

The InSIDE Story on SIDE Effects During Treatment for Drug-Resistant Tuberculosis

A RESOURCE BOOK
WITH WHAT YOU
NEED TO KNOW
FROM HEAD TO TOE

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The illustrations in this publication are inspired by the idea that the human body is not a machine, but a living ecosystem. Just like plants, our bodies are constantly growing, adapting, repairing, and transforming. By bringing together anatomy and botanical forms, I wanted to invite you to look at the human body through a different lens, one that emphasizes our connection with nature. Each organ is composed of plants whose structures echo its anatomy or function. Tropical leaves, roots, flowers, seaweed intertwine to create familiar silhouettes. I hope these illustrations encourage a moment of curiosity and reflection. Medical information often focuses on diagnosis and treatment, while these images might remind us that our bodies are living environments constantly evolving, adapting, and deserving of care and compassion.

Sincerely,
PAULINA SINIATKINA
Artist and TB survivor

Introduction

All people diagnosed with drug-resistant tuberculosis (DR-TB) should be offered treatment with regimens containing four or more drugs. Studies show that these drugs are powerful at killing the TB germ. These drugs can also affect the normal functions of the body. These unwanted impacts on normal body function are known as “side effects.” Different people experience these side effects in different ways, but it is important to know about them so they can be prevented and addressed. This guide will help describe some of the more common side effects associated with DR-TB and its treatment in a “head to toe” fashion.

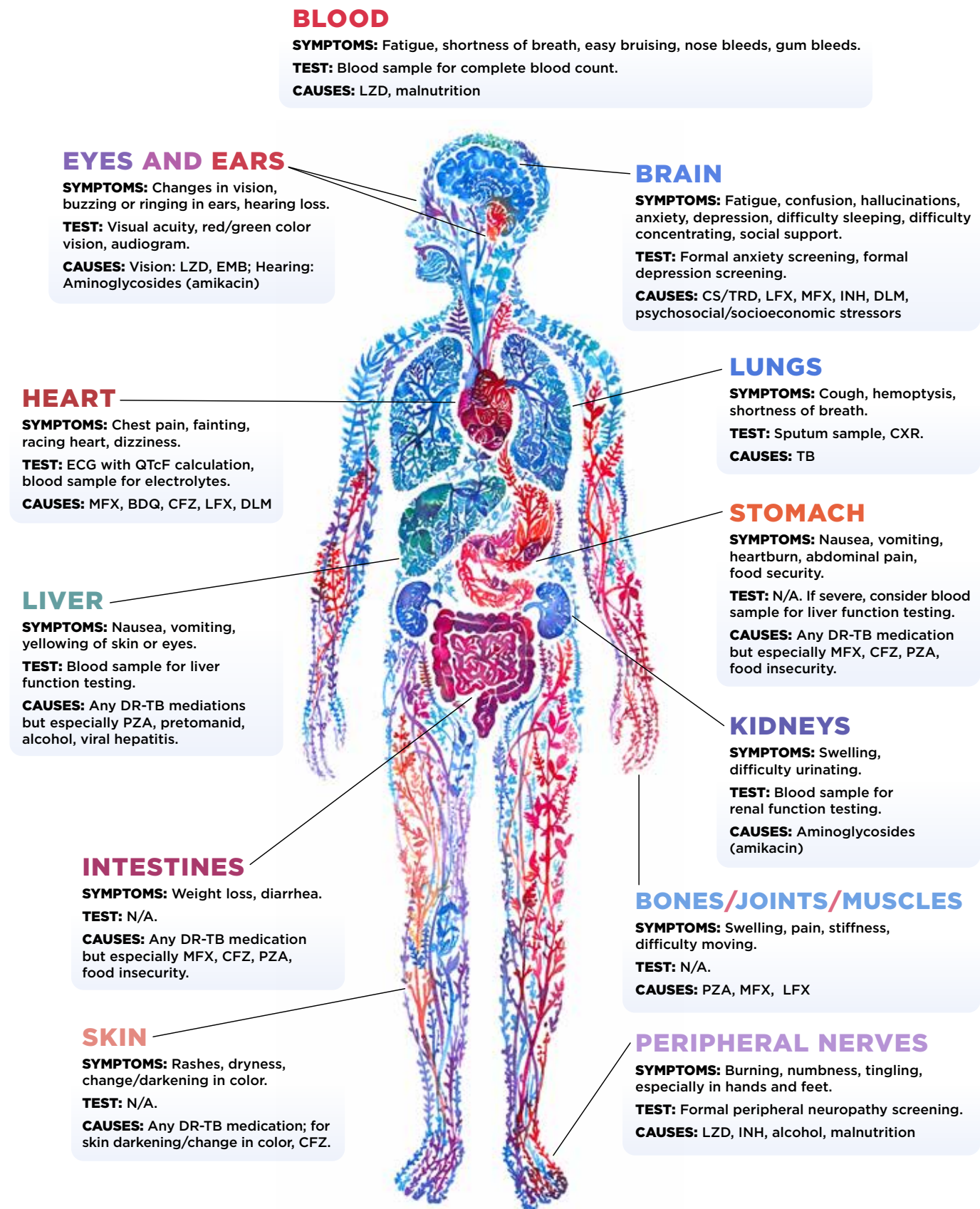
In general, side effects are usually temporary problems and are likely reversible if they are identified early. If a provider determines a drug is causing a side effect, the provider will usually suggest doing one of three things: (1) prescribe a medication to help with the side effect, (2) lower the dose of the drug they think is causing the side effect if this can be done without impacting the chance of successful treatment, or (3) stop the drug they think is causing the side effect and replace it with another effective drug if indicated and if this can be done without impacting the chance of successful treatment. The specifics of what is done will depend on multiple factors, including the severity of the side effect and the availability of alternative treatment.

TB is caused by a small germ known as *Mycobacterium tuberculosis*. This germ enters the body through the air, and once inside the body, it can cause problems with the way the body is supposed to work. It is most common for the TB germ to cause problems in the lungs, but the TB germ can go anywhere. Figure 1 highlights important parts of the body that may be affected by TB or by the medications that are used to treat DR-TB

There is nothing “normal” about the experience of becoming sick with and being treated for DR-TB with medications that cause side effects. Having side effects, however, is something that commonly happens during DR-TB treatment. Most of these side effects are mild and temporary, and they can be overcome. The purpose of this resource book is not to frighten people who need DR-TB treatment or to make the experience a negative one. Rather, it is to empower people with DR-TB to know the medications and to be active participants in their own care. Historically, people with DR-TB were not informed of side effects because providers felt it would make them not want to take treatment.

