

TUBERCULOSIS AND YOU



FROM PATIENT TO PATIENT

We have made the journey you are just about to make. For now, just remember; **TB** is curable and nothing else matters.

TBPEOPLE

IFRC

LILLY PARTNERSHIP

2018

ABBREVIATIONS

TB — tuberculosis

MTB — mycobacterium tuberculosis

MTB(+) — bacteriologically confirmed **TB** case

DR — drug resistance

MDR — multiple drug resistance

XDR — extensively drug resistance

MDR — human immunodeficiency virus

TB MDR — double diagnosis, **TB** diagnosed in an **MDR**-positive person

PLWHA — people living with **MDR/AIDS**

WHO — World Health Organization

CONTENTS

I HI

3 Myths and misconceptions about **TB**

II TUBERCULOSIS AND YOU

4 What exactly is tuberculosis?

5 What is going to happen?

6 How is **TB** transmitted?

8 What kind of **TB** do I have?

11 Diagnosis of extra-pulmonary or non-infectious **TB**

12 How is **TB** treated?

14 **ANTI-TB** drugs

16 How to deal with side effects?

17 How can you help yourself?

18 Surgical Treatment of Tuberculosis

20 **TB** and **HIV**

III WHERE TO BE TREATED

23 Ambulatory care

23 Treatment at home

25 Hospital Life — in-patients

IV RELATING WITH YOUR DOCTORS

27 Mental health counselling

V YOUR FAMILY AND FRIENDS

31 How to protect and be honest to your loved ones

34 Hospital visits and safety

35 **TB** prevention

35 What is a latent **TB** infection?

35 Diagnosis of **LTBI**

36 Signs and symptoms of active **tb** disease

37 Preventive Therapy for **LTBI**

37 Infection control

VI HOW TO PROTECT YOURSELF

39 How to protect your rights

41 Drug stock-out problems

42 Safety on internet

44 Who can help?

VII LIFE AFTER TB

47 Back to reality

You are reading this because you or someone you love has been affected by a disease called tuberculosis. I know how that feels and understand you need support. I have been there myself.

My name is Paulina, I come from Russia and I am a **TB** survivor. I spent a long time in the hospital fighting for my life, and watching others struggle for survival. Many people were afraid to talk openly about the disease. My personal experience has made me want to change that. Silence is what makes **TB** invincible.

As an artist, I spent my time in the hospital painting portraits of other patients. When I was cured I left the hospital with a series of artworks. These paintings tell the stories of people who shared my fate.

This is how my art project **“HOLD YOUR BREATH”** was born. It's an exhibition that travels the world and tells everyone **TB** still exists, even here and now.

Today I am a **TB** activist and a member of **TBPEOPLE**, a network of **TB** survivors. But not so long ago it was hard for me to imagine I could ever overcome the disease, and recover as well as I did.

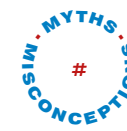
During my illness, long and complex medical texts about **TB** were hard to read. After my exhibition I wanted to create an illustrated guidebook about **TB** to help others understand and overcome the disease. **THE LILLY PARTNERSHIP** and **TBPEOPLE** supported my idea. When the Russian version was done and being distributed, **THE INTERNATIONAL FEDERATION OF RED CROSS** and **RED CRESCENT SOCIETIES** enabled me to make an international version.

The guidebook you are reading now is the result. It was created by **TB** survivors, my friends from **TBPEOPLE** and myself. We all recovered and now want to help you too. We understand how you may have felt when **TB** was diagnosed, how you may have struggled to accept your doctor's diagnosis, and how scary the stories from other **TB** patients can sound. We also know what your family and friends went through, and what myths and misconceptions are still commonly shared.

We have made the journey you are just about to make. For now, just remember; **TB** is curable and nothing else matters.



From patient



MYTHS AND MISCONCEPTIONS ABOUT **TB**

With this sign we address a common myth about **TB**

It's normal to feel scared when you're first diagnosed with **TB**. **FEAR** comes from ignorance, but when you know what you are fighting, it becomes less scary. Some people may say **“TB sticks with you for life!”** or **“You'll never be cured!”** or maybe even **“It's your own fault, it's your lifestyle!”** ...**DON'T LISTEN TO THEM!**

We discuss the 12 most commonly spread myths about **TB** in this book. We've asked patients from many countries to tell us the most worrying stories they hear about the disease in the clinics and hospitals. Then we asked **TB** experts from all over the world to comment on those myths, and separate truth from fiction, one by one. You can learn the truth about **TB** and know what you are facing, and what you can and cannot do.

It is important to understand **“STIGMA”**.

STIGMA IS HOW SOCIETY JUDGES A PERSON, BASED UPON A PREJUDICE. USUALLY IT'S SOMETHING THAT MOST PEOPLE DON'T KNOW MUCH ABOUT, AND ARE A BIT AFRAID OF. PEOPLE DON'T LIKE TO TALK ABOUT IT. IT'S A COLLECTION OF OLD IDEAS AND STUPID STEREOTYPES. STIGMA COMES FROM FEAR.

The stigma of **TB** is still very strong. It's hard to admit you have **TB**, you might feel afraid to be rejected. But we must fight this if we want to defeat the disease.

REMEMBER: TB CAN INFECT ANYONE! IT IS NOT YOUR FAULT YOU GOT TB.

IGNORANCE	>	FEAR	>	STIGMA
Learn about TB		Spread awareness		Destroy TB stigma

If you told someone about your disease and they've judged you for it, give them this brochure. You can also write to us.

NOBODY SHOULD HAVE TO DEAL WITH STIGMA ALONE.

to patient

TUBERCULOSIS AND YOU

WHAT EXACTLY IS TUBERCULOSIS?

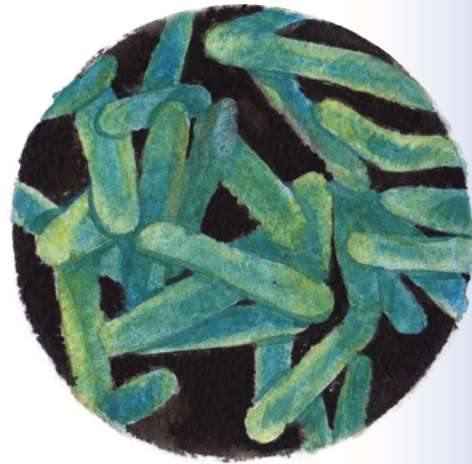
Different tests and X-rays will tell you the exact nature of your disease and how sick you are. So what exactly is **TB**?

In our picture you can see **MYCOBACTERIUM TUBERCULOSIS**, or **KOCH'S BACILLUS**. Every **TB** patient carries it in his or her body, and this is what causes the disease. Most often it is the lung that is affected, but it can damage other parts of the body as well.

For a long time **TB** has been the world's biggest killer, sometimes called the "**WHITE PLAGUE**". Even the Pharaohs were known to have been victims. For centuries humankind has struggled to find out what it is and how to cure it. At last there was a breakthrough on March 24, 1882 when scientist Robert Koch announced that after countless experiments he finally uncovered the cause of **TB** — the **TB** bacillus.

AND NOW WE KNOW THAT...

TB is an infectious disease, the infection starts by inhaling **TB** mycobacterium. Being infected does not necessarily mean you will become sick with **TB**. **M.TUBERCULOSIS** can live inside you for many years and never cause problems. Our immune system is very strong, but sometimes it fails. A poor diet, lack of sleep, a change of climate, **MDR**, immune-suppressing medications, even stress, fatigue or heavy emotions can temporarily block your immune system, and cause your body to be overrun by multiplying **MTB**. That's when you are most susceptible for **TB** to develop into disease. But even people with strong immune systems can also get **TB**. In short, nobody gets **TB** because they're poor or have bad habits — anyone can get it.



From patient



WHAT IS GOING TO HAPPEN?

