  - ~ Nails
  - ~ Teeth

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# SIGNS AND SYMPTOMS OF TB DISEASE

- Coughing for two weeks or more.
- Sputum containing blood.
- Chest pain.
  
- Difficulty in breathing.
- Fever.
- Sweating at night, even when the weather is cold.
  
- Loss of weight.
- Loss of appetite.
- Tiredness.

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**OTHER SIGNS DEPEND ON PART  
AFFECTED BY TB  
E.G. LYMPH NODE TB**



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# DIAGNOSIS AND TREATMENT OF TB

- How does one confirm they have the disease?
- Is TB disease curable?
- How long is the treatment?
- How can TB patients on treatment be supported?

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# TB DIAGNOSIS AND TREATMENT

- Confirmation of TB disease is by having sputum examined in a laboratory
- TB is curable if medicines are taken correctly. Drugs are taken according to body weight.
- Diagnosis and treatment is free in GoSS, NGOs
- TB drugs are a combination of many tablets taken for 6 or 8 months. Treatment must be regularly taken daily and completed
- Treatment support is necessary and can be done by community leaders, Community Health Workers, Village health Volunteer, family member, etc.

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# HOW CAN TB BE PREVENTED?

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# PREVENTION AND CONTROL OF TB

- People who are sick with TB can prevent spreading TB to others in their family and community by:
  - ~ Going for treatment and being cured of TB.
  - ~ Covering their mouth and nose when coughing and sneezing.
  - ~ Making sure that people who have spent time with them, particularly children and adults who are coughing, get tested for TB.
- Avoiding overcrowding.
- Staying in a well-ventilated house.
- Preventing yourself from getting HIV infection.
- Immunizing young children with BCG vaccine, which is given at birth. The vaccine protects them against severe forms of TB (e.g., TB meningitis and miliary TB).
- Eating a well-balanced diet, by using locally available food.

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# **STIGMA AND DISCRIMINATION**

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- **What is stigma?**
- **What is discrimination?**
- **Types of stigma**

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# STIGMA AND DISCRIMINATION

- Any action that leads to reduction of a person's or group's status in the eyes of the society.
- Stigma can result from:
  - ~ a physical characteristic, such as the visible symptoms of disease,
  - ~ a negative attitude towards the behaviour of a group such as people living with AIDS.
- Discrimination is stigma in action.
- Stigma related to TB, HIV, and AIDS is intimately linked to discrimination.

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## **Forms of stigma**

- Physical and social isolation from family, friends, and community.
- Gossip, name calling, and judging.
- Loss of rights and power to make decisions.

## **Signs of stigma and discrimination are:**

- Self-denial among those infected by TB HIV.
- Those affected and infected by TB HIV not opening up about their status.
  
- What causes stigma?
- What are the effects of stigma on TB HIV?
- Why should stigma issue be addressed in the community?

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## CAUSES OF STIGMA

- Ignorance of the facts regarding TB HIV.
- Irrational fears and beliefs about the causes of TB HIV.
- Negative attitudes of leaders towards those living with TB HIV.
- A lack of a working policy on TB HIV.

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# EFFECTS OF STIGMA ON TB HIV PATIENTS

- TB and HIV/AIDS-related stigma is the single greatest challenge to slowing the spread of the disease and seeking early care. It makes coping with and fighting the disease challenging.
- Stigma can cause patients to become withdrawn, fearful, silent, and secretive. It can lead them to not accept their condition
- It can make a person delay going for early diagnosis and treatment for TB–HIV/AIDS.
- It can cause a person to discontinue TB treatment.
- Stigma can also lead to loss of jobs. This is because some employers may dismiss an employee due to their status.
- Stigma can also make people feel worthless, inferior, and ashamed of themselves. It makes them feel as though they have let their families and community down, although it is the family/community that has let them down by not offering the necessary help and support that the sick require in their time of need.

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## HOW A TB PATIENT CAN DEAL WITH STIGMA

- **Begin with yourself (health worker/patient).**
  - ~ Examine your own attitudes, assumptions, and beliefs about TB/HIV/AIDS and people living with TB, HIV or AIDS.
- **Reach out to your family and community.**
  - ~ Examine the role that you can play to promote dialogue, understanding, and support for people living with TB, HIV and AIDS in your workplace, family, and community.

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## WHY LEADERS NEED TO ADDRESS STIGMA

- To talk about the beliefs and attitudes community members have towards TB and HIV.
- It is also important that people have the correct information.
- There are many false beliefs about TB that can contribute to stigma. These may include:
  - ~ being bewitched,
  - ~ having a curse,
  - ~ inheriting TB from your father or mother,
  - ~ thinking that TB is a disease of the poor,
  - ~ thinking that when someone has TB he or she must also have HIV.
- For people with TB to feel and know that they have the support of their leaders, family, neighbours, and whole community.