This resource book is an attempt to overcome those decades of keeping people in the dark about the medications they were asked to take. But it must be remembered that while side effects are common, serious and permanent side effects are not. The best way to avoid serious and permanent side effects is to work in collaborative teams to detect and prevent them early.

FIGURE 1. BODY PARTS AFFECTED BY TB AND DR-TB MEDICATIONS



ABBREVIATIONS: BDQ=bedaquiline; CFZ=Clofazimine; CXR=chest X-ray; CS/TRD=cycloserine/terizidone; DLM=delamanid; DR-TB=drug-resistant TB; EMB=ethambutol; INH=isoniazid; LFX=levofloxacin; LZD=linezolid; MFX=moxifloxacin

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Brain



Provides instructions for the rest of the body using a series of “electrical” signals that travel through the nervous system. The brain coordinates movements and bodily functions and is responsible for thinking, feelings, memories, sleep, and dreams.

TB germs can cause swelling of the brain, sometimes referred to as “TB meningitis” or “TB meningoencephalitis.” This type of TB is rare. TB can also cause the brain to process information more slowly and make people feel more tired/sleepy.

DR-TB medications can affect the way the brain works, leading to changes in thinking, feeling, sleeping, remembering, and dreaming. Some medications may cause the brain to perceive things that are not there—known as “hallucinations” or “psychosis.” Some medications can lead to increased feelings of fear (sometimes called “anxiety”) or sadness (sometimes called “depression”).

Many people with TB worry about how they will be treated by other people when they find out they have DR-TB and how they will work, eat, or pay for the things they and their families need. These worries can lead to fear or sadness, difficulty sleeping, or problems with thinking. These feelings are not caused by the DR-TB germ itself or by medications used to treat DR-TB. They result from the social aspects of being sick with TB.*

MONITORING

Questions should be routinely asked about any changes in thinking, feeling, or sleeping, and thoughts about self-harm or harming others. These should include questions specifically designed to determine if the brain is affected by anxiety or depression (using a questionnaire form like [“Patient Health Questionnaire/PHQ-9”](#) or similar standard measures). If any problems are detected, additional tests may be performed.

MANAGEMENT

Most often the brain will resume working normally, although it may take some time. Treatment may be changed, or doses may be lowered. New medications specifically targeting impacts on the brain may be started, like medication for anxiety or depression. Nonmedical interventions, such as counseling or joining support groups, may also be recommended.

Medications that can cause the side-effects: cycloserine, terizidone, levofloxacin, moxifloxacin, delamanid, and isoniazid

*Social factors that can be associated with these symptoms are discussed more in the section on “Putting It All Together.”

Eyes

Translate objects we see in the world into pictures we can understand and remember. Parts of the eye work like a camera, sending images through electrical signals along the network of nerves to the brain.

TB germs can cause problems with the way the eyes see or capture images.

DR-TB medications can also cause problems with the way the eyes take pictures or the network of nerves used for sending these pictures to the brain.



MONITORING

Questions should be asked about any problems like blurred or double vision. The eyes should also be tested each month using an eye chart (a series of increasingly small letters, numbers, or shapes read from a set distance). Patients may also be asked to look at images with the colors red and green and different numbers to make sure the way the eyes see colors isn't being affected by the TB medicines. Health care providers may also use a special light to examine the eyes. Problems with the eyes are sometimes temporary but other times become permanent. It is important for the eyes to be checked at each visit so that problems can be detected early, when they can best be treated.

MANAGEMENT

If problems with the eyes are detected early and there are other medications that can be given instead, the treatment may be changed. If the medications cannot be changed, sometimes the dose may be lowered. If these tests find any problems, then consultation with an eye specialist may be recommended.

Medications that can cause the side-effects: linezolid and ethambutol

Ears

Translate noises out in the world into sounds we can understand and remember. The ear sends sounds through electrical signals along the network of nerves to the brain.

TB germs don't usually cause problems for the ears.

DR-TB medications can cause problems with the way the network of nerves in the ear hear sounds and send these sounds to the brain.



MONITORING

Questions should be asked about any problems with hearing. Hearing should also be tested each month using a special machine that plays sounds called an "audiogram." A "buzzing" or "ringing" sound in the ear or difficulty hearing are very late symptoms and indicate permanent damage. If problems are found with the ear, these are usually permanent. It is important for the ears to be checked each month so that problems can be detected early.

MANAGEMENT

If hearing problems are detected, the DR-TB treatment should be changed. If the medications cannot be changed, sometimes the dose may be lowered.

Medications that can cause the side-effects: amikacin and other medications in a family known as the "injectables" or "aminoglycosides"

Heart

Responsible for circulating blood that carries nutrients and oxygen our bodies need to survive. The heart works as a pump, using electrical “beats” to push blood to where it is needed.

TB germs can sometimes affect the heart and areas around the heart, making it difficult for the heart to fill and pump blood. This type of TB is rare.

DR-TB medications can cause problems with the electrical signals that tell the heart when to beat. If these signals are not sent at the right time, then the heartbeat may not be coordinated, which although very rare, could lead to serious problems.

Symptoms are usually a sign of more severe problems and include chest pain, racing heart, dizziness, or fainting.



MONITORING

An “electrocardiogram” or “ECG” detects the electrical system of the heart. If the interval between heartbeats lasts too long, it signals a problem that might be caused by TB medications. An ECG should be checked before starting treatment and then at regular intervals. The electrical system of the heart can also be affected by other factors detected using a blood test.

MANAGEMENT

Treatment may be changed, or doses may be lowered. If the changes are caused by something else, like a low level of salts/electrolytes in the blood, health care providers may recommend supplements. In some instances, health care providers may recommend hospitalization to monitor the heartbeat. These changes with the electrical system of the heart are not permanent and usually get better with medication changes.