TB is very curable nowadays. Your diagnosis of **TB** might make your head spin. In panic you may ask yourself, "Is that it, am I going to die?" or "What about my family, have I infected them as well?" You may be in denial: "No way, they've got it all wrong". Trust me, we have all asked ourselves the same questions.

Newly diagnosed patients often dig for information in all the wrong places: websites full of alternative tips, or advice from "a friend of a friend of a **TB** patient". If you act on false information you might do yourself more harm than good, so do your medical research carefully.

CONCENTRATE ON YOUR RECOVERY

What to expect in the months to come:

1. You will undergo tests and examinations for a more accurate diagnosis.
2. You will find out how "**SENSITIVE**" your **TB** is to certain medicines (that is, does it respond well to anti **TB** drugs, or is it resistant to antibiotics).
3. A course of treatment will be prescribed.
4. You will be treated in a hospital as an "**IN-PATIENT**" or at home as an "**OUT-PATIENT**".

to patient



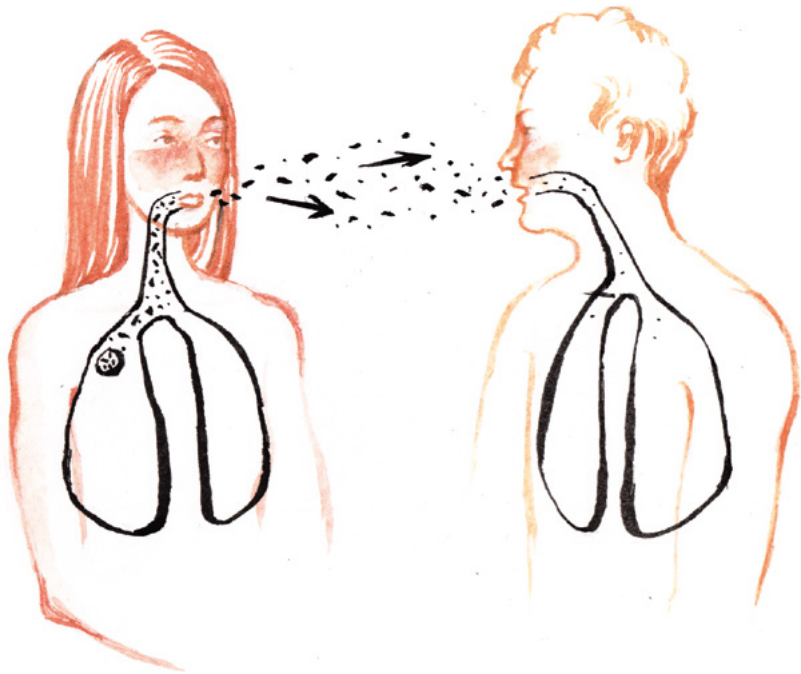
HOW IS TB TRANSMITTED?

TB is transmitted through the air. Usually, someone with active **TB** disease in his or her lungs is the source of the infection. By coughing or sneezing he or she spreads droplets (aerosol) with bacteria through the air. The aerosol containing **TB** bacteria can drift around for a long time. They can then be inhaled by somebody else, if the room is not properly ventilated. The bacteria must enter the lungs to cause an infection.

The World Health Organization (**WHO**) estimates that one third of the world's population is infected with **TB**-bacteria. But no more than 10% of the infected will actually get sick.

TB IS NOT TRANSMITTED BY HANDSHAKE OR SHARED TOOTHBRUSHES AND BEDCLOTHES. YOU WILL NOT GET TB IF YOU EAT FROM A TB PATIENT'S PLATE OR DRINK FROM THEIR GLASS.

This is what our first myth is about.



“YOU CAN CATCH TB THROUGH CONTACT WITH FORKS AND SPOONS, CLOTHES, GADGETS, BOOKS AND OTHER THINGS TOUCHED BY A TB PATIENT”

This was proven wrong long ago, but it can still be heard, even in hospitals and clinics around the world. Doctor **MICHAEL RICH** explains:

MICHAEL RICH, MD, MPH IS A GLOBAL HEALTH PHYSICIAN AND LEADING EXPERT IN THE FIELD OF MULTI-DRUG RESISTANT TUBERCULOSIS AT PARTNERS IN HEALTH, USA.

Almost all **TB** infections are transmitted through a tiny “nuclear droplet”, which must be of the perfect size. When people cough, they produce lots of bacteria. If a single bacteria is breathed into your lungs, you will likely breathe it out without it landing in your lungs, or it will be too small to survive. If the clump of **TB** bacteria is too large, it will land in the back of your throat. You will likely swallow it and it will be killed in the stomach and intestines. The nuclear droplet of **TB** bacteria must be the perfect size to be breathed in and land deep into the lung (in the alveoli of the lung tissue) where it can multiply and lead to an infection. The infection may or may not lead to active disease.

Although it seems like sharing objects, like a spoon, with a **TB** patient could lead to infection, it is virtually impossible because the bacteria on the object will not form the special nuclear droplet, and they will not make it to the alveoli in the lung. Bacteria that land on your skin will also not make it to your lung. Even if bacteria lands in dust on the floor, and you sweep it into the air, it never forms the nuclear droplet shape again. The nuclear droplet only forms from a cough or expelling air from the lungs.

People often wonder if one can get **TB** from being in a room that an infectious patient was recently in but is no longer there. This is rare but can happen in rooms that do not have a lot of ventilation. If the person coughs up a nuclear droplet and then leaves the room, in the correct conditions the nuclear droplet can float around for even a few hours. Having rooms that have at least six air exchanges per hour is a good way to clean out a room of bacteria.

WHAT KIND OF TB DO I HAVE?

TB bacteria can be anywhere in your body, not only your lungs, it can be “sleeping”, and it may be resistant to antibiotics. That’s why **TB** diagnostic tests are your main weapon. Doctors need to assess how much damage has been done, find out how contagious you are and which drugs will work best to cure you.

THE TESTS:

1. IMAGING

PULMONARY (=in the lungs) **TB** is most often diagnosed by **FLUOROGRAPHY** or **AN X-RAY SCAN**. A chest scan can show any changes in the lungs caused by the disease. This method has its drawbacks; it can only detect **TB** after you’ve been sick for quite some time. **COMPUTED TOMOGRAPHY (CT)** is a more advanced diagnostic tool that produces a 3D high-resolution image. It can help detect **TB** in its early stages and is used when there are signs of **TB**, but the X-ray shows nothing. **CT** also helps diagnose some forms of **EXTRA-PULMONARY** (=outside of the lungs) **TB**.



The other thing to keep in mind is that changes in the lung caused by **TB** on imaging scans can be similar to changes caused by other infectious diseases. You will usually need more than just an imaging scan to say for sure whether you have **TB**.

2. SPUTUM MICROSCOPY AND CULTURE.

SMEAR/CULTURE POSITIVE AND NEGATIVE TB

SPUTUM (the slime you cough up) is examined by smear microscopy and culture growth. Smear microscopy will look for **M.TUBERCULOSIS** in your sputum sample. A culture means your sputum will be placed in a test tube with a nourishing agent to see if any **TB** bacteria will grow. This may take a few weeks but tells you if your mycobacteria are, indeed, tuberculosis. A “**SMEAR/CULTURE POSITIVE**” result means you have “**ACTIVE TB**”; it also means when you exhale, bacteria can leave the lung and can be contagious to others. A “**SMEAR/CULTURE NEGATIVE**” result means you probably do not have active **TB**. Unfortunately there is no way to completely rule out **TB**. However, when the smear/culture is positive it is very certain that you have **TB**.

3. DRUG SENSITIVITY TESTING – MDR-TB OR NOT?

In 2010 **WHO** recommended a molecular test called “**GENEXPERT**” as a primary diagnostic tool to screen for **TB**. This is a very useful test because it tells you two things: **1)** Do you have the **DNA** of the **TB** bacteria in your sputum: and **2)** If the bacteria are present, are they resistant to the **ANTI-TB** drug rifampicin. Antibiotic-resistant **TB** strains are very common worldwide now.

