

#### **Coming Together to STOP TB**

An Interactive Training Package
For Peer Educators and Outreach Workers







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#### Foreword

Avahan, the India AIDS Initiative of the Bill & Melinda Gates Foundation, is implementing an HIV prevention intervention among an estimated 270,000 individuals from communities at high risk for HIV infections (sex workers, men having sex with men and injecting drug users) in Tamil Nadu, Andhra Pradesh, Maharashtra, Karnataka, Nagaland and Manipur. Individuals from these high risk communities potentially have high burden of active tuberculosis due to high HIV infection prevalence and the high burden of tuberculosis in India. A partnership between Avahan and the Revised National Tuberculosis Control Program (RNTCP) was developed to improve access to tuberculosis services for these high risk communities. The goals of the partnership are to intensify tuberculosis case finding by verbal screening for symptoms and to ensure access to timely and complete TB diagnosis and treatment.

Avahan works through state and local level implementing partners to organize outreach, community mobilization and dedicated clinics for high risk communities. Through this collaboration, peer educators will now be involved in sensitization of community members about tuberculosis, intensified case finding, facilitate treatment adherence and address stigma related to tuberculosis.

Family Health International along with a communication development agency, 'The Communication Hub' worked together to develop a training package for peer educators for these tuberculosis services, which includes a module, pictorial aids and a video film. The training package uses low literacy, highly interactive training aids and tools to build the requisite knowledge and skills for peer educators to carry out their TB related tasks.

We hope that this training package will be useful for the trainers of peer educators and will help implementing partners to maximize the opportunities to get tuberculosis care to these communities.

Dr. Gina Dallabetta Senior Programme Officer Avahan

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# About the TB Training Package

#### Introduction

Avahan, the India AIDS Initiative of the Bill & Melinda Gates Foundation, is working with high risk behavior groups in six states and along the national highways to reduce HIV prevalence. The key population (KP) includes female and transgender sex workers and men having sex with men. Avahan has recently integrated care and support services for HIV positive persons which includes management of Opportunistic Infections such as Tuberculosis (TB). To this end, Avahan has initiated linkages with the Revised National Tuberculosis Control Programme (RNTCP) for training of clinical staff and referral services. FHI is a key partner under the Avahan India Initiative.

It is proposed to undertake training of Outreach Workers (ORWs) and Peer Educators (PEs) at the implementing NGO level with technical assistance from the State Lead Partners (SLPs). This TB training package has been developed by FHI for this purpose. Besides providing basic knowledge about TB, it aims to build skills in TB detection, screening, referral, and motivation for treatment and adherence. The package has been developed in a participatory manner, in consultation with trainers, ORWs and PEs.

The package consists of an integrated set of materials and tools to facilitate the learning process. It is composed of the following items:

- 1. A Training Manual
- 2. Visual Aids (8 flash cards, treatment chart, TB quiz)
- 3. Animation Film: "All in a Day's Work"
- 4. Take-away Booklet

Taken together, the above constitutes an integrated set of tools for a two day training curriculum.

#### **Methodology and Content**

The training manual will be used by trainers at the time of conducting capacity building workshops on tuberculosis for outreach workers and peer educators.

The manual is divided into 8 sessions and covers the following topics:

- Basics of TB
- Tests related to TB
- Treatment for TB-Part I
- Treatment for TB-Part II
- Adherence
- Referrals and linkages in the context of TB treatment
- Roles and responsibilities of ORWs and PEs
- Field challenges

#### Visual Aids accompanying the manual

In order to incorporate interactivity, build skills and aid recall of key learning, a set of visual aids have been designed to be used in specific sessions during the training.

#### **Flash Cards**

There are 8 flash cards in the training package. They depict thematic situations covering the spectrum from detection to treatment. The cards are to be used by the trainers after specific sessions that have covered the content around which each thematic card has been developed. The cards have been numbered and titled for easy identification at the time of usage.

The trainer will show the card and describe the situation depicted therein; questions will be asked to the participants on the situation to generate a discussion. The questions to be asked and the tips to the trainer are printed on the reverse of each flash card to facilitate ease of usage.

An instruction card on usage has been provided.

#### **Treatment Chart**

A visual depiction of the treatment protocol has been included in the form of an easy-to-use chart that the trainer can display during the session on treatment.

#### **TB Quiz**

This game is a participatory tool to test learning and reinforce it. A set of statement cards which are either 'true' or 'false' have been developed. Each card carries a statement about TB on one side and the correct answer with an explanation on the reverse. The game can be played in more than one way and options have been provided in the manual as also in the instruction card. A lab coat with labelled pockets to keep the cards has also been provided as a prop for the game options.

#### Animation Film: "All in a Day's Work"

The 9 minutes long animation film "All in a Day's Work" forms a core component of the training package. While the film may be used independently by trainers in settings such as refresher training, it has a defined place in this package as an enter-educate tool that summarizes key learnings in a manner that's memorable and concise.

#### Take-away Booklet

A small booklet that may be replicated in required numbers, serves as a workshop 'take-away' for the participants. This booklet captures key visuals and learnings from the film and serves to act as a ready-reckoner once the training is over.

#### Do remember!

- The sessions need to be interactive and participatory. Encourage discussion and clarification of doubts
- Assess the level of the participants and modify the sessions in order to help them understand in the best possible way
- Do remember that some sessions are 'content heavy'. You may need to give participants additional time to absorb the information
- The context of the training is important. Please use local terminology, examples and stories where you can to illustrate the information
- While the manual is structured, the trainer has the freedom to use the sessions in a flexible manner if s/he feels the need for the same

#### Caution!

Knowledge about TB is important for the ORWs and PEs as they work with populations at risk for HIV and consequently, for TB. However, while information on HIV-TB co-infection must be shared with the participants, care must be taken that they do not communicate the same in the community in a manner that may cause unnecessary fear or add to stigma.

## Day One

**Ice Breaker** 

The trainer could choose one or more of the following options as an ice

breaker depending on the time s/he has.

Option 1: "In search of self"

Duration: 20 minutes

The participants are asked to walk around the room/ training area for 5 minutes and pick up an object which they feel best or most closely relates

to their personality.

They then come forward one by one and introduce their names and their

object. They also share the reason(s) for choosing the object.

**Option 2: "Arty expressions"** 

Duration: 20 minutes

Materials required: Drawing sheets, pencils/ pens/ crayons

The participants are given a drawing sheet each with some pen/ pencil/

crayons. They are asked to draw a visual which best describes them.

It could be anything from an object to a scene depicting their personality,

their work or their likes/ dislikes.

Each one of them by turn then comes forward and introduces their names

and shares their visual with an explanation.

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#### Note to the trainer:

- The focus of the exercise is self expression and not so much the artistic capabilities of the participants
- Drawings may range from abstract to being very simplistic. Do appreciate the efforts of the participants!

#### Option 3: "It's all in the name"

Duration: 20 minutes

The participants are asked to introduce their name non-verbally by enacting its meaning while others try and make a guess.

#### Session One: Basics of TB

#### **Objectives:**

To help participants understand the basics of TB

#### **Duration:**

2 hours

#### **Materials Required:**

Flip chart, markers, Flash card # 1 - Pinky's persistent cough

#### **Activity 1**

Ask the participants to state all the associations that come to their mind on hearing the word 'TB'. It is likely that the associations will be that of disease, death, stigma, infection etc. Write them on the flip chart.