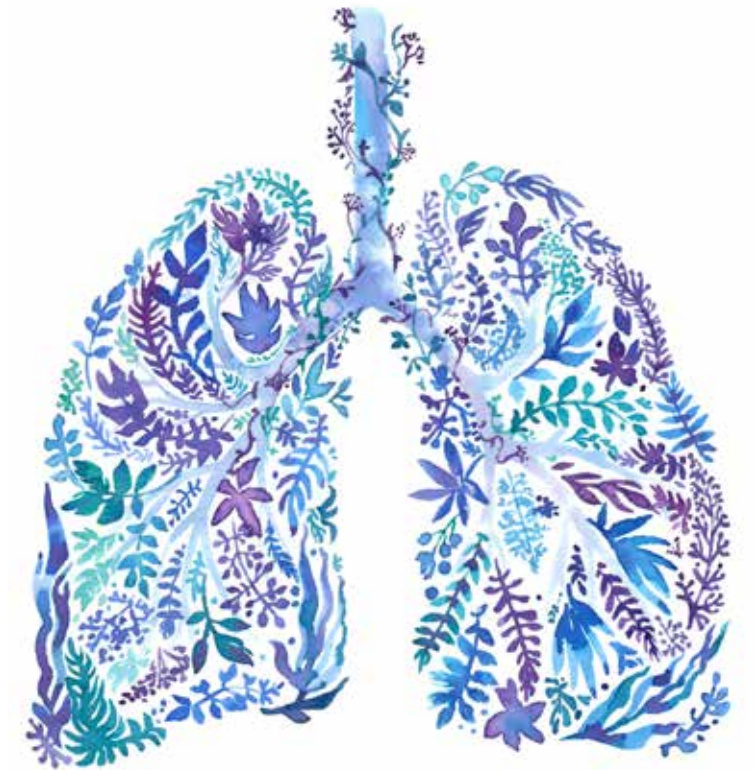
Medications that can cause the side-effects: moxifloxacin, clofazimine, bedaquiline, delamanid, and levofloxacin

Lungs

Take in oxygen and release carbon dioxide. The lungs inflate and fill with oxygen, which then moves into the blood in exchange for carbon dioxide, which is breathed out when the lungs deflate like balloons.

TB germs enter the body through the lungs and fill up spaces normally used to exchange oxygen and carbon dioxide, making the lungs’ job more difficult. The germ can cause bleeding and scarring in the lungs. As the body tries to fight TB, it sends its defenders — otherwise known as immune cells — to the lungs, which can then fill up with pus and mucus. The battle between the TB germ and the immune system cells in the lungs can lead to swelling in and around the lungs and small holes or “cavities” in the lungs. Sometimes this leads to fluid in the space between the lung and the chest wall called an “effusion.”

DR-TB medications do not usually cause side effects in the lungs. Most of the lung symptoms people experience are from the TB germ itself and not from the medications.



MONITORING

Health care providers should ask about lung-related symptoms (cough, shortness of breath, sputum, coughing blood) at each visit. Sputum samples are collected throughout treatment to look for the TB germ and make sure that it is decreasing in number or completely gone. X-rays may be done prior to starting treatment and at the end of treatment or if there are new lung symptoms.

MANAGEMENT

If there are scars or more permanent damage to the lungs, then health care providers may give an inhaled medication to help open the airways and improve gas exchange. They may also suggest an exercise program (sometimes called “pulmonary rehabilitation”) to help improve the person’s ability to carry out normal physical activities.

Stomach

Breaks down food and liquids into smaller pieces that can be absorbed by the body. The stomach contains acid that helps with breaking down food and liquids and small muscles that help it mix and squeeze.

TB germs don't usually cause problems for the stomach, although they can reduce people's level of hunger.

DR-TB medications can cause problems for the stomach, as most TB medications are taken by mouth and enter the stomach to be broken down and distributed to other parts of the body. Some of these medications irritate the inside of the stomach, leading to an increased amount of acid, felt as a burning or pain. The irritation can also lead to a feeling of nausea or vomiting. These side effects can make it difficult to keep taking treatment, but they do not usually lead to permanent damage to the stomach.



MONITORING

Health care providers should ask about any stomach problems at each visit. Because a lack of food can make the stomach problems worse, any challenges with access to food should be reported. All people with DR-TB have a right to access nutritional support, usually as a part of their DR-TB treatment.

MANAGEMENT

Health care providers may prescribe medications to help reduce the level of acid in the stomach and to help with nausea and vomiting. Taking DR-TB treatment with food may help, and so it is important that nutritional support be offered as part of treatment. If the stomach problems continue, treatment may be changed, or doses may be lowered.

Medications that can cause the side-effects: moxifloxacin, clofazimine, and pyrazinamide

Intestines

Break down and absorb nutrients from food and remove parts of food our body does not use and other waste products in the form of stool (poop).

TB germs can infect any part of the intestine and lead to swelling and blockages. It can also interfere with the way nutrients are absorbed and waste is eliminated, which can cause malnutrition, weight loss, and diarrhea.

DR-TB medications can also cause swelling in the intestines and lead to problems with the way that nutrients are absorbed and waste is eliminated, although this is very rare. This can lead to malnutrition, weight loss, and diarrhea. These side effects are usually not permanent and improve over time.



MONITORING

Health care providers should ask about any intestinal problems or diarrhea at each visit. Because a lack of food can make intestinal problems worse, any challenges with access to food should be reported. All people with DR-TB have a right to access nutritional support, usually as a part of their DR-TB treatment.

MANAGEMENT

Health care providers may prescribe medications to help with diarrhea. Taking DR-TB treatment with food may help, and so it is important that nutritional support be offered as part of treatment. If the intestine problems continue, treatment may be changed, or doses may be lowered.

Medications that can cause the side-effects: moxifloxacin, clofazimine, and pyrazinamide

Liver

Filters waste products generated by other parts of the body, makes chemicals that help digest and break down food, and helps to activate and break down (“metabolize”) medications.

TB germs do not usually cause problems for the liver.

DR-TB medications have the potential to cause liver side effects that range from very mild to quite severe. Alcohol and viruses (such as hepatitis B and C) also affect the liver. When liver problems begin, they may not be noticeable, which is why routine blood tests to check for liver problems are so important. When liver problems are more severe, they may cause nausea, vomiting, a change in the color of the stool, excessive itchiness, and a yellowing of the eyes or the skin (especially on the palms of the hands, the soles of the feet, and under the tongue). When detected late, liver problems may be serious and permanent

