

TAG

Treatment Action Group

IMPAACT4TB 
PREVENTING TB TO END TB

Sharing Your Tuberculosis Diagnosis with the People in Your Life:

TIPS FOR ENGAGING THEIR SUPPORT

Written by:

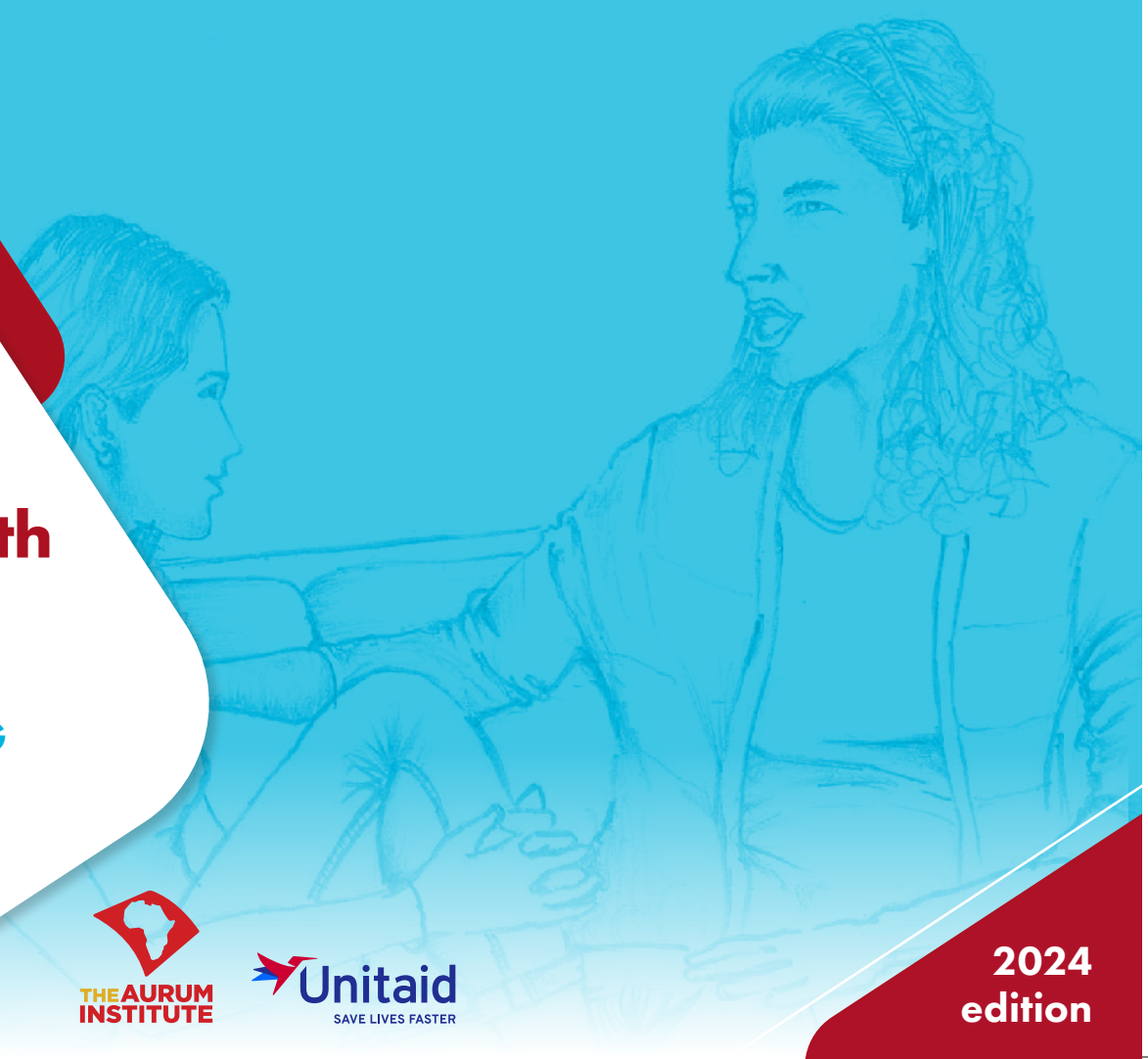
Jennifer Furin and Busisiwe Beko

Edited by:

Mike Frick and
Lynette Mabote



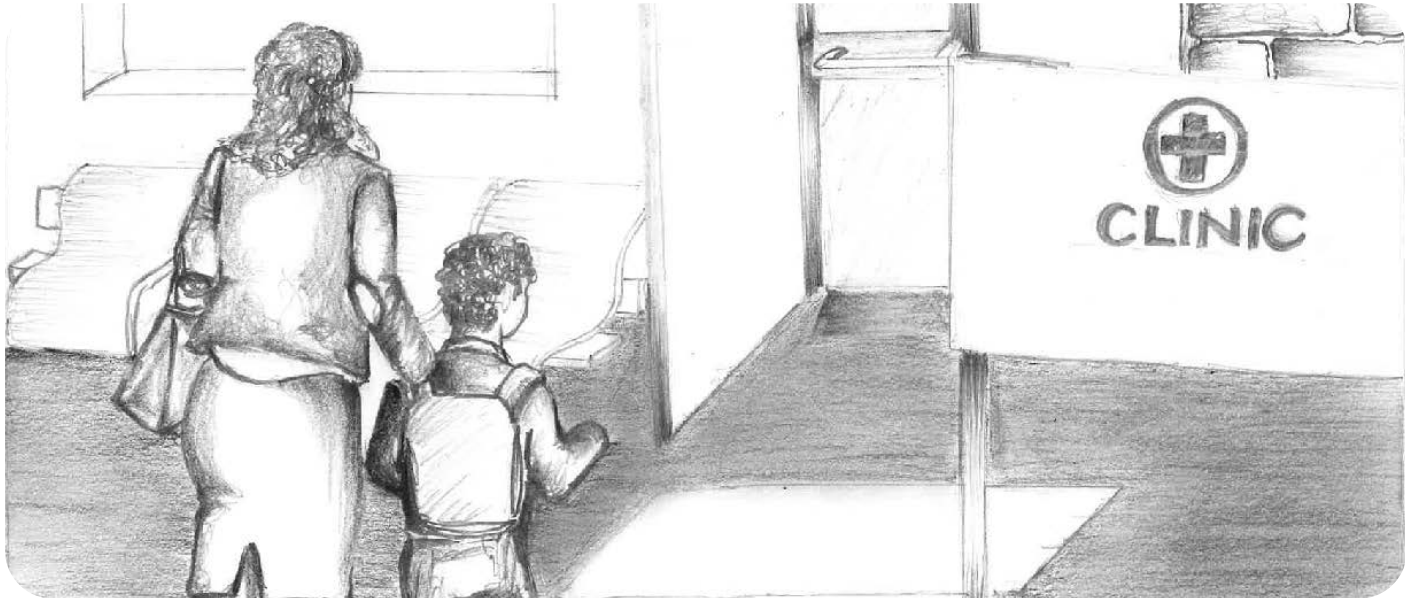
**2024
edition**





Tuberculosis (TB) is a common, preventable, and curable disease that is caused by a germ spread through the air. Ten million people become sick from TB each year around the world. When people share the same air — from living together, working together, or doing other things together — the TB germ can spread. TB germs get into the air when someone who has active TB disease of the lungs or throat coughs, speaks, or sings. Anyone who breathes in the air containing the TB germs may also get TB.

Hearing that you have TB can be overwhelming. The symptoms often cause physical discomfort, and diagnosis can also cause emotional strain. But TB is not a death sentence: once you have been diagnosed, your healthcare providers will start you on four to six months of treatment. This treatment will target your specific type of TB and will work to kill the TB germ when taken in the right way. Taking the treatment daily, as per the instructions from your healthcare providers, will ensure that you return to good health and stay TB free in the future.





As TB is spread through the air, it is important to let those with whom you live, work, travel, or have other contact know about your TB status. Since time is of the essence when it comes to TB, you should do this as soon as you are on treatment and feel emotionally strong enough to speak about what you are going through.

There are many things you may want to share with people about your TB. The most important is to let them know that TB is common, preventable, and curable. You should advise them to visit the closest clinic to get tested for TB. Remind them that treatment works, and in most cases, taking treatment daily cures the sick person and protects others from getting TB.

What are some ways to share news about your TB with the people in your life?

The process of sharing news about your health is called disclosure. Disclosing information about your health is not always necessary but becomes more important if you learn that you have a disease like TB that can be spread to others. In this situation, disclosure is about doing two main things.

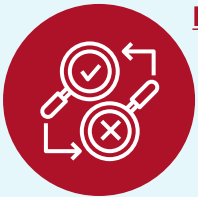
First, let people know about your situation so that you get the help you need from the people who care about you to take treatment effectively and return to good health quickly.



Second, encourage the people close to you to protect their health by getting tested for TB. If someone close to you learns that they also have TB, they can begin treatment, too. If people close to you do not have TB, they may be offered something called “**preventive treatment**,” which is a shorter, simpler form of treatment that stops the TB sickness from developing in the first place.

Stopping TB takes a team, and you are one of the most important people on that team!

The process of sharing information about a TB diagnosis is different for every person, but there are some key things you can do to make it as smooth as possible.



Learn the facts. People often have many questions when you share news about your TB status with them.

Ask your doctors, nurses, and counselors at the clinic any questions you might have about TB and your treatment. It is important that you understand the facts before trying to explain them to others.