When **TB** bacteria are resistant to two of the most powerful antibiotics, **ISONIAZID** and **RIFAMPICIN**, it is called “**MULTI-DRUG RESISTANT TB**” (**MDR-TB**). Patients suffering from **MDR-TB** must be given the right kind of antibiotics from the start. For them it is a matter of life and death.

GeneXpert takes about two hours to show if your **TB** strain is sensitive to rifampicin. If it is resistant, you probably have **MDR-TB**, because resistance to rifampicin alone is extremely rare.

DRUG SENSITIVITY TESTING (DST) is used to find out which other drugs can help an **MDR-TB** patient. This test is done if GeneXpert shows resistance to rifampicin or when a standard first-line **TB** treatment fails to work.

“POSITIVE TEST CAN BE A LABORATORY MISTAKE. MAYBE THEY USED SOMEBODY ELSE’S SPECIMEN”

Doctor **SVETLANA DOLTU** comments on this:

The way your sputum is collected and processed makes **SVETLANA DOLTU, MPH, TB EXPERT FROM AFI, NGO, MOLDOVA.** cross-contamination or false labeling almost impossible. To avoid mistakes the specimen is collected in the presence of a healthcare worker. A container for the specimen is labeled with your unique **ID**, the type of test to be performed, date of sputum collection and accompanied by a standard referral form. All laboratory work including smear preparation is done by qualified staff in biosafety cabinets — enclosed workspaces where **TB** infection is contained and cannot spread. The sputum is processed with special dyes that immobilize (kill) any **TB** bacteria, clearly seen under a microscope in red. That means **TB** bacteria in the lab can’t be “accidentally blown over” to another person’s sputum.

MICHAEL RICH:

All these special steps make laboratory cross-contamination or mislabeling very rare, but not impossible. If there are unusual results, like a person with no or little symptoms is testing positive for **TB**, the doctor may decide to repeat the **TB** test to be sure. If it still comes back positive, it is high likely the test is correct.

From patient

TUBERCULOSIS AND YOU

to patient

TUBERCULOSIS AND YOU

DIAGNOSIS OF EXTRA-PULMONARY OR NON-INFECTIOUS TB

(no sputum and nothing seen by imaging, what now?)

When you have non-infectious and/or extra-pulmonary **TB**, doctors will try other ways to find it. If they still see no **TB** the doctors might try the first-line of **ANTI-TB** drugs empirically. If they help, **TB** is likely.

You could also be diagnosed with a different disease with similar symptoms, like pneumonia, but your treatment doesn’t work. In case a few weeks of therapy for pneumonia shows no improvement, **TB** becomes a suspect.

Sometimes a biopsy is done. They’ll remove a tiny piece of the affected tissue for a close examination, which usually includes doing the molecular test GeneXpert or a culture.

Extra-pulmonary **TB** is not easy to diagnose. Various internal organs of the patient’s body will be screened by different diagnostic methods including **CT SCANS, ULTRASOUND, MRI, BIOPSY** or **A BLOOD TEST**. If *M.tuberculosis* is confirmed, they will test its sensitivity.



HOW IS TB TREATED?

TB is treated with a special regimen of antibiotics that kill **TB**. Once all tests are done, your doctor will tell you how long your treatment may last. If your treatment is working, you will no longer be contagious within a few weeks, often even sooner.

The first line of **TB** treatment consists of four main drugs: **RIFAMPICIN (R)**, **ISONIAZID (H)**, **PYRAZINAMIDE (Z)** and **ETHAMBUTOL (E)**. This standard treatment is six months, but sometimes longer. The typical treatment is 2 months of the drugs **H-R-E-Z** followed by four months **H-R**. The medicines are all put in the same tablet, but depending on your weight you might have to take 2, 3 or 4 tablets a day.

If your **TB** is resistant, you will be treated with a more complex combination of **ANTI-TB** drugs. Prior to August of 2018, most **MDR-TB** regimens included daily intramuscular injectable **TB** drugs. However, the World Health Organization (**WHO**) has now re-classified the **ANTI-TB** drugs and prioritized the stronger oral **TB** drugs. The treatment may take between 9 and 24 months depending on the severity of your condition, and whether you have **MDR-TB** or **XDR-TB**. When treating resistant **TB** it is advised to avoid the use of injectable drugs whenever possible. Discuss this with your doctor.



From patient

TUBERCULOSIS AND YOU

to patient

TUBERCULOSIS AND YOU

MDR-TB (MULTI-DRUG RESISTANT TB) is a form of **TB** resistant to rifampicin and isoniazid. **XDR-TB (EXTENSIVELY DRUG-RESISTANT TB)** is a form of **MDR-TB** which is resistant not only to isoniazid and rifampicin but also to two other second-line **ANTI-TB** drugs — at least one fluoroquinolone and a second-line injectable drug.

The August 2018 re-classification prioritized three drugs that should be used in all **MDR** patients (unless more resistance is present or intolerability exists). The three priority drugs are fluoroquinolones (levofloxacin or moxifloxacin), bedaquiline, and linezolid. All **ANTI-TB** drugs are listed in the table below.



ANTI-TB DRUGS

Classification of the anti-tuberculosis drugs (WHO, August 2018)

This information shows the regular anti-TB regimens. Your personal medication may differ for various reasons. Never take any medication not prescribed by your doctor!

FIRST-LINE ANTI-TUBERCULOSIS DRUGS

(drugs used to treat “DRUG-SENSITIVE TB”)

ISONIAZID (H) This most powerful bactericidal agent kills rapidly-multiplying **MTB**, makes you feel better and stops you from being infectious. It is the main drug to treat sensitive **TB**.

RIFAMPICIN (R) This has a strong bactericidal and sterilizing effect. It kills the rapid and slow multiplying types of **MTB** as well as ‘dormant’ intracellular strains. By taking this drug, a course of treatment to treat sensitive **TB** takes only six months for most patients.

ETHAMBUTOL (E) This bacteriostatic agent does not kill **MTB** strains but it prevents their reproduction. It also prevents resistance to isoniazid and rifampicin, the main **TB** drugs.

PYRAZINAMIDE (Z) This has a sterilizing effect and suppresses bacterial growth. It works where other drugs cannot get in.



From patient

TUBERCULOSIS AND YOU

||

||

to patient

TUBERCULOSIS AND YOU

MEDICINES USED IN MDR-TB

(most are second-line **ANTI-TB** drugs, but sometimes some of the first-line **TB** drugs are still used)

GROUP A Medicines to be prioritized: **LEVOFLOXACIN, MOXIFLOXACIN, BEDAQUILINE** and **LINEZOLID**. All **TB** patients should get all three **GROUP A** medicines, provided their **TB** is not resistant and they can tolerate the drugs.

GROUP B Medicines to be added next: **CLOFAZIMINE, CYCLOSERINE/TERIZIDONE**.

GROUP C Medicines to be included to complete the regimens and when agents from **GROUPS A** and **B** cannot be used: **ETHAMBUTOL, DELAMANID, PYRAZINAMIDE, IMIPENEM-CILASTATIN, MEROPENEM, AMIKACIN (STREPTOMYCIN), ETHIONAMIDE/PROTHIONAMIDE, P-AMINOSALICYLIC ACID**.

The medicines are listed in a hierarchy based on effectiveness, adverse events that they might cause and how commonly they are resistant.



HOW TO DEAL WITH SIDE EFFECTS?

Most of the side effects can be relieved by other medication, such as **ANTI-NAUSEA PILLS, MUSCLE RELAXANTS, PRO-BIOTICS, or PAIN-KILLERS**. If your side effects are too severe, your doctor might change the dose or completely replace one of your drugs. It is important to trust your doctors and tell them how you feel. Even if the side effect are mild, still tell your doctor. Sometimes minor symptoms can prelude more serious problems, like ringing in the ears can turn into severe hearing loss, or mild numbness in the legs into painful and permanent nerve damage. So better be on the safe side, and tell your doctor or nurse about any side effects.