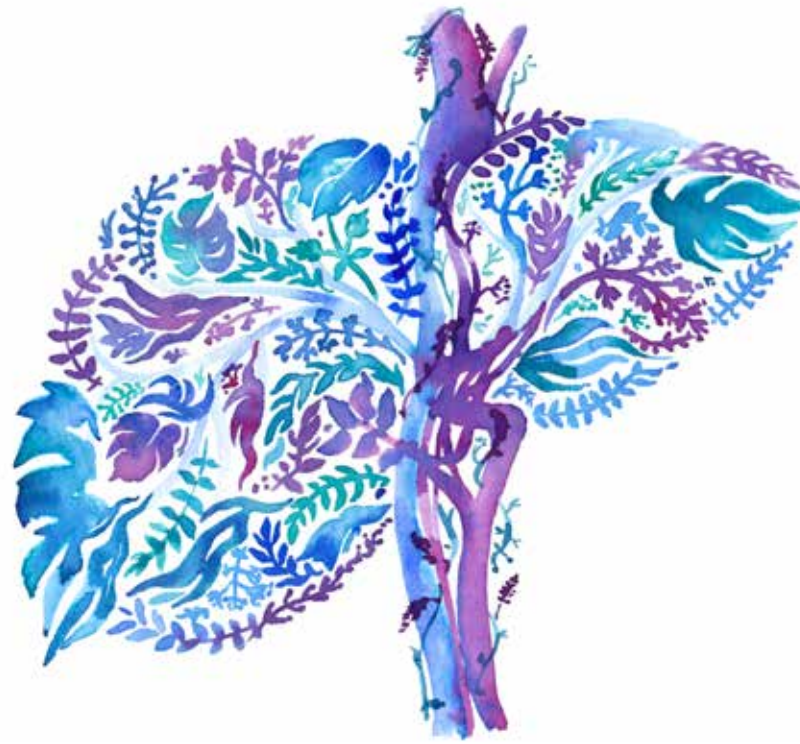
MONITORING

Blood tests should be performed before starting treatment and at routine intervals while on treatment (every one to three months, depending on the medications). Anyone experiencing a yellowing of the skin or eyes or nausea and vomiting that does not improve with other interventions should have their liver checked. If blood tests suggest a problem with the liver, images may be taken using an ultrasound or a CT scan.

MANAGEMENT

If there are liver side effects, health care providers will take several steps, including asking the person to stop using alcohol and checking the blood for viral infections. If there are mild liver problems, treatment may be changed, or doses may be lowered. If there are more worrisome liver problems, all the DR-TB medications will likely be stopped (for one to two weeks) and then slowly reintroduced while monitoring the liver function using blood tests. This may require a stay in the hospital so that the medications can be reintroduced safely and with close monitoring.

Medications that can cause the side-effects: pyrazinamide and pretomanid, especially in people who consume alcohol or who have other problems with their liver

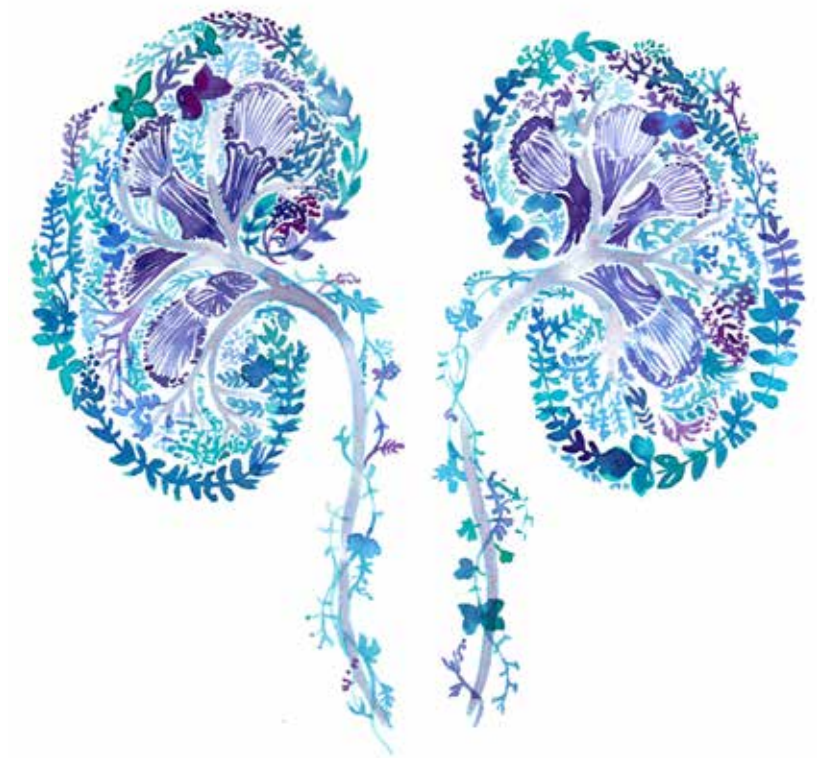


Kidneys

Filter waste products generated by other parts of the body and help control the amount of fluid in the body. Waste products and extra fluid pass from the kidneys into the bladder (via tubes called ureters) and out of the body when we urinate/pee (via a tube called the urethra).

TB germs can cause problems in the kidneys as well as in the bladder, ureters, and urethra, sometimes causing blockages and scarring that can lead to swelling and increased waste products being left in the body, which can make people feel tired and sick.

DR-TB medications can also damage the kidneys, affecting their ability to filter out waste products or extra fluid, which can lead to swelling and increased waste products being left in the body, causing people to feel tired and sick. Some TB medications can also cause the urine to change color (for example, rifampicin, rifabutin, and rifapentine), but these medications are not usually given to people with DR-TB. Problems are usually not permanent when detected early but can be when detected late. Symptoms tend to only occur when the damage to the kidneys is severe and could include swelling, confusion, nausea, and vomiting



MONITORING

Blood tests can be used to check how the kidneys are functioning. This may be done prior to starting treatment and then at regular intervals (every one to six months, depending on the medications). Health care providers may also ask for a urine test. If the blood or urine tests suggest a problem with the kidneys, images may be taken using an ultrasound or a CT scan.

MANAGEMENT

If there are kidney side effects, health care providers will generally stop the medication that is causing them and start a different medication, or they may decrease the dosing of the medication if there are no alternatives.

Medications that can cause the side-effects: amikacin and other medications in a family known as the “injectables” or “aminoglycosides”

Bones, Joints, and Muscles

Work together to support our bodies to move. The bones are the basic structure, the places where they connect are called joints, and muscles are the soft flesh of the body that activate movement when signaled by the brain through the electrical system of the body (the “nerves”). Taken all together, the bones, joints, and muscles are called the “musculoskeletal system.”



TB germs can affect the bones and joints but do not usually affect the muscles. When TB gets in the bones and joints, it can cause swelling, pain, and stiffness, making it difficult to move. These problems can be permanent.

DR-TB medications can also cause problems in the bones, joints, and muscles. Most of these problems are not dangerous or permanent, but they can be painful and make it difficult to do usual activities. There is one very rare side effect in which the muscles and ankle joints can be affected called “Achilles’ tendon rupture”

MONITORING

Health care providers should ask about any problems with the bones, joints and muscles at each visit.