Discuss why these words were most strongly associated with TB. Tell the participants that in the next two days they will get to understand TB in a manner that will enable them to clarify their doubts.

Emphasize that today TB is curable. With correct knowledge, participants would change their perceptions of the disease and clarify their misconceptions on the same.

Tell the participants that they need to pay attention to the information being shared with them as they will have an active role to play in the prevention and cure of TB. Their role starts with the screening of TB patients and so they need to understand the signs and symptoms in order to identify the cases among the KP.

#### **Activity 2**

Tell the participants that they may be wondering why information on TB is important for them. Ask them whether they and their KP are vulnerable to TB. Explain to them that while TB can affect anyone, the learning on TB is particularly important to people working in the field of HIV/AIDS. A person living with HIV is easily prone to opportunistic infections which attack the body due to its lowered immunity. As HIV weakens the immune system of people living with the virus, they are at greater risk of TB.

Of the key population affected by TB, all may not be HIV positive. Having this knowledge, the participants would be in a position to work towards prevention of TB as well as support those with the TB infection to seek and complete their treatment.

Take the participants through the following information areas.

#### **Understanding the basics of TB**

#### What is TB?

TB is an infectious disease caused by a bacterium, Mycobacterium Tuberculosis.

#### How does it spread?

TB is spread through the air by a person suffering from active TB. TB in the lungs or throat can be infectious. This means that the bacteria can spread to other people.

The bacteria get into the air when a person with active TB of the lungs or throat, coughs or sneezes. People nearby may breathe in these bacteria and become infected.

Emphasize that is it important that we do not spread TB to others.

After 2-3 weeks of treatment TB can cease to be infectious. TB in parts of the body, other than the lungs, such as the kidney or spine, is not infectious.

#### How does one prevent spreading TB to others?

- Start the treatment for TB immediately
- Cover your mouth while coughing
- Keep the home well ventilated; fresh air takes away the germs

#### What are the different types of TB?

Tuberculosis can affect any part of the body. The most commonly affected are the lungs. When lungs are affected, it is called "Pulmonary TB".

Other organs of the body like the lymph nodes, bones, intestine, reproductive system, skin etc can also be affected. When TB occurs in any of these organs (other than the lungs), it is called "Extra-pulmonary TB". \*\*

#### What are the signs and symptoms of TB?

TB should be suspected if a person has cough for 2 weeks. Persistent cough is the major symptom of TB.

Other symptoms of TB that may accompany cough are:

- fever, especially rising in the evening
- coughing up of blood
- pain in the chest while breathing
- breathlessness
- loss of weight
- loss of appetite
- night sweat
- swelling of glands in the neck, armpit and groin

Remind the participants that if a KP has any of these, they must get checked for TB. Anybody-young, old, rich or poor, can get TB! PEs and ORWs have an active role to play in the screening, referral, and treatment of TB.

\*\* In case of Extra-pulmonary Tuberculosis, depending on the organ affected, the patient will have specific symptoms. Example: Lymph node TB is the commonest form of Extra-pulmonary TB. A person with TB in the Lymph nodes will have enlarged nodes that may grow over time. There may be no other signs that the person has TB. TB of the joints presents as swelling and pain of the affected joints. TB affecting the brain presents with headache, fever, neck stiffness and mental confusion.

#### **Activity 3**

Identification of signs and symptoms of TB

Use the Flash card # 1 - Pinky's persistent cough. Show the card and describe the situation depicted therein; ask questions to the participants on the situation to generate a lively discussion. The questions to be asked and the tips to the trainer are printed on the reverse of the card to facilitate ease of usage.



#### Flash Card 1: Pinky's persistent cough

Pinky has been coughing for 2 weeks now and has had fever in the evenings. Her partner Raghu thinks the cough will go away with cough syrup and is irritated with Rani, the Peer Educator who is trying to convince him that Pinky should see a doctor and get a TB test done.

#### Ask the participants:

- 1. Why does Rani suspect that Pinky may have TB? Besides a cough and fever, what other symptoms could indicate that a person may have TB?
- 2. Why do you think Raghu is reluctant to let Pinky go to the clinic? What can Rani tell him to allay his fears?
- 3. If Pinky is not keen to go the health centre, can Rani collect her sputum and take it for a test? If not, why not?
- 4. Can other household members get the infection from Pinky? What precautions should she take to prevent the infection from spreading?

#### **Note to Trainer:**

- Help participants enumerate symptoms of TB, emphasising that persistent cough (2 weeks) must be investigated for TB
- Encourage them to understand their audience's fears and to empathize with them
- Discuss how the verbal screening tool may be used by the PEs in this situation and help participants generate strategies for motivation and persuasion
- Clear their doubts on the infectiousness of TB by focusing on the fact that TB ceases to be infectious after 2 weeks of regular treatment
- Emphasize the importance of cough hygiene such as covering one's mouth with a cloth/dupatta while coughing/sneezing etc
- Reiterate the importance of communicating on the curability of TB if complete and regular treatment is taken

#### Session Two: Tests Related to TB

#### **Objectives:**

To help participants understand the tests related to TB

#### **Duration:**

1 hour

#### **Materials Required:**

Flip chart, markers, Flash card # 2 - Rahul and the sputum test, and sputum container (if available)

#### **Activity 1**

Ask the participants what are the ways to detect whether a person has TB or not. Most likely they will come up with the signs and symptoms of TB. This will help the trainer assess their understanding from the previous session and also start a discussion on testing.

Take the participants through the following information areas. The trainer could make the session participatory by asking them the questions and then explaining the correct responses in detail.

#### How is TB detected?

The best way to detect TB is through a sputum test for TB germs. Any person suffering from cough for 2 weeks should get the sputum tested for TB germs.

The results of your sputum test will help the doctor decide on your treatment or further testing.

#### Where can one get the sputum test done and how much does it cost?

The sputum examination can be done at any government or municipal health centre, known as a Designated Microscopy Centre (DMC). The test is free of cost under the Revised National Tuberculosis Control Programme (RNTCP). \*

Emphasize that the participants need to play an active role in the screening of TB patients and in referring them to the nearest DMC for a test!

<sup>\*</sup> Designated microscopy centres (DMC) are available at most taluk level and in larger health centres. They are easily accessible to the patient, and the patient can avail of sputum testing. The Revised National Tuberculosis Control Programme (RNTCP) is based on the DOTS (explained in a later section). Under it the diagnosis and treatment of TB is free at all government and private health facilities.

#### How many sputum tests are needed?

It is essential to test two sputum specimens of a single patient. Even if one sample of sputum is positive it is taken as a confirmation of TB diagnosis.

#### How is the sputum sample collected?

Two sputum samples - one spot and another early morning- are required for the diagnosis. The clinic/peer educator will explain the correct way to collect a sputum sample and give the patient a container to collect the early morning sample and bring it to the DMC later in the day. At the DMC the patient will be given another container for the spot sample. However, if the clinic/peer educator does not have sputum containers, then the patient will need to visit the DMC to give the spot sputum sample. Here s/he will be given a container for the early morning sample to be collected the next day and brought back to the DMC.

The trainer could show the participants a sample of the sputum collection box.

The trainer could also draw two containers on the flip chart for easy visual recall of this learning.