Unfortunately some side effects will have to be tolerated (especially if they are not dangerous), but there are tricks to help you cope. For example, patients with **MDR-TB** and **XDR-TB** tolerate their treatment better if they take the most 'problematic' pills just before bedtime. Most pills are taken on an empty stomach, but some are better tolerated after a meal or snack. At some point your body will get used to the drugs, and side effects may stop bothering you.



HOW CAN YOU HELP YOURSELF?

It is essential to eat healthy, as well as taking your pills. Sometimes just thinking about food will make you feel sick, especially at the beginning of your treatment. But you **HAVE TO EAT** because your body needs the energy to fight against the disease. Vary your diet and add lots of protein to your meals. Poultry, red meat, beans, nuts, fish and eggs. It's also important to eat plenty of fruits and vegetables! Berries, oranges, broccoli, spinach, garlic etc. are loaded with important vitamins and antioxidants that boost your immune system and help fight off **TB**. In addition, do not smoke and avoid drinking alcohol. Many of the medicines interact with alcohol and can cause damage to the liver.

Take some exercise, go for a daily walk. As soon as your fever (if any) subsides and you feel stronger, spend time outside, enjoy the sunshine.



“TB PATIENTS SHOULD AVOID SUNSHINE, EVEN AFTER THEY ARE CURED, OR THEY MAY RELAPSE”

Sunshine helps your body produce **VITAMIN D**, needed by your immune system to fight **TB**. Avoiding exposure to the sun results in lower levels of **VITAMIN D**. So lack of sunshine actually increases the risk of contracting **TB**. Remember, the Sun is our friend, not an enemy!

However, be careful. Some drugs, most commonly the **FLUOROQUINOLONES (LEVOFLOXACIN, MOXIFLOXACIN ETC.)** can cause your skin to become more sensitive. If you develop a rash on the skin when exposed to the sun you should avoid sunlight, or you risk getting badly sunburnt. This is a toxic reaction, called **“PHOTOSENSITIVITY”**.

While undergoing **TB** treatment you must complete the full course. Once cured you can resume your normal life.

DR VERA ZIMINA advises:

DR VERA ZIMINA, TB AND INFECTION CONTROL SPECIALIST AT PEOPLE'S FRIENDSHIP UNIVERSITY OF RUSSIA, DEPARTMENT OF INFECTIOUS DISEASES, RUSSIA.

Once you are cured of **TB** you should live your life to the fullest... Make healthy life choices and look forward to every new day. That is the best way to prevent **TB** relapse. You don't have to avoid sunshine, but sunbathing for too long is not good for you. Remember, too much sun may cause skin cancer for everybody, regardless of their **TB** history.

SURGICAL TREATMENT OF TUBERCULOSIS

Operations can be scary. You may feel pressured to agree to surgery, but **IT'S OK TO DOUBT**. It's important to understand when surgery becomes a viable option.

REMEMBER: SURGERY IS AN EXTREME MEASURE AND SHOULD ONLY BE CONSIDERED WHEN MEDICATION ALONE IS INSUFFICIENT. IF YOUR BODY RESPONDS TO ANTIBIOTICS AND YOU MAKE STEADY PROGRESS, YOU PROBABLY WON'T NEED SURGERY.

Good reasons for surgery:

1. **DIAGNOSTIC.** Surgery as a diagnostic tool is only used when all other diagnostic methods failed to either confirm or rule out **TB**. This happens, for example, when an X-ray shows firm lumps in the lungs that may be caused by **TB**, or by something else.
2. **EXTENSIVE AND IRREVERSIBLE DAMAGE TO THE LUNGS.** The damage can be so big that **ANTI-TB** drugs are unable to reach the heart of the infection.
3. **BONE AND JOINT TUBERCULOSIS** very often requires surgical treatment.
4. **LARGE CAVITIES** that won't heal, even after several months of correctly applied medication.
5. **TB THAT IS PROGRESSING SO FAST LIFE-THREATENING COMPLICATIONS COULD DEVELOP.** Surgery is used as a life-saving measure in this case.

IMPORTANT: SURGERY ONLY REMOVES DAMAGED TISSUE, SO IT IS JUST A PART OF THE TREATMENT, AND NOT SUBSTITUTE FOR MEDICATION.

From patient

TUBERCULOSIS AND YOU

to patient

TUBERCULOSIS AND YOU



“IF YOU REFUSE SURGERY YOU WILL RELAPSE” OR “SURGERY WILL DESTROY YOUR BODY COMPLETELY” OR “NO ONE LIVES LONGER THAN FIVE YEARS AFTER AN OPERATION” OR “SURGEONS JUST GET PAID FOR EVERY PATIENT THEY OPERATE”

If you just have some scarring in your lungs, you don't need surgery. Your body will take care of it with time. But if your doctor still insists on surgery, you have the right to get a second opinion from another doctor before you agree.

DR LEE B. REICHMAN explains:

DR LEE B. REICHMAN, MPH, MD, THE FOUNDING EXECUTIVE DIRECTOR OF THE NEW JERSEY MEDICAL SCHOOL GLOBAL TUBERCULOSIS INSTITUTE, USA.

Surgery for **TB** is **EXTREMELY RARELY** necessary. In our practice (100 new patients a year) we will end up doing surgery on only one or at most two. That is because drugs cure **TB** and surgery is only necessary in very localized drug-resistant cases. Any surgery has a risk, although small in appropriate patients, but our practice is to avoid

surgery unless it is absolutely necessary. All of the reasons you give are valid but are not reason enough to endanger a patient when drug treatment can be given with virtually no risk to the patient.

It is true that lots more surgery is done in Post Soviet countries due to the large number of trained lung surgeons. These patients often do well. However nearly all could have been treated as well or better and easier, and less painfully **WITHOUT** surgery.

Also surgery is **NOT** a way to safeguard a future pregnancy. If your treatment works, then don't have to worry about relapse when you become pregnant.

Some words from **TB** expert **DR VERA ZIMINA** to all women of reproductive age:

Sometimes, women are advised not to become pregnant for at least 2–3 years after they are cured. However you can have a baby earlier without complications. Just make sure you check yourself after giving birth, and before you start breastfeeding, to rule out a **TB** relapse. The radiologist will compare your X-ray with the one taken before your pregnancy.

TB AND HIV

Many people are unaware they are **MDR**-positive. **MDR** weakens your immune system, which increases the chance to develop **TB**. In an **MDR**-infected person, **TB** can at first masquerade as the common flu or a simple cold. **MDR** is on the rise. In Russia alone, more than a million people live with **MDR**. Often when women become pregnant they have their **MDR** status checked for the first time, and sometimes, to their shock, the outcome is positive. This can happen with unprotected sex, a blood transfusion, surgery or sharing a syringe for an injection. **TB** as a result of **MDR** infection is much more difficult to treat, so it is important to know your **MDR** status and to undergo a test.

HOW TO DIAGNOSE TB IN AN HIV-POSITIVE PERSON?

DR ALEXANDER PANTELEEV explains:

TB in **MDR**-positive patients is diagnosed in the same way as in **MDR**-negative patients. However, a compromised immune system may behave differently. For example, as the **MDR** infection progresses, the **CD4** cell count may drop to 350 and less. Such a patient will have a negative Mantoux test result because the body stops reacting to **TB** infection normally. People living with **MDR/AIDS (PLWHA)** are routinely screened for **TB** twice a year, but at advanced **MDR** stages **TB** may be progressing very fast and become dangerous in the six months between screenings. The main symptoms of **TB** in people with advanced **MDR** disease are high fever, rapid loss of weight, weakness, night sweats and cough. If you have these symptoms, go to see a doctor immediately.

A commonly used test is **THE GENEXPERT**, discussed above. An additional test for diagnosis of **TB** in **PLWHA** is computer tomography (**CT**) with contrast media. This screening tool provides a detailed view of the internal organs. One can see any changes caused by **TB**. **TB** in an immune-compromised individual will probably affect several organs at once, causing **GENERALIZED TB DISEASE**. This means it can strike everywhere, except for hair and fingernails.