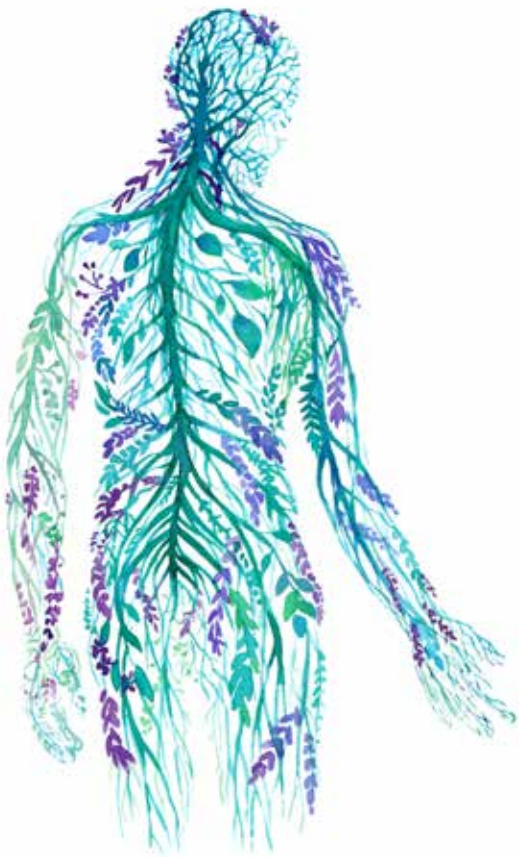
MANAGEMENT

Health care providers may recommend putting warm compresses or creams on the impacted area of the body. If the pain is severe, they may recommend medications to decrease the pain. Some exercises can help the bone, joint, or muscle feel better. Achilles tendon rupture may require the placement of a cast or, in severe cases, surgery.

Medications that can cause the side-effects: pyrazinamide, levofloxacin, and moxifloxacin

Peripheral Nerves

The brain controls all our bodily functions by sending electrical messages along a network known as the nervous system. The central part of the nervous system is composed of the brain and a long tube of nerves that run down the back and through the spine (called the “spinal cord”). The branches of this central system that travel to the rest of the body are known as the “peripheral nerves.”



TB germs can cause problems in the kidneys as well as in the bladder, ureters, and urethra, sometimes can affect the brain and spinal cord (“TB meningitis” or “TB meningoencephalitis”), but it does not cause any problems for the peripheral nerves.

DR-TB medications can affect the peripheral nerves, as can alcohol, diabetes, a lack of vitamins, and other medical conditions common among people with TB. When the nerves are affected, people may experience pain, burning, numbness, or tingling, especially in the hands or feet. If detected early, these side effects are not permanent. If they are found at the later stages, there may be permanent damage to the nerves.

MONITORING

Health care providers should ask about any symptoms such as pain, tingling, or burning in the hands, feet, or other body parts. They should also examine the nerves by testing reflexes and the sensation in the hands and feet using a small pin, a reflex hammer, and/or a tuning fork.

MANAGEMENT

Some problems with the peripheral nerves can be prevented with vitamin B6 (also called “pyridoxine”), which may be given as part of DR-TB treatment. If the pain is severe, a health care provider should be contacted immediately. They may recommend medications to decrease the pain. If the peripheral nerve problems continue, treatment may be changed, or doses may be lowered.

Medications that can cause the side-effects: linezolid and isoniazid

Skin

Covers our body, protects us from the outside world, helps control our body temperature, and makes sure the body does not lose too much moisture.

TB germs can sometimes impact the skin, causing small sores.

DR-TB medications can affect the skin, including its color and sensitivity to the sun, leading to sunburns. People on these medications should use sunscreen (if possible), wear clothing/wide brimmed hats that cover the skin, or avoid being out in the sun for extended periods of time. The medications could also cause dryness of the skin or the development of rashes.



MONITORING

Health care providers should ask about any skin changes or rashes at each clinic visit.

MANAGEMENT

Almost all the skin related side effects are reversible, but they can become severe if not managed early. Most minor skin side effects can be managed with creams or “topical” therapy (applied to the surface of the skin). If the DR-TB medications cause a severe rash, then all the DR-TB medications will likely be stopped (for one to two weeks) and then slowly reintroduced while monitoring the skin. This may require a stay in the hospital so that the medications can be reintroduced safely and with close monitoring. Skin color changes are not permanent but may take several months to go away, even after treatment is completed. It is also important to talk through how to manage any questions that other people might ask about skin changes, since people may notice a change in appearance.

Medications that can cause the side-effects: Clofazimine (skin color changes), levofloxacin and moxifloxacin (increased sun sensitivity)

Blood and Blood Cells

The fluid and cells inside our bodies that transports oxygen, nutrients, and waste products and defend us from germs and infections. The heart pumps the blood all around the body through tubes known as “arteries” and “veins.” The cells that carry oxygen are called “red blood cells.” The cells that defend us from germs are called “white blood cells.” If we cut or bruise ourselves, the body stops bleeding by a process called “clotting” using blood cells called “platelets.”



TB germs do not usually directly affect the blood. However, as the body tries to fight the TB germs, it may use up white blood cells. The TB germ may also interfere with the creation of red blood cells, leading to “anemia,” a condition when there are not enough red blood cells, making it difficult for the body to transport oxygen, causing fatigue and shortness of breath.

DR-TB medications can also cause side effects that impact the amount of red and white blood cells and platelets in the blood, causing symptoms like easy bruising, nose bleeds, bleeding gums, and fatigue/being tired. These side effects are not usually permanent, but they can lead to infections, difficulty breathing, and excess bleeding, so it is important to identify them early.

MONITORING

Blood tests should be performed prior to starting treatment and every month to check on the amount of red blood cells, white blood cells, and platelets in the blood. Health care providers should ask about signs that the blood is being impacted by treatment, including bruising and fatigue.

MANAGEMENT

If there are problems with the blood, treatment may be changed or doses lowered. In some instances where the amount of red blood cells and/or platelets is too low, health care providers may recommend hospitalization and blood transfusion (refilling the blood cells with blood that is donated by someone else). Impacts of treatment on the blood are not permanent and usually get better with medication changes.

Medications that can cause the side-effects: linezolid

Reproductive System

Regulates hormones and sexual function and supports reproduction. Hormones regulate growth and development during puberty and affect weight, energy, fertility, the immune system, the brain, and how you feel. The male and female reproductive organs each produce sex cells that when combined become an embryo that develops and grows into a baby.