You should also be mentally prepared for negative or unkind reactions from those with whom you share your TB status. People have prejudices about TB — usually because they do not have sufficient knowledge about it. You may also want to ask a trusted professional at the clinic to practice how you will share the news about your TB diagnosis with others. The healthcare workers may even be able to join you when you are disclosing your TB status. This is not always a comfortable conversation to have, but knowing the facts makes it easier.



Start with the people close

to you. The people you live with and frequently spend time with are more likely to have been breathing the same air, and it is important to tell all of them so they can get tested for TB. In general, if you live in the same dwelling, work alongside each other, share meals together, or spend more than a few hours a day in a closed space with someone, letting them know about your TB status is the responsible and caring thing to do.

Remember that you do not need to tell everyone all at once. It is probably a good idea to tell someone you trust first — a person who supports and loves you. This person can then help you share the news with others in your life.





Be kind to yourself. It is important to remember that receiving a diagnosis for TB does not mean you “got it first” and spread it to others. People’s minds are quick to judge, blame, and shame, and people may think you have TB because you did something wrong. This is not true! Remember, because people share space and air, we are all susceptible to TB. Given your health and the status of your immune system, the symptoms of TB in your body might have shown up earlier than in other people.

You did the right thing by visiting the nearest clinic to get medical care when you were not feeling well. So be kind to yourself in this process! Having TB is not your fault or anyone else’s fault.





Think about what to share. Remember that even though you need to share the news about having TB, you also have a right to keep as much of your health information private as you feel necessary. When deciding how you want to tell people about your TB status, think about what is most comfortable for you to share and what you do not want to share.

A simple statement explaining what happened and what you are going through can go a long way. For example: “We are often in the same places together, and I just found out I have active TB disease. I am on treatment and will have to take it for the next few months. I am doing well, and because I am on treatment, there is little risk of my TB passing to others. But since we were together before I started my treatment, I thought it was best to let you know, as you also may have been exposed to TB. I would encourage you to go to the clinic to find out if you have TB, so you can stay healthy, too.”



Give people time. If the initial reaction to your news is negative, this usually happens because people are worried about their health. With a little time, most people become more supportive. If you think someone might threaten or hurt you if they find out you have TB, it is best to let a professional from the clinic talk to them. There are ways in which healthcare workers can share the news about TB exposure while keeping your identity private so that you can be safe.

Sometimes people do not take news of TB seriously and they may not go to the clinic to get tested. You may continue to encourage them to seek medical care, but always remember your health takes priority and your only responsibility to others is sharing your status.



Ask for help if your rights are violated. Keep in mind that people with TB have a right to work, access housing, and be treated with care and support in all settings. If you lose your job, your home, or other rights, you can turn to the law to assist you. There may be specific housing and labor laws in your country that protect people with TB that a lawyer can use to fight for your rights. There may also be other types of advocacy groups for people with TB who can help protect you. These groups are there to stop discrimination against people with TB. Let your healthcare providers at the clinic know if you have faced discrimination and see how they can help you.



Find friends and supporters.

Identify someone in your community or clinic who is knowledgeable about TB and who can help you on this journey.

In many places, there are treatment support groups available in person or on social media. TB is a disease that may seem scary at first, but most people who have it are able to take treatment and be completely cured. Having someone you trust to help you on your path back to health is an important part of treatment.





Call in an expert. If you wish, you can request that a nurse or a community health worker come to your home to also speak with your close contacts and family members. This can be very helpful, as you may be feeling too sick or too overwhelmed to respond to the questions your contacts might have about TB. Do not be afraid to ask for this or other kinds of support you may need from the clinic.



Stay connected to friends and family. You may wonder or be asked how long the TB germ can spread after someone is found to have TB. In general, if someone with TB is started on effective treatment, and stays on treatment until it is completed, the risk that the TB germ can still be spread is almost completely gone after the first few days of treatment. This is another good reason to start and complete TB treatment. While you are on treatment, you can still hug your family members, share meals, and do most of the normal things people do (as long as these activities do not disrupt your TB treatment).





Remember the good news.

TB is a curable disease! Most people with TB can complete treatment and lead healthy, productive lives afterward. But even though TB is curable, finding out you have TB can cause anxiety, stress, or depression. You may not feel like yourself, and it is important to ask for counseling help or support. These feelings usually get better over time, especially if you talk with people about them.





The information contained in this guide was developed by a group of TB experts, survivors, and advocates using participatory methods to generate community-informed materials. These included the use of open-ended interviews with people in the community of Khayelitsha, South Africa, who were diagnosed with TB and open-ended interviews with their close contacts.

The illustrations were drawn by a South African artist named Samkelo and first appeared in a counseling guide used at the former MSF clinic in Khayelitsha.