To diagnose **TB** we must look for **TB** bacteria. As **TB** bacteria may be found anywhere in the body, we screen not only the lungs but all other internal organs as well. It is not only the sputum but other bodily fluids that are tested. The diagnostic method of choice in this case is a test called **PCR** (polymerase chain reaction), which looks for the **DNA** of the **TB** bacteria., **GENEXPERT** uses **PCR** technology, so it is commonly used in testing body fluids. **PLWHA** should be referred for **PCR** testing if **TB** is suspected. The sooner they are diagnosed, the less complicated the treatment.

||

From patient

TUBERCULOSIS AND YOU

||

to patient

TUBERCULOSIS AND YOU

If an **MDR** patient has a very weak immune system, indicated by a low **CD4** (cluster of differentiation 4) cell count, one should start both **TB** and **ANTI-RETROVIRAL THERAPY (ART)**. This kills **MDR**, the immune system recuperates, **TB** therapy kills **TB** bacteria, and so the patient can successfully fight against both diseases.

If the **CD4** cell count falls to 350 or less, the **MDR** patient may lose their protective immunity to **TB**, and run a higher risk of developing **TB** disease. In this case, **PREVENTIVE TB CHEMOTHERAPY** is prescribed. This is discussed in more detail on page 37.

HORROR STORIES ABOUT TB/HIV

Many people think patients with **TB/MDR** are “doomed to die”, and call them “the walking dead”. This is just not true. **TB** is very curable in **MDR** patients nowadays. The problem is they are facing two stigmas, for **AIDS** and **TB**, at once. You may even notice it in the hospital. Patients are sometimes divided into “normals” and “**MDR**’s”. Some **TB** patients may look down on their fellow **TB** patients with **MDR**. They regard them as scum, just like they themselves are regarded by society. That’s why **TB/MDR** patients are in even more need of our support.



KATYA EMELYANOVA emphasizes:

Your diagnosis is no reason to become isolated, or to give up on yourself. As long as we hide our problems in shame, we will be regarded as outcasts. That's why we reach out to you, to give you hope. So you will regain your trust in your recovery, and you will never feel alone.

KATYA EMELYANOVA, TB PEOPLE-MEMBER, CREATOR OF A SPECIFIC SUPPORT GROUP OF AND FOR TB/HIV PATIENTS ON FACEBOOK, RUSSIA.

From patient

TUBERCULOSIS AND YOU



WHERE TO BE TREATED

to patient

WHERE TO BE TREATED

AMBULATORY CARE

If you have “active lung **TB**” you are spreading lots of **TB** bacteria, meaning you can infect others. Or when you are in such poor health that you need constant medical care, then you will be admitted to a hospital.

However, if your **TB** was diagnosed early and it's sensitive, you will stop being contagious after about two weeks of treatment. You can then be discharged from hospital and collect your pills at a **TB** clinic. Such a model of **TB** care is called “**AMBULATORY CARE**”. This means you can stay in the comfort of your own home as an “out-patient” with your family and have a lower risk of catching other **TB** infections from hospitalized **TB** patients.

TREATMENT AT HOME

In some countries there exists a patient-centered model of **TB** care; the so-called “**HOSPITAL AT HOME**”. All requirements for good quality care can be met if you have a separate room in your home. They'll bring you healthy meals, your room will be regularly ventilated and you are reminded to take your pills. Ask your doctor whether staying at home for treatment is an option for you.



“THERE IS NO REAL RISK OF RE-INFECTION WHILE YOU ARE IN HOSPITAL. ANTIBIOTICS YOU ARE TAKING WILL PROTECT YOU FROM ALL OTHER TB BACTERIA”

This is not true. **NOSOCOMIAL (HOSPITAL-ACQUIRED) INFECTIONS** and cross transmissions of other **TB** strains are possible in certain situations. It is essential to separate infectious **TB** patients from non-infectious and **MDR-TB** patients from those with drug-sensitive **TB**. The best way to avoid cross transmission is to discharge **TB** patients as soon as their sputum test comes back negative. If there are no other reasons for them to stay in the hospital, they should continue their treatment as out-patients.

DR MICHAEL RICH says:

A patient who is on effective **TB** treatment quickly becomes non-infectious to those around him. Even patients who are still smear-positive, if they are on correct treatment, will be much less infectious because the bacteria in the sputum are either killed or highly weakened by the antibiotics used in the treatment of **TB**.

However, patients who are on ineffective treatment can still be very infectious. An example would be a patient with multi-drug resistant **TB (MDR-TB)** who is only being treated with first-line drugs. This smear-positive **MDR-TB** patient on an ‘ineffective treatment’ would still be able to infect a smear-negative **TB** patient, even if that patient is taking first-line anti-**TB** drugs.

The situation can be improved by isolating patients until their **DST** pattern is known and they are placed on the proper therapy; and using rapid molecular tests to identify patients with **MDR-TB** or drug-resistant **TB**, such that we can separate them from drug-sensitive **TB** patients and treat them with **MDR-TB** regimens.

KSENIYA’S STORY

Hi, I am Ksenia Shchenina. Just like Paulina, I am a **TB** survivor. I spent 14 months in hospital surrounded by shame and fear. You either whisper about **TB**, or keep your mouth shut. I did not like it one bit. I decided to raise awareness in every way I can. Over the past eight years I talked to many **TB** survivors. What you read here is part of the experiences they shared with me. I hope this helps. I can be found on Facebook.



WHERE TO BE TREATED

From patient



WHERE TO BE TREATED

to patient



HOSPITAL LIFE – IN-PATIENTS

Even an out-patient will probably be recommended to spend “some short time” in the hospital. In reality “some short time” may easily stretch into weeks and months, especially if you have resistant **TB**. Most people find it hard to stay in a hospital for long. However, your hospital stay may be a blessing in disguise.

You have some time to re-evaluate your life. Maybe you can realize what exactly interfered with your health. Sickness is often linked to self-neglect. Sometimes it has nothing to do with hygiene, or a healthy diet, but simply with a lack of rest. We put the needs of our work, or families and children before our own. But how can you help others, if you ignore yourself? It’s the immediate “rule of the airplane” emergency: put on your own oxygen mask first, before helping others.

Also you can use these months to take up something you have put off for years. Many hospital patients start drawing and painting, study or enjoy photography, learn a foreign language, knit or start a freelance business online. Many of us even turn our hospital acquired experience into a new profession.



RELATING WITH YOUR DOCTORS

It's important to follow your doctor's professional advice in everything that concerns your treatment, and not to rely solely on the advice of other **TB** patients or people who recommend a "miracle cure". There is no quick & easy fix for **TB**. Don't pay attention to gossip or scary stories. It will only cause emotional distress, which can potentially cause even more damage by obstructing your immune system!

Be polite at all times to your doctors and nurses. They have to tend to many patients, they may be overworked, and they also need a bit of patience and understanding.

Try not to over-complicate things. For example, phrase your questions well about your treatment, and try to write down the answers. You may need them later.

Doctors are only human and can be burned out as well. If you really feel like a doctor or any other healthcare worker has violated your rights, you can file an official complaint. You can also find help in the organizations supporting the victims of **TB**. Remember, no one has the right to insult your dignity for any reason. But first, ask yourself why your doctor comes across as impolite. Maybe you've broken the hospital rules, got drunk or high, skipped your therapy, or spoken rudely to the staff?



MENTAL HEALTH COUNSELLING

Attitudes towards mental health care differ in different countries. Often you'll find old prejudices, presuming if you are seeing a psychotherapist, you must be crazy.

As a patient, it can be hard to rely on family and friends for emotional support, because they too are struggling to make sense of what it all means. And the other **TB** patients have problems of their own. It can be very helpful to have someone look at your situation from a different angle, more objectively. Counseling can be a valuable tool to help you deal with your disease. Professional therapists can work with emotions better than anybody else. You can tell them everything, they have to keep it secret and will never judge you.