TB germs can affect the organs of the reproductive system in both men and women. It can make it difficult for the sperm to travel outside of the male body or for the egg to travel and meet up with the sperm inside the female body. It can also make it difficult for the baby to grow during pregnancy. Often, there are few or no symptoms when the TB germ affects the reproductive system, but if left untreated it can cause significant damage. TB in the reproductive system is often diagnosed during infertility evaluations using imaging techniques like an ultrasound. TB may also lead to malnutrition, which can affect reproduction and pregnancy as well.

DR-TB medications may also impact the reproductive system in both men and women, although it is often difficult to figure out if this is the case. Most of the understanding we have about how DR-TB medications affect the reproductive system come from studies done on animals, and these studies do not always match up with the way the drugs impact humans.

MONITORING

It is generally recommended that people avoid pregnancy during treatment for DR-TB and for 8 – 12 weeks afterward. This usually means using some kind of birth control method. Most medications used for birth control can be given with DR-TB treatment. The risks and benefits of specific treatment regimens and the drugs included in them should be discussed by individuals with their health care providers, as what to do with regard to treatment and pregnancy, should an unanticipated pregnancy occur during treatment, is a very personal discussion and decision.

MANAGEMENT

The DR-TB medications most likely to cause problems with the reproductive system are not well understood. Animal studies have suggested that **pretomanid** may cause problems with the male reproductive system, but this was only shown in animal studies and not in humans. **Ethionamide** and the **aminoglycoside** medications (amikacin) are not given during pregnancy as ethionamide can exacerbate nausea and vomiting and the aminoglycosides can cause congenital deafness.

Is It TB or a SIDE Effect?

The TB germ, being sick with DR-TB, and DR-TB medications can cause many changes in the body, leading to multiple symptoms. Actively monitoring and reporting these to health care providers is an important part of participatory medical care. But how does a person know if the symptoms and changes in the body are being caused by DR-TB or by medication side effects?

There is no simple rule to tell the difference. But some symptoms are more likely to be associated with DR-TB than with medication side effects. For example, cough, fever, and shortness of breath are more likely to be associated with DR-TB than with medication side effects. Vision changes, liver abnormalities, and cardiac events are more likely to be side effects of the DR-TB medications. The timing of the development of symptoms can often be a clue. Symptoms that were present before treatment started are more likely to be due to DR-TB, while those that came after treatment started are more likely to be side effects of medications. Sometimes, people may pay more attention to their bodies and how they are feeling after they are diagnosed with DR-TB, so not every new sensation is due to medication side effects. Most TB-related symptoms, however, should get better over time whereas medication side effects may get worse over time.

The first one to four weeks of treatment are usually the most challenging in terms of symptoms and impact on the body. This is true for two reasons. First, the body is getting used to the medications, and this can take time. Second, the medications are killing the TB germ. This “battle” between the TB germ and the medications is necessary but it can lead to reactions in the body. The first one to four weeks are when most of the TB germs are dying, so the symptoms can be worse then. It is important to have support during these first difficult weeks of treatment.

It is also important to remember that DR-TB can affect almost any part of the body. Usually, DR-TB causes problems in the lungs (referred to as “pulmonary disease”). It can also occur outside the lungs (referred to as “extrapulmonary disease”). A person with extrapulmonary DR-TB may have more symptoms outside the lungs that are caused by DR-TB rather than by side effects of the medications. For example, DR-TB can affect the eyes, so if a person has eye symptoms before starting treatment, this is more likely due to extrapulmonary DR-TB rather than a side effect of the medications. Establishing what symptoms are present prior to starting DR-TB treatment is an important way to determine if there is extrapulmonary DR-TB and to help understand if symptoms are related to DR-TB or to medication side effects.

Table 1 summarizes some symptoms and timing factors that can help determine if the cause is DR-TB or a medication side effect.

TABLE 1. IS IT A SYMPTOM OF THE DISEASE OR A SIDE EFFECT OF THE MEDICATION?

MORE LIKELY TO BE DUE TO DR-TB	EITHER DR-TB OR A MEDICATION SIDE EFFECT	MORE LIKELY TO BE DUE TO A MEDICATION SIDE EFFECT
Symptom present prior to starting DR-TB treatment	Symptom occurs within the first 1 – 4 weeks of treatment	Symptom occurs after 4 weeks of treatment
Cough (sputum, blood)	Fatigue	Vision changes
Shortness of breath	Weight loss	Hearing changes
Fever	Headache	Nausea
Symptoms in a part of the body where extrapulmonary TB has been diagnosed	Difficulty sleeping	Vomiting
	Anxiety	Diarrhea
	Depression	Fainting
	Anemia	Yellowing of eyes or skin
	Chest pain	Rash
		Skin color changes
		Muscle aches
		Joint pain
		Easy bruising
		Gum/nose bleeding
		Numbness/tingling in hands or feet

Putting It All Together

Our bodies are more than the sum of our parts, and although this resource book is organized by bodily system for ease of explanation, it is important to stress that people experience sickness and side effects as a whole. It is therefore important to have an integrated approach to symptom management and care, as feeling unwell in one part of the body can affect other parts too. For example, if someone has nausea or vomiting, then they may not have an appetite. This can lead to fatigue/weakness, dizziness, and malnutrition. These symptoms may also cause psychological distress and lead to trouble sleeping. The person may experience some of these symptoms as more distressing than others. There may also be cultural norms about how symptoms are expressed or which symptoms are acceptable to report. It is important to keep these nuances in mind and to think about the body experience as a whole.

It is important to remember that, in general, side effects are usually temporary problems and are likely reversible if they are identified early. If a provider determines a drug is causing a side effect, the provider will usually suggest doing one of three things: (1) prescribe a medication to help with the side effect, (2) lower the dose of the drug they think is causing the side effect if this can be done without impacting the chance of successful treatment, or (3) stop the drug they think is causing the side effect and replace it with another effective drug if indicated and if this can be done without impacting the chance of successful treatment. The specifics of what is done will depend on a variety of things, including the severity of the side effect and the availability of alternative treatment.

This resource book has focused on physical symptoms, but there are important social experiences that come from having DR-TB and being treated for the disease. These social experiences are different for every individual, but there are some common things that can happen when someone is undergoing treatment for DR-TB. Many people experience economic stresses, as they might have to miss work or income activities due to their physical symptoms or to attend medical visits. Some people find they have extra expenses for things like food or transport. Some people feel worried about what other people might think of them or how they might treat them.