#### Things to remember during sputum collection

- Patients should take a deep breath and try hard to get the thick sputum out from deep inside the chest
- Be careful to get the sputum out and not the saliva from the mouth
- The sputum must be put in the container provided by the health worker and covered immediately
- When collecting the sample the patient's mouth should be clean and not contaminated with food particles
- When taking sample at home it must be the first sample in the morning

#### If the sputum test is negative, does it mean that the patient does not have TB?

Not always!

If the sputum test does not show TB but the patient has some signs, then antibiotics are given for 10-14 days. If the patient's symptoms do not go away the sputum test is repeated. If it is still negative, the patient is further examined by doing an X-ray of the chest and other tests. If the X-ray shows TB lesions, the patient is said to have sputum negative TB. \*\*

Tell the participants that they need to follow up with the suspected cases to make sure diagnosis is confirmed.

#### Is TB curable?

Yes! Today TB is curable provided the patient follows the prescribed course of medication- known as Directly Observed Treatment Short Course Strategy (popularly known as DOTS).

Emphasize the curability of TB! Also tell the participants that this may be one of the first pieces of important information that they may need to tell their patients

#### How much does TB medication cost?

TB medication-DOTS (discussed at length in the next session) is available free at the government and private health centres.

\*\* Pulmonary TB can be of two types: Sputum positive pulmonary TB and sputum negative pulmonary TB. The investigation of Extra-pulmonary TB depends on the organ affected. It may not be easy for the health care worker at the centre to suspect Extra-pulmonary TB and the patient should be referred to the doctor.

#### **Activity 2**

#### Understanding testing

Use the Flash card # 2 - Rahul and the sputum test. Show the card and describe the situation depicted therein; ask questions to the participants on the situation to generate a lively discussion. The questions to be asked and the tips to the trainer are printed on the reverse of the flash card to facilitate ease of usage.



#### Flash Card 2: Rahul and the sputum test

Rahul has had persistent cough for several weeks. Here is a picture of the DMC where he has come to give his sputum for TB testing.

#### Ask the participants:

- 1. Would it be a part of your responsibility to accompany Rahul for the test?
- 2. Would Rahul have to pay for the test at the government clinic?
- 3. How many samples would need to be collected, and over what period of time?
- 4. If treatment starts, would Rahul need to come back for sputum tests again?
- 5. If Rahul's test is negative, does he need to do anything further?

#### **Note to Trainer:**

- Generate a discussion on roles and responsibilities of PEs/ORWs about referrals, accompanied referrals, follow up, etc
- Emphasize that the participants need to play an active role in the screening of TB patients and in referring them to the nearest DMC for a test!
- Emphasize that all tests and treatment under RNTCP at government clinics and hospitals are free
- Reiterate the importance of two sputum tests
- Clarify that repeat sputum tests are necessary before the patient moves from the intensive phase of treatment to the continuation phase and also at the end of treatment
- Focus on the fact that even if smear microscopy is negative, the patient may still have TB. Additional testing may be needed to address the problem

#### Session Three: Treatment for TB - Part I

#### **Objectives:**

To help participants understand the treatment for TB - Part I

#### **Duration:**

2 hours

#### **Materials Required:**

Flip chart, markers, treatment chart

#### **Activity 1**

Ask the participants whether TB is curable. The most important information that the participants need to know at this point is that it is!

Also tell them that this is the first and perhaps the most important information that they need to communicate to all patients.

Take the participants through the following information areas.

#### Why is it important to treat TB?

- To prevent death from TB
- To stop the infection from spreading to other parts of the body
- To feel well and strong again and lead a healthy and productive life
- To prevent spreading infection to others

#### What is the duration of TB treatment?

TB treatment requires at least 6 months of regular medication. In some cases it may take 6-9 months to be cured.

#### What is the treatment for TB?

The treatment for TB is known as DOT. This stands for Directly Observed Treatment. It means that the patient swallows the anti-TB medicines in the presence of a health worker or a trained volunteer other than a family member.\*

\*The most common medicines used to cure TB are isoniazid (INH) rifampicin (RIF) ethambutol and pyrazinamide

#### Where can one get TB medication? How much does it cost?

Treatment for TB is available free of cost from any DOT centre. DOT centre/provider can be just about anyone (other than a family member) who is accessible and acceptable to the patient. This includes Government Health Centres, NGO clinics, local doctors, teachers, community volunteers and such like.

#### Is there an injection for TB?

The tablets are as good as any injection and injection is not usually necessary. In case a patient had TB treatment previously, the doctor may add an injection to the regime as an extra assurance for effective treatment.

#### The trainer displays the Treatment Chart on the board and refers to the same while explaining the next 2 sections.

#### What are the categories of TB treatment?

There are three treatment categories for TB patients. Patients are classified into one of these categories based on sputum examination and other test results. The medicines for each patient are kept in a box with the patient's name on it. The boxes are marked by the colour category and the patient details. Each box contains two pouches- one for the intensive phase and the other for the continuation phase. The medicines are kept in blister packs in the pouches.

#### What are the phases of TB treatment?

**Intensive Phase:** The duration of this phase is two months for Category I and III, and three months for Category II. The drugs in intensive phase are to be taken three times a week, either on Mondays, Wednesdays, Fridays OR Tuesdays, Thursdays and Saturdays. The patient consumes all the doses of intensive phase under supervision of the DOT provider.

The phase is prolonged by one more month if the patient is still sputum smear positive at the end of the intensive phase.

**Continuation Phase:** The duration of this phase is four months for Category I and III and five months for Category II. The anti-tuberculosis drugs are to be taken on three days a week and on other days a single tablet of Vitamin B is taken. The patient visits the DOT centre/ DOT provider once a week and consumes the first dose under supervision and the rest of the doses at home. On the next visit in the subsequent week the patient brings back the empty blister pack.

#### Things to remember:

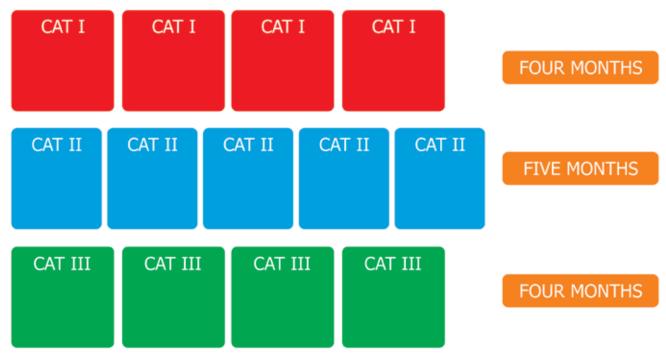
- 1. All the TB medicines for the day should be taken together
- 2. Medicines can be taken after a snack/ light meal
- 3. Medicines can be taken in the morning/afternoon/evening depending upon what the patient arranges with the DOT provider

#### **CATEGORIES AND DURATION OF TREATMENT**





### **SPUTUM TEST**CONTINUATION PHASE



# TWO PHASES OF TB TREATMENT







3 TIMES A WEEK UNDER THE SUPERVISION OF THE DOT PROVIDER



Tuesday

Monday

Vitamin B

FIRST WEEKLY DOSE UNDER SUPERVISION OF THE DOT PROVIDER AND THE REST AT HOME OTHER DAYS A SINGLE TABLET OF VITAMIN B

Vitamin B

Vitamin B

Sunday

Saturday

Friday



#### Session Four: Treatment for TB - Part II

#### **Objectives:**

To help participants understand the treatment for TB - Part II

#### **Duration:**

2 hours

#### **Materials Required:**

Flip chart, markers, Flash card # 3 - Helping Radha understand her treatment, and Flash card # 4 - Kumar and the side effects of medication

#### **Activity 1**

Tell the participants to remember:

- It is important to complete the entire treatment (even if you start feeling better)
- Inform your DOT provider about any side effects or changes
- Pay attention to nutrition. Have a high protein diet when on medication
- When you are on DOT take all the drugs of the intensive phase and the first dose of the weekly course of the continuation phase in front of the DOT provider
- In the continuation phase, bring the empty pack during the next weekly collection of drugs
- You need to repeat the sputum test to know your progress. After a few months of treatment, your health provider will advise you to repeat the test. At the end of your treatment you will repeat it again
- Children who have been in contact with a case of TB need to be checked immediately. It is important to screen children specially those under five at the earliest. If anyone else of any age in the household is ill, they should also be checked for TB at the earliest.