HOW TO FIND A THERAPIST?

TB hospitals should offer professional counseling, if you want it, ask your doctor. These therapists specialize in **TB** healthcare, they understand what you're going through and know the difference between mental issues and side effects of **TB** drugs, for example.

If no counseling service is offered at your **TB** facility, the state might offer mental health services. Often you can access those anonymously, for example, a mental crisis hotline.



IMPORTANT: A GOOD THERAPIST WILL NEVER FORCE THEIR OWN OPINION UPON YOU. INSTEAD THEY WILL LET YOU FIGURE OUT YOUR OWN CASE.

HOW DO I KNOW IF MY THERAPIST IS ANY GOOD?

Just like choosing any other specialist, check his/her public profile. Look for professional education and good references. If you feel comfortable at the first consultation and you can talk easily, you've come to the right place.

To find the right person may take time and a few failures before you succeed. This is normal, just don't give up.

“TB TREATMENT IN THE WESTERN WORLD IS BETTER, THEY USE DIFFERENT DRUGS AND THEIR THERAPY REGIMENS ARE SHORTER”

E. JANE CARTER explains:

There is no treatment for **TB** disease that is shorter than six months. Six months is the shortest treatment length that is shown to cure **TB** in 95–99% of patients with drug susceptible **TB**. Drug-resistant **TB** takes much longer, but there are new regimens being approved and studies that are shorter than previously given. Still, short-course therapy for drug resistant **TB** is nine months at a minimum. Patients may feel significantly better in even a few weeks and therefore mistake this as being cured, but if the medications are stopped too early, the disease will return.

E. JANE CARTER, ASSOCIATE PROFESSOR OF MEDICINE AND FORMER PRESIDENT OF THE UNION (INTERNATIONAL UNION AGAINST TB AND LUNG DISEASES) TEACHES AT THE WARREN ALPERT SCHOOL OF MEDICINE AT BROWN UNIVERSITY, USA.

“IN THE USSR, TB TREATMENT LASTED LONGER (UP TO 18 MONTHS) BUT CURED YOU FOR LIFE. THE PERCENTAGE OF TB RELAPSES WAS MUCH LOWER”

DR NATAILA BOROVOK explains:

Modern **TB** treatment regimens include more anti-**TB** drugs than those in the past. This accounts for shorter time treatment. There were no treatment protocols for **MDR-TB** in the Soviet times. The strategy used in **TB** control nowadays is evidence-based and proved its effectiveness in many western countries. Post-war Europe struggled with **TB** epidemics just like the USSR did. They have defeated **TB**. Ex-Sovjet countries are taking the same path of evidence-based medicine now.

DR NATAILA BOROVOK, A TB SPECIALIST AT KHARKOV TB CLINIC, UKRAINE.

THE COUNSELING SESSION. PAULINA'S STORY

I was always very skeptical about psychologists. I regarded them as people who demand money for having a chat. The treatment of **TB** requires a lot of patience, and I had none.

I spent seven months in the hospital and I cried every single day. I started reading self-help books to lift my spirits. I did learn a lot and I thought I had it all under control until I was discharged from the hospital. At home I felt euphoric, of course. But after a while I was drowning in despair and didn't want to live. I was overwhelmed by everything that had happened to me.

My family was so concerned that they forced me to get professional help. Fortunately I found a therapist who knew how to talk to me. I was able to open up and share my story. Actually we didn't talk much about my disease, but more about my emotional ups and downs. After ten counselling sessions I had already developed an inner strength, I realized and accepted many things about myself. My worldview changed on many levels. Now I believe counseling can really fundamentally help people.



AN EXAMPLE OF ONLINE COUNSELING.

QUESTION:

"I suffer from panic attacks. If anyone coughs, I think 'Oh God it's TB' even if it's just a cold. I know I am overreacting but I can't help it. My biggest fear is to make someone else sick. I'm constantly scared to infect others. I cannot live a normal life, What can I do?"

PEER COUNSELING (AN EX-TB PATIENT REPLIES):

"Many of us had this kind of fear. I used to feel like this between screenings. But I come for screening regularly, so I know I did all I could. I don't have to torture myself. It is normal to worry about your family, we know how hard it was for us and we don't want them to go through the same. But if you go to regular screenings they are at very low risk. This is my way of coping and I have not found any better solution yet."

PROFESSIONAL COUNSELING (A PSYCHOLOGIST REPLIES):

"Your fears are normal. Just imagine you survived an air raid. Now every time you hear an airplane, you run for cover. What you are experiencing is called '**POST-TRAUMATIC STRESS DISORDER**'. This will ease with time. You will see your loved ones recover quickly after a cold, and you will re-learn that a cough does not always mean **TB**. But if you feel like your fear is taking control of your life, a professional therapist can help you deal with **PTSD**."



YOUR FAMILY AND FRIENDS

HOW TO PROTECT AND BE HONEST TO YOUR LOVED ONES

During your treatment, you will have a regular schedule of taking medication every day, so you more or less know what to do. But your family might feel lost and confused, not knowing how to help you. They might even come to you for their support. This can be very inconvenient, because you will need all of your energy to deal with the process of your own recovery. Patients trying to calm their family members down, or exploding in anger and accusations, or simply trying to joke and laugh their troubles away. We've all seen it. Be honest with them. Tell them you need all your attention on your recovery right now, and that they should take care of themselves for a while. You can show them this brochure, or otherwise advise them to seek professional help.



NO SECRETS!

Tell your friends you have **TB**.

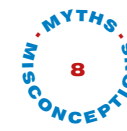
- 1. IF YOU DON'T, YOU RISK THEIR LIVES.** They might be ill too. Let them check themselves every half a year.
- 2. IF YOU DON'T, YOU RISK YOUR OWN HEALTH.** Possibly you got ill because of a friend who didn't know that he was sick. You might recover and then catch it again.
- 3. IF YOU DON'T, YOU RISK THE HEALTH OF EVERYBODY.** Telling your friends will help them realize the reality of **TB**.
- 4. REAL FRIENDS WILL STAND BY YOUR SIDE.** They might be shocked, they will need some time to figure out how to deal with it, but they won't abandon you. If your friends have small kids, better talk to them on the phone. Support can also come from a distance.
- 5. SOME FRIENDS WON'T UNDERSTAND HOW TO DEAL WITH YOU.** That's OK, they simply can't relate to you, because they never had a similar experience. You can tell them exactly what kind of support you wish for, but don't expect too much.

Having **TB** may influence your mood but it doesn't make you a different person. Remind your friends and family that it's still you, you're just temporarily sick.

FEELING GUILTY

Being in a hospital for **TB** treatment is a long difficult process. You will have plenty of time to think about when and how you contracted **TB** for instance. But please don't start blaming yourself, and don't let anyone else blame you. What you did in the past doesn't matter, even if you were drinking and smoking and taking all kinds of drugs. The only thing that matters now is your treatment and recovery.

Some members of **TBPEOPLE** have had troubled pasts. But since they are cured they're helping others to overcome the same obstacles. They recovered and came out stronger, simply because they refused to give up on themselves.



“TUBERCULOSIS IS A GENETIC DISEASE, THAT’S WHY I GOT SICK”

Scientists have not identified any “genetic predisposition to **TB**”. This means that anyone can get it. Having a weakened immune system for any reason increases your chance. It is an airborne infection spread from the sick to the healthy. It is a normal ‘chain of infection’ with three links: the pathogen, the mode of transmission and the susceptible recipient.

DR JANE CARTER writes:

We do not know the exact reasons that cause the immune system to fail and allow the **TB** germ to become active. We know that a person who is infected has a 10% lifetime risk of developing disease. 5% of those people will become ill in the first two years after infection; the other 5% will develop disease later in life. Factors that weaken the immune system to allow the **TB** germ to activate are **HIV** co-infection, other illnesses such as diabetes and renal failure, malnutrition (being more than 10% below your ideal bodyweight) and other conditions that depress the immune system. Tobacco use is a factor that contributes both to infection and **TB** disease. Some medications can allow the **TB** organism to break out as well: chemotherapy for cancer, prednisone and use of **TNF** alpha blocking agents.