Anybody who breathes can become sick with DR-TB. People diagnosed with DR-TB are just like everyone else. There are misperceptions in society about DR-TB, however, that can lead to people being treated differently by others once they are diagnosed with the disease. When other people feel or think differently about someone with DR-TB, this is called “stigma.” When other people treat someone diagnosed with DR-TB

differently, this is called “discrimination.” People diagnosed with DR-TB may also feel badly about themselves (sometimes called “self-stigma”), which can contribute to anxiety, depression, and isolation.

Having someone by your SIDE to help with all of this can be an important part of the therapeutic journey. Think about people in your network who are kind, thoughtful, and trustworthy and consider letting them know about your DR-TB diagnosis and treatment journey. This process is called “disclosure,” and when the news of a DR-TB diagnosis is shared with a trusted person, this can have multiple benefits. Often, people with DR-TB feel shame and are afraid to talk about what is happening to them. This can be a heavy burden to carry, and while some people may not react in a positive way, if a close and trusted person is given this information, they can often provide much needed support. For advice and tips of how to share a DR-TB diagnosis with other people, please see [Talking with People About Your Diagnosis of Drug-Resistant Tuberculosis](#).

If there is no one within your social networks to stand by your SIDE during this time, consider connecting with other types of support groups or networks. Many settings have active DR-TB survivor groups where people diagnosed with DR-TB can turn for assistance. Sometimes these groups meet in person, but sometimes they can be accessed online or via social media platforms. Some examples of these groups are “We are TB” (<https://tbcontrollers.org/community/tb-survivors-we-are-tb/>), TB People (<https://tbpeople.org/>), and the Global Coalition of TB Advocates (<https://gctacommunity.org/>).

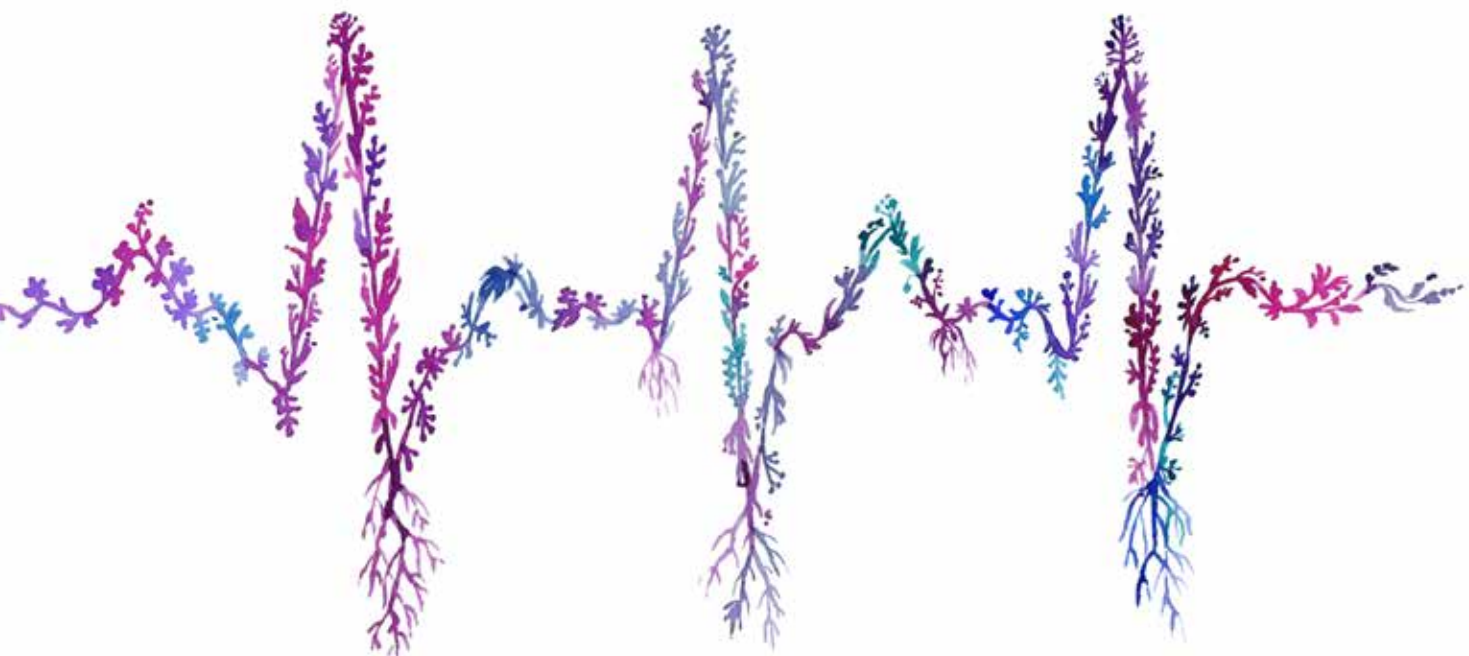


TABLE 2. SIDE EFFECTS SYMPTOMS, TESTS, AND POSSIBLE CAUSES ORGANIZED BY BODY SYSTEM

BODY SYSTEM	SYMPTOMS	TESTING/ ASSESSMENT	POSSIBLE CAUSES
 Brain	Confusion, fatigue, nightmares, depression, anxiety, hallucinations (seeing or hearing things that are not there), difficult sleeping, difficulty concentrating	Formal assessments for depression and anxiety	Cycloserine, terizidone, levofloxacin, moxifloxacin, delamanid, isoniazid, Psychosocial stressors
 Eyes	Blurred vision, loss of ability to differentiate colors	Vision testing, red/ green color testing	Linezolid, ethambutol
 Ears	Buzzing or ringing in ears, decreased hearing (late symptoms)	Audiometry	Aminoglycosides (amikacin)
 Heart	Dizziness, chest pain, fainting, racing heart	ECG, blood sample for electrolytes if ECG abnormal	Moxifloxacin, bedaquiline, clofazimine, levofloxacin, delamanid
 Lungs	Cough, shortness of breath, increased sputum, coughing blood	Sputum sample, X-ray	TB
 Stomach	Nausea, vomiting, abdominal pain, heart burn May be worse with lack of food	N/A If severe and intractable, consider blood sample for liver function	All DR-TB medications but especially moxifloxacin, clofazimine, pyrazinamide Lack of food
 Liver	Nausea, vomiting, yellowing of skin, yellowing of eyes	Blood sample for liver function	All DR-TB medications but especially pyrazinamide, pretomanid Alcohol Viral hepatitis

TABLE 2. SIDE EFFECTS SYMPTOMS, TESTS, AND POSSIBLE CAUSES ORGANIZED BY BODY SYSTEM (continued)