#### **Activity 2**

Use Flash card # 3 - Helping Radha understand her treatment. Show the card and describe the situation depicted therein; ask questions to the participants on the situation to generate a lively discussion. The questions to be asked and the tips to the trainer are printed on the reverse of the flash card to facilitate ease of usage.

Emphasize that is common for people on TB treatment to start feeling better after starting medication. Reinforce that the medication should not be stopped even if the patient is feeling better!

Poor treatment like irregular medication or stopping treatment early means that TB will return and the patient will be sick again. It may also lead to multi-drug resistant TB (MDRTB) which is a very serious type of TB where the usual medicines are no longer effective. Treatment of MDRTB is very expensive and not easily available. Also if MDRTB is not treated, it can cause death.



#### Flash Card 3: Helping Radha understand her treatment

Radha is confused about the TB treatment she has just started and meets Maya, the Outreach Worker, to ask her about the medicines and how often and where they need to be taken. She tells Maya that she has heard that the medicines can also be taken at home, whereas she has been asked to take it in front of a DOT Provider.

#### Ask the participants:

- 1. Do you think Radha can take her medicines at home at this stage?
- 2. What is the treatment regimen she will have to follow?
- 3. Why do patients get medicine from different coloured boxes when they are all getting treated for TB?
- 4. How will the doctor know when Radha can shift from the intensive to the continuation phase?

#### **Note to Trainer:**

- Discuss the categorization of treatment with the participants
- Explain the transition from the intensive to the continuation phase and the supervision of doses under each
- Emphasize the importance of adherence to the participants
- Generate discussion on how the treatment regimen can be communicated in a simple manner to patients

#### **Activity 3**

Take the participants through the following information areas.

#### When is treatment complete?

A patient who had tested positive at the time of the initial sputum test but has now completed treatment and has tested negative sputum in two samples (one of which was at the end of treatment) is known as a 'cured' patient.

#### Are there any side effects of the TB medication? What are they?

It is normal for all patients to have red-orange colored urine. It is harmless and goes after completion of treatment. Patients may experience some side effects when taking the anti-tuberculosis drugs. These side effects may be classified as minor or severe.

**Minor Side Effects:** Gastrointestinal upset, mild rash and drowsiness are common side effects. These go away on their own and the rash does not leave any scars.

**Severe Side Effects:** A few patients may develop serious nausea, vomiting, numbness in hands and feet or a rash. If that happens the patient should return to the doctor so that s/he can help sort out the matter. Patients taking the injection can also sometimes have giddiness and rarely loss of hearing or kidney problems. Any concern should be discussed with the doctor.

#### Should TB medication be stopped in case of side effects? What should be done?

In case of side effects the patient must seek counsel from the DOT provider or doctor but the decision should always be by a doctor.

#### Popular myths associated with side effects:

- Medicines cause heat in the body and should be stopped
- Side effects mean that the medicine is not suiting the patient
- Some health centres give ineffective medicines which do not cure TB

#### **Activity 4**

Use Flash card # 4 - Kumar and the side effects of medication

Show the card and describe the situation depicted therein; ask questions to the participants on the situation to generate a lively discussion. The questions to be asked and the tips to the trainer are printed on the reverse of the flash card to facilitate ease of usage.



#### Flash Card 4: Kumar and the side effects of medication

Kumar has recently started his TB medication. These days he finds that his urine is discoloured and this has made him anxious. Kumar's supervisor Mr Raman warns him that he is not being attentive at work. Kumar is very worried that he may lose his job and he feels that the TB medicine is not suiting him. He approaches Hari, the Peer Educator, stating that he wants to stop the medication.

#### Ask the participants:

- 1. Should Kumar stop the medication?
- 2. What are the common side effects of TB medication?
- 3. How should Hari reassure Kumar?
- 4. If the symptoms continue over time, what can Hari do next?
- 5. Which side effects are categorized as serious?

#### **Note to Trainer:**

- Clarify that minor side effects are normal and also emphasize the need for consulting the doctor in case of major side effects
- Focus on the communication and counselling skills needed to handle the fears of side effects of the patient which could lead to non-adherence
- Emphasize the importance of reassuring the patients that side effects are not fatal and sometimes, are an indication that the treatment is working
- Generate discussion on the next steps like visiting the doctor with the patient if the symptoms continue

#### Session Five: Adherence

#### **Objectives:**

To help participants understand the importance of adherence in case of TB medication

#### **Duration:**

2 hours

#### **Materials Required:**

Flip chart, markers, Flash cards # 5 - Julie stops her medication and # 6 - Kasim leaves the city

#### **Activity 1**

Take the participants through the following information areas.

#### What is adherence?

Adherence refers to following the regular treatment regime as prescribed by the doctor/health worker.

#### Why is it important to adhere?

Missing the doses or dropping makes treatment less likely to work and increases the chances of death. It is important not to miss even a single dose. Missing doses means TB illness can return. It may also lead to multi-drug resistant TB (MDRTB) making it almost incurable. Treatment of MDRTB is very expensive and not easily available. Also, if MDRTB is not treated, it can cause death.

#### What is defaulting?

Missing the doses or dropping out of treatment is known as interrupting. Those patients who interrupt treatment for a long time (> 2 months) are known as "defaulters" or "defaulting clients".

It is important to understand and be empathetic towards default cases.

#### **Activity 2**

#### Generate a discussion on the reasons for defaulting and ensure that the following points are covered

- Side effects of medication
- Response to early treatment and belief that one is cured
- Poverty
- Migration
- Social/ family issues (non supportive family members)
- Stigma
- Gender issues
- Mobility
- Alcoholism
- Infrastructural issues
- Attitude of health staff

Use Flash card # 5 - Julie stops her medication

Show the card and describe the situation depicted therein; ask questions to the participants on the situation to generate a lively discussion. The questions to be asked and the tips to the trainer are printed on the reverse of the flash card to facilitate ease of usage.



## Flash Card 5: Julie stops her medication

The DOT provider at the DOT Centre has noticed from the records that Julie has not been coming for her medicines for some time now. He asks Sushila, the ORW, what could be the problem. Sushila finds out that Julie has stopped coming as her cough has lessened, she is feeling better, and believes she has been cured.

#### Ask the participants:

- 1. What would your responsibility be towards Julie in this situation?
- 2. How would you convince her to continue her treatment?
- 3. Would you involve Julie's family members in helping her adhere to her treatment?
- 4. What are some of the other reasons because of which patients discontinue their treatment?