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# HOW LEADERS CAN HELP FIGHT STIGMA

- Effect change
  - ~ Advocate to end TB/HIV/AIDS-related stigma and discrimination in your workplace, family, and the community at large
  - ~ Promote improved care and support for people living with TB/HIV/AIDS.

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# HOW COMMUNITY MEMBERS CAN HELP FIGHT STIGMA

- Think positively
  - ~ Speak out and mobilize others to speak out against TB/HIV/AIDS-related stigma and discrimination.
  - ~ Use language that acknowledges and accepts people living with TB/HIV/AIDS as part of a family, a workplace, and a community.
  - ~ Listen to and honour the courageous voices and experiences of people living with TB, HIV, and AIDS.
  - ~ Be a good role model

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# APPROACH TO COMMUNITY SENSITIZATION

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# WHAT IS COMMUNITY SENSITIZATION IN RELATION TO TB?

- Community sensitization on TB means raising people's awareness of TB facts.
- This will encourage community members to support people who have or think they may have TB, to correct common TB beliefs that are not true, and increase the demand for TB services.
- This is aimed at enhancing awareness, encouraging positive changes in health-related behaviour, decreasing stigma surrounding TB and TB-HIV, and creating a community that supports good health practices.

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# HOW AND WHAT INFORMATION TO SHARE WITH THE COMMUNITY YOU LEAD

- The information to be shared should be the right information at the right time and to the right audience at the right place
- Should include:
  - ~ Before people are tested for TB.
  - ~ After people are tested and learn they are sick with TB disease.
  - ~ When people are undergoing treatment for TB.

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## BEFORE DIAGNOSIS

- Aim –To encourage people to seek prompt diagnosis
  - ~ TB signs and symptoms
  - ~ Need for TB testing at a health facility to correctly diagnose the disease.
    - It is important for people to know that TB testing and treatment is free and that TB is curable.
    - This process and time can be long and costly for the patient and family.
    - Families, friends, and neighbors might also be wondering whether he or she has TB and if their own health is at risk.

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# STARTING AND CONTINUING TREATMENT

- **After people learn they have TB**
  - ~ Just because someone has been diagnosed with TB disease does not mean that he will go for treatment
  - ~ It is important for people to know that with proper treatment TB is curable even in people who are HIV positive.
- **During treatment**
  - ~ Starting one on TB treatment does not mean that he or she will continue with treatment properly therefore
  - ~ It's important for family and community members to support him or her to continue until he or she completes treatment.
  - ~ People who do not follow treatment properly
    - will not be cured of TB
    - they are still infectious to others
    - and it will become more difficult for them to be cured as they can develop resistant to the drugs they were taking.
    - People need support during this time from their families, community members, friends, and health workers to ensure that they complete their treatment.

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# SOME GUIDE TO GOOD LEADERSHIP

- Share your knowledge.  
Remember that you do not have to have all of the answers to help people. Many times there are no easy answers. It is fine to admit when you do not know something. People will be happy with your honesty.
- Treat people with respect.  
Each person should be treated as someone who is capable of understanding his or her own health problems and of making good decisions about treatment. Never blame people for their problem or for past decisions they have made.
- Keep health problems private.  
Never tell anyone else about a problem someone has unless the person with the problem has given you permission. It is important to keep information confidential.
- Remember that listening is more important than giving advice.  
A person often needs someone who will listen to his or her problem without judgment.
- Solve problems with others, not for them.  
Even when a person's problems are very large and cannot be solved completely, that person usually has some choices. You can help that person realize he or she has choices, and help him or her find information to help make a decision.
- Learn from the people you help.  
Learning how others solve their own problems can help you to better help others (and sometimes yourself, too).

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# **SUMMARY OF KEY MESSAGES FOR LEADERS**

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# POLITICAL LEADERS AND ADMINISTRATORS

- Why involve these leaders
  - ~ Political leaders and administrators enforce the law and talk with authority. Their words are taken as the law and government voice.
  - ~ The objectives of using this level of leaders are:
    - To bring about changes in TB-related policies in order to strengthen and help advocate for funding to the TB program.
    - To promote and enhance integration and collaboration between HIV/AIDS and TB program at all levels.
    - To promote the formation of civil society organizations to advocate on behalf of TB patients and TB program implementers on policy changes.
    - To empower community leaders and influencers to help reduce stigma and fear related to TB and TB/HIV co-infection.
    - To empower community leaders and influencers to help reduce stigma and fear in the face of the possible emergence of MDR-TB and XDRTB.
    - To bring about political will, commitment and sustained financial support for the TB/HIV program.