BODY SYSTEM	SYMPTOMS	TESTING/ ASSESSMENT	POSSIBLE CAUSES
 Kidneys	Swelling, decreased urination	Blood sample for kidney function	Aminoglycosides (amikacin)
 Intestines	Weight loss, diarrhea May be worse with lack of food	N/A	All DR-TB medications but especially moxifloxacin, clofazimine, pyrazinamide Lack of food
 Bones, Joints, and Muscles	Pain, swelling, stiffness, difficulty moving	N/A	Pyrazinamide, levofloxacin, moxifloxacin
 Peripheral Nerves	Burning, numbness, tingling, especially in hands and/or feet	Peripheral neuropathy screen with reflex and sensation testing	Linezolid, isoniazid Alcohol Malnutrition Diabetes
 Skin	Rash, dryness, change/ darkening in color	N/A	All DR-TB medications Clofazimine for skin color changes
 Blood/ Blood Cells	Fatigue, easy bruising, shortness of breath	Blood sample for complete blood count	Linezolid Malnutrition

Glossary and Abbreviations

- Aminoglycoside:** An injectable form of a medication used to treat TB (amikacin).
- Anemia:** A low level or shortage of red blood cells.
- Anxiety:** A feeling of worry or fear that can be overwhelming.
- Audiogram:** A formal test done to measure how well the ears are working.
- Blood:** A fluid in the body that carries oxygen and nutrients so the body can perform its functions.
- Blood vessel:** A tube in the body that carries blood from the heart to the rest of the body.
- Carbon dioxide:** A waste product gas formed by the body that is breathed out through the lungs.
- Cardiac:** Related to the heart.
- Cavity:** A hole.
- Cell:** A small building block of the body.
- Clot/clotting:** A plug or patch the body makes to stop the blood from spilling out.
- CT Scan (or “CAT” scan):** A Computed Tomography scan in which multiple, fast X-rays are taken, which the computer then puts together to generate an image that health care providers can look at to see what is happening inside. This is generally painless.
- Depression:** A feeling of sadness or lack of engagement that can be overwhelming.
- Diagnose:** To figure out the cause of something.
- Diarrhea:** A watery form of stool/poop.
- Disclosure:** The processes by which the DR-TB diagnosis and treatment journey are shared with others.
- Discrimination:** Behaviors directed toward people with TB that keep them from participating in activities that they have a right or desire to participate in. This may be against the law.
- DR:** Drug Resistant
- ECG:** Electrocardiogram
- Electrocardiogram:** A test done to measure the electrical system of the heart. This is generally painless.
- Extrapulmonary:** Outside the lungs.
- Germ:** A small organism that is not part of the normal body and can cause sickness, like TB.
- Hallucinations:** Seeing, hearing, smelling, or feeling something that is not actually there.
- Hepatic:** Related to the liver.
- Immune system:** The part of the body responsible for fighting infections.
- Joints:** The places where bones connect with one another that allow them to bend and move.
- Meningitis:** Swelling of the tissues around the brain or nerves inside the spine.
- MRI:** Magnetic resonance imaging, a special method to look at the brain in which multiple, fast X-rays are taken, which the computer then puts together to generate an image that health care providers can look at to see what is happening inside. This is generally painless.

Musculoskeletal: Related to the bones and joints.

Nerve: A cell in the body that sends electrical signals out to the rest of the body.

Oxygen: A gas in the air that is required by the body to carry out its functions.

Peripheral: Outlying or in the more remote parts.

Platelets: Cells in the blood responsible for clotting.

Prescribe: An order for a medication or treatment done by a health care provider.

Psychosis: A condition in which someone is confused and believes things that are not really there.

Pulmonary: Related to the lungs.

Renal: Related to the kidney.

Side effect: A problem in the body caused by a medication.

Stigma: A set of negative and unfair beliefs that a society or group of people have about something.

Symptom: A physical feeling or perception of something that is wrong or abnormal.

TB: Tuberculosis

Topical: Applied to the surface of the skin.

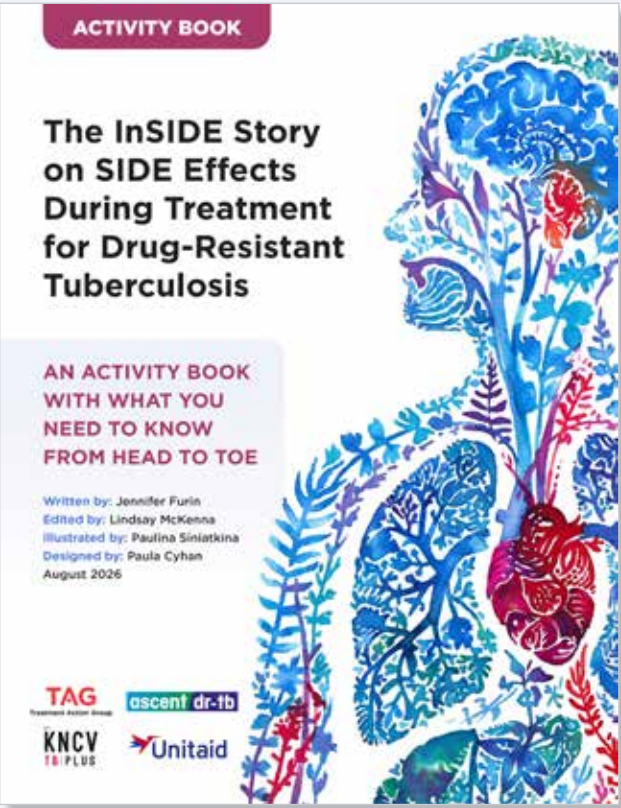
Transfusion: Replenishing the blood/blood cells using blood that is donated from another person.

Ultrasound: An ultrasound is a way of taking pictures of the inside of the body using sound waves. This is often done by placing some gel on the body part of interest and then placing a transmitter, which is attached to a machine, on the body to generate a picture of the internal part of the body. This is generally painless.

Virus: A small part of an organism that is not part of the normal body and can cause sickness.

X-ray: A picture taken, often of the lungs, to help health care providers see what is happening inside the body.

This **RESOURCE BOOK** has an accompanying **ACTIVITY BOOK** designed to facilitate improved communication between people on DR-TB treatment and their healthcare providers.



It includes:

- Strategies and tools to help people better describe and track their symptoms and severity
- Advice on how to prepare for consultations with their healthcare providers
- Activities to help people on DR-TB treatment feel more centered and connected to their bodies

Find the Activity Book and other community materials here:

www.treatmentactiongroup.org/2026-drtb-community-materials/

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