#### **Note to Trainer:**

- Generate discussion on roles and responsibilities of PEs/ORWs in defaulting situations
- Reiterate importance of empathizing with patients who interrupt treatment and understanding the reasons for their behaviour
- Emphasize the skills needed to handle interrupters and enlist suggestions from participants on strategies that could be used
- Discuss drug resistant TB and how information about this may be communicated to patients without causing undue alarm

Based on the above discussions and activities, sum up what must be done to deal with patients who interrupt their TB treatment.

#### How to deal with treatment interruptions?

When a patient fails to attend a DOT appointment, a system should be in place that allows prompt patient follow-up. The DOT provider should visit the patient's home on the same day to find out why the patient has not appeared for his/her appointment/treatment, and ensure that treatment is resumed immediately.

- Contact the concerned health worker so that the patient can be helped
- Be empathetic towards the patient
- Understand the reasons for interruption and work with the patient to help solve the problem
- Reiterate the importance of adherence
- Contact the patient within 24 hours to ensure that treatment is continued right away

The situation should be addressed in a sympathetic, friendly, and non-judgmental manner. It is important to understand the reasons for missed dose(s) and to work with the patient and his/her family to ensure that treatment is not disrupted again.

#### What if the patient has to move to another town?

DOTS is available in every district of India. Contact your provider as soon as possible so that a transfer can be arranged. Some medicines can also be given for travel time so that no doses are missed.

Use Flash card # 6 - Kasim leaves the city

Show the card and describe the situation depicted therein; ask questions to the participants on the situation to generate a lively discussion. The questions to be asked and the tips to the trainer are printed on the reverse of the flash card to facilitate ease of usage.



## Flash Card 6: Kasim leaves the city

Meera, a Peer Educator, drops by at Kasim's house to see how he is progressing with his treatment. Kasim has been on DOT medication for a month now. Kasim's wife informs Meera that he has gone to book train tickets as they are all planning to leave the city forever and return to their home town.

#### Ask the participants:

- 1. How should Meera respond to this information she has just received?
- 2. Can Kasim be allowed to take all his medicines with him to his hometown?
- 3. If not, what options does he have to be able to continue his treatment in his new location?
- 4. If Kasim does not continue the treatment, what could the results be?

#### **Note to Trainer:**

- Ensure that participants understand the issues related to migrant patients
- Discuss the role of the family in the case handling
- Ensure that participants are equipped with information about case transferring and referrals
- Emphasize the significance of adherence and the hazards of defaulting and reiterate that continuity of treatment has been made possible under RNTCP

Divide the participants into two groups. No props are needed for these role plays. The participants choose the roles in their groups and enact the play before the larger group.

Give the two groups the following situations:

- 1. Shyam is a TB patient and is on DOT medication. His wife approaches the PE Preeti, saying that Shyam is unable to adhere to the medication as he sleeps through the day after a drunken night. She wants Preeti to help her deal with the situation.
- Malti is on DOT medication. She does not want to continue her treatment as she has a lot of household work to do and feels that visits to the DOT centre take up too much of her time. The PE, Nirmala, wants to help her out.

Hold a discussion on the role plays once they are done. Talk about each of the main characters. Also discuss the situation and related situations. Think of alternate ways and problem-solving techniques to address the issue. Provide constructive criticism.

#### Tips to the trainer

- Encourage participants to take part in the role plays
- Allow them to use their imagination and add characters if needed to the situation
- Encourage participants to have fun while enacting without losing the seriousness of the issue
- Remind participants to focus on problem solving techniques and strategies rather than on acting ability

Day Two

## TB Quiz: A game to revisit core learning

#### **Objectives:**

Revisit core learing from Day 1

#### **Materials Required:**

Flip chart, markers, Visual Aid (doctor's lab coat with True & False Statement cards)

#### **Duration:**

30 minutes

Tell the participants that the day will begin with an interesting game. Ask which one of them would like to become a doctor for a day. Ask the volunteer to wear the lab coat. The lab coat has 20 statement cards on TB in one of its pockets.

### **Option 1**

Select a volunteer to wear the lab coat and become a doctor. Divide the rest of the group into 2 teams. Team 1 sends a volunteer to pick a question from the doctor's lab coat pocket labelled "TB Quiz". The trainer reads the statement aloud and team 2 has to answer whether it is true or false. If their answer is correct, they get a point. If not, the trainer provides the correct answer. Discussions are held on the answer.

Team 2 now sends a volunteer, and the game is played again. At the end, the team with more points is declared the winner.

## Option 2

The trainer wears the lab coat with the statement cards kept in the pocket labelled "TB Quiz". The group members sit in a circular formation on the floor as the trainer plays music. The group passes a cushion around. The trainer stops the music. The person holding the cushion when the music stops must pull out a statement card from the trainer's lab coat pocket. The trainer reads the statement aloud and the person who has picked the card answers whether the statement is true or false. If the answer

is correct, the person gets to stay in the game; otherwise the person is 'out'. The trainer provides the correct answer with an explanation (written on the reverse of the card). The cushion is passed again and the game continues.

The trainer could think of other ways to use the cards during the training. Whichever way you play it, the card game is an entertaining way to reinforce core learning on tuberculosis.

There may be disagreement in the group about statements being true or false. Encourage discussion and then give the correct answer which is written behind the card with a detailed explanation.

Note: The second lab coat pocket labelled "Ask the Doctor" can be used for participants to put in their queries and doubts. These may be answered over the course of the training. In case of non-literate participants, they may approach other group members or the trainer to help write their questions.

## 1 TB patients should sleep in a separate bedroom, away from other family members.

#### **False**

TB bacteria are released into the air when a person with 'active' TB disease of the lungs or throat, coughs or sneezes. People nearby could breathe in these bacteria and become infected. However, there is no need to isolate a TB patient! Simple cough hygiene practices such as covering one's mouth while coughing are sufficient. Most important, the patient should undergo sputum testing for diagnosing TB, and take complete and regular treatment.

After taking medicines for about 10-14 days, the patient may no longer be able to spread TB bacteria to others.

(One caution: The room where the patient lives or sleeps should be well ventilated otherwise theoretically the patient does pose a risk of transmitting infection to other members of family.)



## 2 TB can spread through handshakes, sharing toilet seats, or using the same utensils as someone who is infected with TB.

#### **False**

People <u>cannot</u> get infected with TB bacteria by the above means. TB is spread through the air when a patient with the disease of the lungs or throat, coughs or sneezes. TB germs from the lungs are then sprayed into the air in tiny drops. If another person breathes in some of these drops, s/he can get TB.

### 3 TB is hereditary.

#### **False**

TB is NOT hereditary. It is a disease that is transmitted from an infected person to a non-infected person through the air during coughing and sneezing. When this happens, the droplets containing Mycobacterium tuberculosis enter the air where those around them can inhale them and become infected.

## 4 HIV greatly increases the risk of getting ill from TB.

#### **True**

An HIV positive person has 50-60% lifetime risk of developing TB disease as compared to an HIV negative person who has a risk of just 10% of developing TB in a lifetime. HIV debilitates the immune system of our body thus increasing the vulnerability to TB infection and increasing the risk of progression to TB disease.