HOSPITAL VISITS AND SAFETY

It's nice to have visitors, especially if they bring some gifts. Something new to read or something tasty to eat is always most welcome. But it is important to remember you are in an infectious ward. Visitors should wear shoe covers and wear a mask specially designed for keeping **TB** from entering their lungs for their own protection. The special masks are usually labeled "**N-95**". Ordinary surgical masks do not protect a visitor. However, a surgical mask should be worn by all patients who are still contagious. Having patients wear surgical masks prevents the release of **TB** aerosols into the air (the bacteria get trapped inside the mask).



"TB CAN BE CURED BY HOME REMEDIES LIKE BEAR OR BADGER FAT, MOLE-CRICKETS, ICELAND MOSS ETC."

Some people look for magic cures. In their desperation they are easy prey for swindlers. "This potion is your only chance!" or "Money can't buy you a new husband, consider this an investment!". Who can withstand such marketing? Frauds will push expensive stuff that "renews your energy levels" or "recuperates the inner cells" or some other pseudo-scientific nonsense. For all you know you might be buying powdered bugs or alcohol-soaked larvae. Don't believe everything you hear. They don't care about you, they just want your money. If you're in doubt, ask your doctor. But always remember, the most effective weapons against **TB** are well known, and they're already used in your treatment.

A comment from **TB** doctor **NATALIA BOROVOK**:

For centuries people tried to cure **TB** with all sorts of remedies and potions, and some of this 'knowledge' continues to this day. But only the advent of modern medicine and discovery of antibiotics turned **TB** into a curable disease. Correctly applied medication does not need any additional remedies. On the contrary, if you start eating bear fat, you will only put more strain on your liver, which is already busy processing the antibiotics. All these noxious things are sold by frauds abusing the trust of sick people.

From patient

YOUR FAMILY AND FRIENDS

to patient

YOUR FAMILY AND FRIENDS

TB PREVENTION

The exposure to **TB BACTERIA** can have three possible outcomes:

1. **THE TB BACTERIA WILL BE STOPPED FROM ENTERING THE BODY BY NATURAL BARRIERS** in the throat (mucous membrane, cilia, cough).
2. **THE TB BACTERIA WILL ENTER THE BODY BUT THE IMMUNE SYSTEM WILL REACT**, and no symptoms or sickness will develop. We call this a latent **TB** infection (**LTBI**).
3. **THE IMMUNE SYSTEM IS TOO WEAK TO FIGHT THE TB BACTERIA**, allowing it to multiply and spread around the body, developing active **TB** disease.

Not every infected person will develop **TB** disease. In most cases the immune system will either kill the bacteria, or make them "sleep"; become latent.

WHAT IS A LATENT TB INFECTION?

When the immune system isolates the bacteria where they can do no harm, we call this a latent infection, "latent" meaning "dormant". Although infected, there will be no symptoms or any sign of **TB**. Someone with a latent infection is in no way contagious. In fact, an estimated one-third of the world population is "infected" with latent **TB**. This condition can only be diagnosed by specific tests. The most common test is the "**MANTOUX**" TEST.

DIAGNOSIS OF LTBI

THE MANTOUX TEST is a tuberculin skin test (**TST**), checking the reaction of a tiny portion on the skin, indicating whether or not a person is infected with **MTB**.

Apart from skin tests **LTBI** can also be diagnosed by blood tests, **INTERFERON-GAMMA RELEASE ASSAYS**, **IGRAs** for short. These tests are more trustworthy than the Mantoux test but they are also much more expensive. Therefore they are used for quick and accurate diagnostics, for example, in **MDR** patients or help to rule out extra-pulmonary **TB** in the absence of **TB** symptoms.

SIGNS AND SYMPTOMS OF ACTIVE TB DISEASE

The most common symptoms are:

1. coughing
2. loss of appetite and loss of weight
3. night sweating
4. persistent low-grade fever (37–38 °C)
5. weakness and fatigue.

REMEMBER: SOME TB PATIENTS NEVER COUGH OR FEEL THE FEVER. IF YOU HAVE ONLY ONE OF THESE SYMPTOMS FOR MORE THAN TWO WEEKS, PLEASE CONSULT A DOCTOR



“TATTOOS, PIERCINGS OR ANY OTHER COSMETIC TREATMENTS MAY DESTROY YOUR IMMUNE SYSTEM”

DR. E. JANE CARTER writes:

All of these activities are safe to do while on treatment for **TB**. They are safe for the patient and there is no risk to the person supplying these services once the patient is smear negative and is reliably on treatment that is effective. None of these activities transmits **TB** and none poses harm to the patient in receiving them.



From patient

YOUR FAMILY AND FRIENDS

to patient

YOUR FAMILY AND FRIENDS



PREVENTIVE THERAPY FOR LTBI

The treatment of **LTBI** is often called “**PREVENTIVE THERAPY**” because we prevent an infection from becoming a disease.

There are different treatment regimens depending on the patient’s age and any concurrent conditions. It may be monotherapy by isoniazid or a combination of drugs. Preventive therapy may be prescribed to **PLWHA** and the close contacts of known **TB** patients. The doctor may prescribe an **MDR-TB** preventive therapy if there was high risk of exposure to **MDR-TB**.

INFECTION CONTROL

Many **TB** clinics and hospitals do not look very flashy and modern, but the infection control is often much stricter.

Ventilating all the rooms as often as possible is the best way to prevent infection at home. Disinfecting the furniture and floors will only help to protect against other infections spread by direct contact.

“VACCINATIONS AGAINST TB CAN CAUSE TB. IN THE WEST THEY DON’T VACCINATE, THAT’S WHY THEY DON’T HAVE TB”

VACCINATING AGAINST TB (BCG) and Mantoux tests are becoming less popular. People refuse to have their children vaccinated in the fear of irreversible side effects. These fears are based on ignorance, in reality they are putting their kids and everybody else at high risk.

DR NATALIA BOROVOK, a **TB** specialist in Ukraine, explains:

BCG protects babies and young children from deadly **TB** forms such as **TB** meningitis. Unfortunately since the supply of **BCG** vaccine in the country is running out, and more parents are refusing to have their children vaccinated, the number of **TB** deaths in young children is increasing again. There’s virtually no risk of complications after a **BCG** vaccination, but the risk of death from **TB** is very real. There is no evidence to prove the link between different illnesses and **BCG** or Mantoux. There are individual cases of allergic reactions to different chemicals but we should not go back to the times when it was normal for children to die of **TB** in large numbers. The tuberculin used for Mantoux has no living **TB** bacteria. It is completely impossible to catch **TB** by having a Mantoux test done.

TB doctor **VERA ZIMINA** explains further:

“Countries with low **TB** incidence rates exclude **BCG** from their children’s immunization programs, simply because there is no infection pool in the region. These children are very unlikely to ever be exposed to a virulent strain of *M.tuberculosis*. These countries have no benefit in applying **BCG** routinely, so they decided to stop. Russia stopped vaccinating people against smallpox back in 1982 for the same reason”.

HOW TO PROTECT YOURSELF

HOW TO PROTECT YOUR RIGHTS

The right to live and the pursuit of happiness are universal human rights.

You are **NOT** an exception, just because you’re a patient. Your health is your right, and your responsibility.

It can be hard and exhausting to fight for your rights, especially when you are all alone and feeling sick. Look for help in places where people may understand you. There are grass-roots organizations dealing with **TB** or other social diseases like **MDR** or hepatitis. Often they have doctors and lawyers on staff, who can offer free advice.

MAKE SURE THAT:

1. you are getting the right treatment,
2. the conditions at your clinic are humane and appropriate,
3. you are not being discriminated against.

WHAT CAN YOU DO WHEN YOUR RIGHTS ARE VIOLATED?