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# WHAT THESE LEADERS NEED TO KNOW

## Basic facts on TB and TB HIV in Southern Sudan

- The country is ranked 17th among the 22 Eastern Mediterranean Region countries.
- TB burden and rates in Sudan are increasing dramatically. There has been over two-fold increase from 45,221 in 1990 to 70,734 in 2000, and then to 93,808 in 2007 (WHO Global report, 2009).
- Southern Sudan has 55% DOTS coverage (the more populous north being 100%)
- Increasing numbers of new TB cases are likely due to HIV infection, malnutrition and poor living conditions.
- Many of the HIV related TB cases present as sputum smear negative.
- In Southern Sudan the diagnosis of smear negative and Extra Pulmonary TB is still not consistent due to lack of facilities and manpower.
- The fact that MDR-TB and XDR-TB have been reported in neighbouring countries means there is need for proper adherence to TB treatment with support from the village health volunteers and family members.
- The health workers too should intensify MDR TB surveillance among TB patients.

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# ADVOCACY REQUIRED FROM THESE POLITICAL LEADERS AND ADMINISTRATORS

- National Policy Guidelines
  - ~ It is important to have a national policy guideline on care and treatment of TB and TB HIV co-infected patients. These guidelines are still in draft form and there is need to be complete them.
- Human resource.
  - ~ Very few health workers, minimal experience on TB and TB HIV
  - ~ GoSS and NGOs trying with little funding

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- TB HIV collaboration
  - ~ This collaboration enables Control of the HIV epidemic and prevention of new infections through the implementation of all of the accepted prevention interventions. These include:
  - ~ Screening persons living with HIV for active TB and referral of newly diagnosed HIV-positive individuals for TB screening.
  - ~ Screening all TB patients for HIV and provision of care.
  - ~ The goal of collaborative TB/HIV services is to reduce the burden of TB in people living HIV and vice versa

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# BUSINESS LEADERS IN TB CONTROL

- The workplace has people who are there on a regular basis, communication systems, and existing structures that can be used for prevention, care, and support. Health is necessary not only for individuals' well being but also for a strong business as well.
- TB is most likely to be spread to family members and colleagues at work place
- TB interrupts workflow, lowers productivity, and raises costs (including having to replace and retrain workers).
- Without treatment, employees who are sick with TB will not be able to work.
- When starting a workplace TB program, make sure everyone involved agrees to keep health information confidential. Lack of confidentiality can lead to stigma and discrimination and prevent those who are sick with TB from going for diagnosis and treatment.

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- Offer to give TB patients a schedule that allows them to work while on TB treatment.
- Should there be need for absence from duty due to the TB illness, allow your employee to come back to work, if necessary with an adjusted workload and different tasks until they are fit.
- Health education can decrease stigma by addressing negative attitudes towards people with TB. The information should stress that;
  - ~ anyone can become infected with TB
  - ~ once treatment is started, most patients are no longer contagious after two weeks of regular drug intake
  - ~ TB will only be cured after completion of treatment.
  - ~ Identify employees who are well respected by their peers and share information about TB with them in order for them to;
    - Recognize the signs and symptoms of TB
    - Encourage people with symptoms to go for diagnosis
    - Support people who are on treatment by DOT.

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# RELIGIOUS LEADERS IN TB CONTROL

- Religious leaders should show compassion and embrace people who are sick with TB as well as those who are infected with or affected by HIV. Provide basic and spiritual support to people who are sick with any disease by:
  - ~ Promoting self-esteem and self-love to help prevent self-destructive behaviors that put people in situations that can risk their health.
  - ~ Helping congregations realize that those infected are not different in other ways and pose no threat, as the disease cannot be spread through casual contact such as talking, dining together, hugging, etc.
  - ~ Talking with people about TB symptoms and make sure people know that TB is preventable and curable.
  - ~ Informing people about health-care services that are available in the community. Tell them also that TB testing and treatment is offered free in government and faith-based health facilities.
  - ~ Discouraging stigmatization due to TB–HIV co-infection. People with TB and TB HIV often experience stigma similar to people who are HIV infected. Religious leaders have an opportunity and obligation to welcome everyone, including people living with HIV and AIDS and people who are sick with TB, into their congregation to gain the spiritual guidance, love, and support they need.
  - ~ Welcoming people who are sick because anyone can become infected with TB.
  - ~ Encouraging open discussions among their faithful about various health topics to raise awareness and improve health.

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## WAY FORWARD: YOUR ROLE AS LEADERS

- This is an exercise where participants sit in groups according to the villages they come from indicating how they want to start their work.
  - Immediately – to start
  - Near future – needs time for preparation
  - Later – needs funding, consultation

Activities	Immediately	Near future	Later

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