TB is the most common opportunistic infection in People Living with HIV/AIDS (PLWHA). Early diagnosis and effective treatment of TB among HIV-infected patients is critical. Anti-TB treatment is the same for HIV-infected persons as it is for HIV-negative TB patients. But HIV infected persons need additional care and treatment. It is important to tell the doctor that the patient is HIV infected (patient should tell him/her self), so that additional care and treatment can be given.

### 5 X-ray screening is the most reliable way to detect TB.

#### **False**

Diagnosis of TB by chest X-ray alone is <u>unreliable</u>. There is a high chance of wrongly diagnosing a patient if X-ray alone is used for diagnosis. Sputum microscopy is cost effective, requires minimum training and is the main investigation for diagnosis, monitoring and defining cure.

X-rays are a complementary tool for the diagnosis of TB. In certain cases, an X-ray may be recommended. For example, when a sputum negative patient does not respond to treatment with 10-14 days of general antibiotics, an X-ray Chest may be required for aiding diagnosis of TB.

## 6 The result of a sputum test is available within two days and correct treatment can start immediately.

#### True

Two samples of sputum have to be examined in two days. For diagnosis of pulmonary TB, sputum smear microscopy is the main tool. Two samples of sputum have to be examined. Even if one of these samples is positive, it is taken as a confirmation of TB diagnosis and correct treatment can start immediately.

## 7 During the entire treatment phase, TB is infectious and one should stay away from TB patients.

#### **False**

Risk of spread of infection depends on the level of infectiousness of the patient and the duration and intensity of contact. Most TB patients are not highly infectious and therefore contracting infection requires prolonged direct contact with a patient who is not on effective treatment.

Patients put on effective treatment rapidly become non-infectious in 10-14 days and are not a risk to others. A patient on regular and effective treatment, particularly one on directly observed treatment, presents virtually

no risk of infection. The highest risk is from patients who are undiagnosed and not on treatment.

## 8 Diagnosis and treatment for TB is free of cost under the government programme.

#### **True**

Sputum microscopy and treatment services for TB are available free of cost through the Revised National TB Control Programme (RNTCP).

## 9 When you have TB it is advisable to stay indoors in a closed room.

#### **False**

germs.

Transmission generally occurs indoors, where bacteria/TB germs can stay suspended in the air for hours to be inhaled by others and thus increases the chance of acquiring infection. Ventilation removes the TB germs. TB germs spread more easily if many people live together in rooms without fresh air or sunlight. Fresh air blows the germs away, and sunlight kills the

## 10 During treatment, urine or tears can become orange or red in colour.

#### **True**

Discoloration of urine happens because of the drug Rifampicin. Reassure the patient that there is nothing to worry about and it is an indication of the medication working. In case of major side effects they should report to the MO (medical officer).

## 11 If you have a persistent cough but your sputum test is negative, you do not need to take any medicine.

#### **False**

Patients with negative smear results are prescribed antibiotics for 10-14 days. Most patients are likely to improve with a course of antibiotics if they are not suffering from TB.

If the symptoms persist after the course of antibiotics, the patient is re-evaluated by repeat sputum examination and X-ray examination. Thereafter, if the patient is diagnosed as having TB, treatment is initiated accordingly.

## 12 TB treatment started in one location can be continued under the DOTS programme in another location.

#### **True**

The Revised National Tuberculosis Control Programme (RNTCP), has made free diagnosis and treatment available in every corner of India. This DOTS strategy ensures that treatment is not interrupted and can be continued in another location. The RNTCP can even trace patients, who interrupt treatment and bring them back to treatment through their structured network all over India. It is important to inform the health worker or STS as soon as possible so that a transfer to the new address can be arranged. Some medicines can be given for the travel time so that no doses are missed.

## 13 After 6-8 months of medication you can stop treatment as you can assume you are cured.

#### **False**

You cannot assume you are cured. You must get repeat sputum tests or examination done as advised.

#### 14 Children cannot get TB.

#### **False**

Children who have family members suffering from TB are more likely to become infected and develop TB disease because the immunity of a child is not as strong as that of an adult.

If a household member has TB, children must be screened for symptoms of TB. If present, regime for paediatric TB should be followed and the child must be given a full course of anti-TB treatment if s/he is diagnosed as a TB case. All children under six years of age in the house of a patient with sputum positive TB must be screened for TB by a doctor and are provided free preventive treatment for TB.

#### 15 When on TB medication one cannot have sex.

#### **False**

Having TB disease should not stop you from leading a normal life. When you are feeling well, you can do the same things you did before you had TB disease. The medicine will not affect your strength, sexual function, or ability to work but you must continue your treatment and complete the course of treatment.

## 16 If TB treatment is not taken regularly, this can lead to serious complication, relapse and drug resistance.

#### True

TB treatment is only effective if patients complete all their drugs for the entire period prescribed. It is dangerous to take only a part of the prescribed drugs because in such cases the disease may become incurable. Also, the patient may develop a resistant form of tuberculosis which requires at least 18-24 months of treatment with medicines which are 100 times more expensive, often highly toxic, and may not be easily available.

#### 17 All HIV+ people have TB.

#### **False**

People with advanced HIV infection are vulnerable to a wide range of infections called 'opportunistic infections' because they take advantage of the opportunity offered by a weakened immune system. Tuberculosis is an HIV related opportunistic infection. People who are HIV+ are likely to develop TB but all HIV+ people do not have TB.

#### 18 All TB patients are HIV+.

#### **False**

TB is spread through the air by a person suffering from active TB. A person with TB can acquire HIV infection through the same modes of transmission that a person without TB can: through unprotected sex, using unsterilized needles or syringes, through transfusion of infected blood, and from an infected mother to her child during pregnancy, delivery or breastfeeding.

#### 19 A TB patient should not get married.

#### False.

Patients who have TB can certainly get married. Risk of spread of infection depends on the level of infectiousness of the patient and the duration and intensity of contact. Most TB patients are not highly infectious. Contracting infection requires prolonged direct contact with a patient who is not on effective treatment.

Patients put on effective treatment rapidly become non-infectious and are not a risk to others. A patient on regular and effective treatment, particularly one on directly observed treatment, presents virtually no risk of infection. The highest risk is from patients who are undiagnosed and not on treatment.

## 20 The chances of getting STIs (Sexually Transmitted Infections) increases if you have TB.

#### **False**

TB is spread through the air from one infected person to another uninfected person. The bacteria are released in the air when a person with active TB disease of the lungs or throat coughs or sneezes. People nearby may breathe in these bacteria and become infected. STIs are sexually transmitted infections that are spread through sex and sexual contact. TB and STIs have different routes of transmission. Therefore, TB does not increase the chances of acquiring STI.

# Session Six: Roles and Responsibilities of Outreach Workers and Peer Educators

#### **Objectives:**

To help participants understand their roles and responsibilities as Outreach Workers and Peer Educators

#### **Duration:**

3 hours

#### **Materials Required:**

Flip Chart, markers

### **Activity 1: Roles & Responsibilities**

Ask a volunteer to come to the blank flip chart that you put up and to draw the steps of TB screening and treatment along with the responsibilities of the ORW/ PE at each stage.

S/he can seek help from the other group members who may prompt him/her. Make sure that the following steps are marked out and the responsibilities are discussed.

- 1. Screening of KP for TB signs and symptoms
- 2. Referring the patients to the nearest Avahan clinic
- 3. Helping with address verification for KP diagnosed with TB
- 4. Following up on results and helping positive cases to start treatment
- 5. Focus on follow up of suspects to make sure diagnosis is confirmed
- 6. Explaining treatment to the patients
- 7. Talking to families to help them support the patient in adhering
- 8. Linking the patients to the nearest DOT centre and provider
- 9. Accompanying patients for tests and medication if needed
- 10. Encouraging patients to adhere to the treatment and to take sputum examinations to assess their progress
- 11. Spreading awareness of TB in the community at large
- 12. Recording in daily dairies for the purpose of monitoring and documentation

### **Activity 2: Communication Skills**

Ask the participants what skills can help them to carry out their responsibilities better.

Answers would include: skills in empathizing, in listening, in asking questions well, in displaying respect, in communicating clearly, and such like.

Ask the following questions to the participants and discuss at length. Encourage them to share their understanding on the same.

#### How do you think TB affects someone's health?

- Physically: Feel sick, tired, and weak
- Emotionally: Feel anxious about getting better
- Socially: How will I work to feed my family? What will people say?
- Spiritually: How could God allow this to happen to me?

Tell participants that they need to understand what the patient is going through and to work with him/her to deal with it.

#### **Demonstration Activity: Listening**

Ask 4 participants to come forward as volunteers. Divide them into two pairs. In each team one person is assigned as the KP and the other the ORW/PE. Now take the 2 KPs aside and ask them to share a happy event of their life with their partner ORW/PE. This could be anything from the birth of a child to passing an exam. Now take the 2 ORWs/PEs aside and tell them that one of them will listen well to the KP as should be done while the other will act disinterested and aloof to what the KP is sharing.

The 2 teams enact the scene before the group. At the end ask the volunteers playing the KPs to express how they felt when the ORW/PE was listening well and was not listening well to them.

Ask the group what they observed and felt.

From this generate a discussion on "good and bad listening" in the context of working with KPs. The following may be noted:

#### Good listening includes:

- Being interested in what the KP has to say
- Letting the KP speak without interruption
- Answering the KP when needed
- Paying attention to what the KP has to say and remembering what has been said

#### **Demonstration Activity: Asking Questions**

Call 2 participants, and ask them to demonstrate a good way of asking questions and a 'bad' way of doing the same. Summarize with learning points on how to ask questions.

Asking questions, and listening carefully to the responses, is important in communicating with the patient. Different patients may need different information. Rather than giving everyone exactly the same messages, first ask questions to determine what each patient already knows or believes about TB.

- Ask questions that are open-ended
- Pay attention to each answer
- Listen to the silence and understand what it means
- Give patients time to think
- Encourage patients to answer elaborately by asking appropriate questions
- Build on the information the patient already has
- Tailor your answers and next question based on the patient's response

#### Sample questions to screen patients:

- Have you ever known anyone who had TB? What happened to that person?
- For how long have you been coughing?
- Have you observed any other changes in your body lately?
   (Probe: fever, especially rising in the evening, pain in the chest, loss of weight, loss of appetite, feeling tired or weak, night sweat, breathlessness, coughing up of blood)

#### **Demonstration Activity: Body Language and Tone of Voice**

Ask one participant to demonstrate through body language and tone of voice that s/he doesn't really care about the patient's health, and ask the other to demonstrate a caring attitude through body language, voice and gestures.

Reiterate that it's important to **demonstrate a caring, respectful attitude, to praise and encourage the patient and to motivate** the patient to continue treatment.

DOT medication is all about building a relationship with the patient to win his/her trust to ensure drug adherence. It is possible to show care through actions, words, tone of voice, and eye contact.

#### Some simple tips on caring for patients:

- Address the patient by name and with due respect as per cultural context
- Speak gently
- Do not rebuke but try and understand the patient's problem
- Maintain eye contact while talking

**Speak clearly and simply.** Inform the patient (and family) about TB and its treatment, ensure that the patient understands and remembers important messages about TB and treatment, and ensure that the patient knows exactly what to do next.

Complex communication	Simple communication		
You are pulmonary sputum-positive	The tests of your sputum show		
for TB.	that you have tuberculosis, or		
	TB, in your lungs.		
TB is not hereditary but is	TB is not a disease that you are		
acquired by airborne transmission.	born with. It is spread from person		
	to person by germs. When an		
	infected person coughs or sneezes,		
	the germs go into the air. Another		
	person can then become infected		
	by breathing these germs.		

#### Remember!

## Good communication is important in the context of TB treatment:

- To inform patients of important messages about TB and its treatment
- To encourage patients to return for the next treatment visit

#### Remember also that TB patients have rights!

#### What are the rights of a TB patient?

**Good quality diagnosis:** Free sputum examination and subsidized X-rays

**Good quality drugs:** An uninterrupted supply of free good quality anti-TB drugs

**Supervised treatment to ensure the right treatment:** The guidance of a health worker or another trained person who is not a family member to watch patients swallow the anti-TB medicines in their presence

**Respect and attention at the health centres:** Regardless of caste, class, gender and occupation

## Remember: Helping people to fight TB is an important job!

- Spread awareness about TB in your community
- Help to identify persons who have symptoms and should be tested for TB
- Motivate them to come for screening
- Focus on follow up of suspects to make sure diagnosis is confirmed
- Facilitate their linkage with TB services
- Help persons follow up on test results
- Encourage persons found to have TB to start treatment
- Talk to family members about support in adherence
- Provide reassurance on side effects
- Ensure adherence to treatment
- Facilitate follow up tests

# Session Seven: Screening of Film "All in a Day's Work"

#### **Objectives:**

To recap through an entertaining medium (animation film) core learning on TB and on roles and responsibilities of the PE/ORW; to provide a forum for discussion on the same

#### **Duration:**

2 hours

#### **Materials Required:**

Flip chart, markers, Film CD
"All in a Day's Work",
projection screen/wall,
equipment to run the film,
take-away booklet

### **Activity 1**

Play the 9 minute film "All in a Day's Work".

"All in a Day's Work" is a nine minute film that covers core learning content on tuberculosis and on the roles and responsibilities of community level health workers, such as outreach workers or peer educators. The film uses animation and weaves in key information content on TB along with little nuggets of advice on how to carry on the challenging task of community outreach on TB.

Shubha, the main protagonist of the film, is an outreach worker who takes pride in her job and is viewed with affection and regard by the community she works with. Through a series of short segments where the viewer gets to share experiences of the many people Shubha works with, the entire spectrum of TB detection and treatment is covered. The viewer, along with Shubha, weaves in and out of people's homes and clinic settings to share 'human' stories of anxiety, misconceptions, fear of side effects, and such like.

The film provides a set of core learning content on TB and also highlights skills to deal with issues that may come up. While the film has been conceptualized and developed as a 'continuous' product, it also lends itself to a stop and start mode should the trainer wish to discuss any particular segment in greater detail.

Ask the participants about their response to the film; what they liked or disliked, whether they could relate to the main protagonist Shubha and the stories she shared with them. Generate a discussion on how Shubha dealt with each specific situation in the film and discuss the qualities and skills she brought to the situations in her capacity as an outreach worker.

Specific discussion points could include:

- Ask the participants whether they liked the film and whether they could relate to Shubha, the outreach worker. Explore what they liked or did not like about the film and the reasons for the same
- Discuss what the main messages were that the participants received from the film. What did they learn about TB, and specifically about their roles and responsibilities in detection, referral and treatment?
- Start a discussion on how Shubha encouraged Ramesh to get tested for TB. What skills did she display in convincing Ramesh? Ask participants what other reasons people could have for hesitating to go for testing.
- Ask the participants what the main message was that Jayant communicated to Shubha about sputum tests. Once TB is detected, does one have to repeat the sputum test at any point?
- Remind the participants about the scene where Prema's husband Mohan was reluctant to have Prema go to the provider for medicines and wanted her to take them at home. How did Shubha overcome

his resistance? What are some of the other reasons why people could hesitate to commence treatment? In such cases, what can the outreach worker/peer educator do?

- Shabana, who is studying to become a health worker, is inspired by Shubha, who is her role model. Shabana asks Shubha how she persists in the face of so many challenges she faces in the course of her work on TB outreach. Ask the participants how they deal with problems they encounter in their work with the community and the strategies they use to cope with these
- The film speaks about minor and major side effects of medication.
   Ask the participants to recall and list them
- In the film, Nizam has stopped taking his medicines as he feels better after a few weeks. Shubha and Mahesh, the Senior Treatment Supervisor, convince him not to stop his treatment. What strategies do they use to do this? What are the consequences of stopping treatment before its completion? Encourage the participants to come up with ways in which they would convince a patient to adhere to medication.
- Discuss the role of the family members in providing support for adherence
- Discuss how an outreach worker/peer educator can develop and sustain a good system of relationships and linkages with the government clinics and health centres

## **Activity 2**

Take the participants through the key learnings in the take-away booklet and hold discussions to clarify their doubts if any.

## Session Eight: Field Challenges

#### **Objectives:**

To sensitize participants to field challenges and to help them to deal with the same

#### **Duration:**

2 hours

#### **Materials Required:**

Flip chart, markers and Flash cards # 7 - Pratap worries about his daughter and # 8 - Jaya looks for solutions

### **Activity 1**

Use the flash card # 7 - Pratap worries about his daughter.

Show the card and describe the situation depicted therein; ask questions to the participants on the situation to generate a lively discussion. The questions to be asked and the tips to the trainer are printed on the reverse of the flash card to facilitate ease of usage.



## Flash Card 7: Pratap worries about his daughter

Pratap is on DOT medication. He is upset as his daughter Gauri's wedding has been called off by the bridegroom's family after they came to know about Pratap's TB. Pratap shares his problem with Sharda, the ORW, who has been facilitating his treatment and follow up.

#### Ask the participants:

- 1. What are the reasons the in-laws may have had for calling off the engagement?
- 2. Are their fears justified? If not, why not?
- 3. How do you think Sharda can resolve this situation?
- 4. Do you know of other such instances where TB has generated alienation and stigma? What can ORWs /PEs do to address stigma?

#### **Note to Trainer:**

- Explain the meaning, implications and instances of stigma and discrimination to the participants
- Help participants identify how stigma can be inadvertently generated, and how this may be avoided
- Generate a discussion on the root causes of stigma and how the lack of complete knowledge may give rise to it
- Prioritize key messages that ORWs/PEs should communicate about TB to reduce the stigma surrounding it

Take the participants through the following information areas. You could make the session participatory by asking them the questions and then explaining the correct responses in detail.

### What is stigma?

Stigma is a mark of shame or discredit upon a person or group. It can manifest itself in a variety of ways, from ignoring the needs of a person or group to psychologically or physically harming those who are stigmatized. Stigma coexists with, and often leads to, discrimination.

The reasons for stigma may include fear of infection, absence of correct knowledge, prevalence of myths and misconceptions and judgement about the patient etc.

#### Instances of stigma faced by those infected or affected by TB

- Patients discriminated within family and asked to change habitation
- Loss of job / livelihood
- Social boycott
- Denial of treatment in health settings
- Abandonment by spouse
- · Unmarried girls unable to find partners
- Denial of entry to public places

#### Instances of stigma faced by Sex Workers infected by TB

- Loss of clients
- Loss of lovers/ regular partners
- Denial of treatment
- Loss of livelihood
- Social stigma by friends and family
- Inability to support family
- Isolation by co-workers, brothel owners and family

Mention that there is a common misconception that people with TB have HIV. This leads to dual stigmatization of people infected with TB. Reinforce that not everyone with TB has HIV!

What are the ways of overcoming stigma?

- Emphasize that TB is curable
- Reiterate that correct and complete treatment is needed
- Equip the patient with adequate and correct information
- Encourage patients to ask questions and try and answer them
- Conduct family counselling
- Host support group meetings and encourage patients to attend.
   Bring cured patients to the meetings

Use the flash card #8 - Jaya looks for solutions

Show the card and describe the situation depicted therein; ask questions to the participants on the situation to generate a lively discussion. The questions to be asked and the tips to the trainer are printed on the reverse of the flash card to facilitate ease of usage.



## Flash Card 8: Jaya looks for solutions

Jaya is facilitating a weekly meeting of ORWs/PEs from a range of projects covering key populations including sex workers, MSM, transgender. 3 field challenges have come up for resolution. One is that transgenders are reluctant to visit the DMC as they fear they may not be accepted at the DMC on account of their gender status. Another problem raised in the meeting refers to a sex worker who refuses to go for treatment as the time spent going to the clinic will cost her clients and income. One of the participants says his friend insists that his alcohol problem will not interfere with TB medication.

#### Ask the participants:

- 1. How would you handle the reluctance that some key populations may express, on going to a public health centre for treatment? What would you tell them/do to reassure them?
- 2. How would you explain to a sex worker who is reluctant to undergo treatment as she fears loss of clients and income?
- 3. Do you agree that alcohol does not interfere with TB treatment? If not, how will you explain it to the patient?

#### **Note to Trainer:**

- Encourage participants to empathize with the concerns and apprehensions of their key populations
- Generate discussion on the challenges in encouraging patients to go to the health centre
- Generate strategies that can be adopted to motivate reluctant patients to go for regular and complete treatment
- Encourage discussion of the gender dimensions of health-seeking behaviour in the context of TB

Ask the participants to briefly describe what they would say or do in response to the following statements. Discuss the answers and come out with the best options.

For each situation listed in the left column:

#### What would you say or do if....?

## A patient has been asked by his employer to stop coming for work since he got to know that the

employee is on DOT medication

## The patient's mother-in-law does not permit her to go out of the house for DOT medication

- The patient is afraid to tell her family that she has TB
- A patient is afraid to seek treatment because he fears that others will find out that he has TB
- A sex worker fears loss of income if her TB status is known to client
- A transgender refuses to go for DOT medication as she faced mockery at the centre in the last visit

#### **Briefly describe your response**

## **Glossary**

AIDS: Acquired Immunodeficiency Syndrome

DMC: Designated Microscopy Centre

DOT: Directly Observed Treatment

DOTS: Directly Observed Treatment Short Course Strategy

FHI: Family Health International

HIV: Human Immunodeficiency Virus

**KP: Key Population** 

MDRTB: Multi-drug Resistant TB

MO: Medical Officer

ORW: Outreach Worker

PE: Peer Educator

PLWHA: People Living With HIV/AIDS

RNTCP: Revised National Tuberculosis Control Programme

SLP: State Lead Partner

STS: Senior Treatment Supervisor

TB: Tuberculosis

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