1. You have a right to a second unbiased medical opinion. Find a research institute or a specialized **TB** care facility and ask for an appointment.
2. If you have issues with your doctor or you are unhappy about your treatment, make an appointment to see the facility manager. If the problem remains unresolved, file a complaint to the Ministry of Health, the national **TB** program management or any supervising agency in charge of healthcare quality control.
3. If you have problems at work, remember that a person on sick leave can be fired only under special circumstances. Your employer may try to force you into voluntary resignation. This is a case of blatant violation of your rights. Complain to a supervisory agency in charge of labour legislation. You can also settle your labour disputes in court.

IT IS IMPORTANT TO KNOW YOUR NATIONAL LEGISLATION ON TB WHICH ENCOMPASSES:

1. The Constitution and its chapters on the human and patients' rights.
2. Health ministries and departments usually have the legislation on health and social care published on their websites.
3. Laws and regulations on **TB**.

IMPORTANT: YOU CAN ALSO ASK YOUR FAMILY OR FRIENDS TO FIND OUT WHAT NATIONAL AGENCY SUPERVISES HEALTH CARE SYSTEMS IN YOUR COUNTRY, AND HOW TO MAKE CONTACT.



From patient

HOW TO PROTECT YOURSELF

to patient

HOW TO PROTECT YOURSELF

DRUG STOCK-OUT PROBLEMS

Uninterrupted treatment is the key to successful recovery from **TB**.

Remember the names and the doses of your medication. If you suddenly receive fewer pills than normally, or one of your **TB** drugs is suddenly replaced by another without any medical reason, you might be dealing with a drug stock-out.

WHY DO DRUG STOCK-OUTS HAPPEN?

Stock-outs can occur for several reasons. Your clinic could have made a mistake over replenishment of stock, deliveries to them could be late, **ANTI-TB** drug prices could be rising.

You might be afraid to complain, but it's your life that is at stake, so do not hesitate to protest.

If you are denied your prescribed medication, act immediately:

1. Go talk to the main doctor. Ask why you did not get the prescribed medication and insist they give you all the drugs listed in your treatment protocol without exception or interruption.
2. Do not leave your doctor's office before you have a written confirmation of the fact that they can not provide you with your prescribed medication.
3. If they can not resolve the situation, call or write to the National Department of Health to complain, naming the hospital you're in. Save the dates and keep copies.

Most countries have a legally set time frame to deal with complaints. In our experience, anything to do with **TB** gets the immediate attention of the authorities.

Those who stand up for their rights have their **TB** drugs re-issued sooner.



SAFETY ON INTERNET

KSENIA SHCHENINA gives advice on how to search the internet.

Once diagnosed with **TB** many people start digging for **KSENIA SHCHENINA**, information. They search the internet or approach any **TBPEOPLE BOARD MEMBER**, doctors or nurses they happen to know. Some even read **RUSSIA** medical journals.

However you must be careful: a random internet search of “how to treat **TB**” can do you more harm than good. The internet is not the world’s best organised library, but rather a huge collection of opinions. You will have to pay close attention to separate the facts from fiction.

TIP NO 1. LOOK FOR CREDIBLE SOURCES

WHO AND NATIONAL TB RESEARCH FACILITIES

Every country with high **TB** rates has a **TB** research institute or a specialist **TB** research centre. They publish the latest news on **TB** patient care on their websites. Online consultations may be available (and all the necessary information on the application process can be found online as well). Type the name of your country and ‘**TB** research’ into the search engine or ask your doctor about **TB** research facilities available in your country. Researchers and doctors at these specialized centers are the key experts in the field, unlikely to be topped by anyone else. Another tip: read the pages about **TB** on the **WHO** website.

REMEMBER: DO NOT CONSULT SPECIALISTS ON A DIFFERENT FIELD THAN TB. THEY MAY HAVE KNOWLEDGE ABOUT THE WAY YOUR BODY WORKS, BUT IF THEY LACK EXPERIENCE IN TB THEY CANNOT REALLY HELP YOU

MEDICAL FORUMS AND SCHOLARLY JOURNALS

If you want to read medical journals on lung diseases, please understand: even the simplest-looking article in these journals is written for an expert in the field. Not being well-versed in medical terminology, you may totally misunderstand the text. This is where the doctors or nurses you know may come in handy. Read the text through and write down all the unknown words so you can ask your nurse or your doctor what it means.

TIP NO 2. BEWARE OF SCAMS

The only thing that effectively cures **TB** is antibiotics. But many people distrust the conventional state-funded medicine, or think doctors will profit from prescribing ineffective drugs, or deliberately keep patients at the hospital. Swindlers feed on these unfounded fears. But they forget that nobody wants a **TB** epidemic. The state cares about the most cost-effective treatment against **TB**, and doctors really need to show good results. If any other cure would be more effective than expensive antibiotics, it would be embraced immediately.

If you still insist to try an alternative cure, please inform your doctor. After all, the seller doesn’t care about you, he already has your money. So if an allergic reaction sends you into anaphylactic shock, it’s your doctor who will have to save your life.

HOW TO SPOT A FRAUDULENT WEBSITE?

1. Fantastic claims, such as “Super fast cure!” are usually a tell-tale sign of a fraud. If it sounds too good to be true, it usually is.
2. Sometimes websites try just a little too hard to look “official”, with links to “scientific articles”. Double check the names of the authors, to see if they are considered real scientists by the scientific community.
3. Check for conflicts of interests. If the website is selling what it is promoting, it is not objective by definition.
4. Positive reviews of people on youtube do not count. You can find many people on youtube who are convinced the world is flat.
5. Use Google to check the website’s claim, followed by the word “scam” or “hoax”, and see what you find.

If you still have your doubts, please contact us at **TBPEOPLE**.



WHO CAN HELP?

TBPEOPLE: TBPEOPLE.ORG

We created **TBPEOPLE** to unite **TB** survivors engaged in activism. Now we have representatives in all **EECA** countries. This booklet is one of our many projects. Please contact us if you need any help.

INTERNATIONAL FEDERATION OF RED CROSS AND RED CRESCENT SOCIETIES: IFRC.ORG

“Tuberculosis (**TB**), a disease that, despite being curable, continues to kill nearly 1.7 million people each year and infect around 10.4 million. Over 95% of **TB** deaths occur in low- and middle-income countries. As a people-centred movement, this is precisely why we warmly welcome the book ‘You and Tuberculosis’ by Paulina Siniatkina. This talented artist shows what to expect to patients hit by **TB**. Paulina made this book inspired by her own experience. As a young artist just a few years ago, she never imagined to fall victim to **TB**. Undergoing treatment, Paulina made sketches that mirrored the pain and fear of living without certainty. When cured, prompted by a belief that everything happened for a reason, the brilliant idea on how best to support **TB** patients was born. This is where this rich book comes to light. It is in fact a must read!

No organization is more familiar to the **TB** plight than **THE INTERNATIONAL FEDERATION OF RED CROSS AND RED CRESCENT SOCIETIES**. As people-centered organization, we provide assistance to people with active tuberculosis, and we never do it alone. We have mobilized over 5 million community members in **TB** endemic countries through more than 80,000 of our active red cross red crescent volunteers. They provide direly needed assistance including psychosocial support. They ensure close follow-up so patients stick to treatment adherence, an important step to avoid drug resistance. They co-operate with national **TB** services to facilitate early diagnosis, ensure provision of effective treatment, facilitate rehabilitation, and prevent of social exclusion or any forms of discrimination against **TB** patients.”

STOP TB PARTNERSHIP: WWW.STOPTB.ORG

WORDS OF LUCICA DITIU, DIRECTOR:

“You are not alone — there are many people that had or have **TB** in the world, in your country, city or village. **TBPEOPLE** and other **TB** survivors networks will always be there for you. Don’t hesitate to ask for help and support. Our work in **STOP TB PARTNERSHIP** is and will be centered in ensuring that all people affected by **TB** are supported, taken care of and empowered to be part of the **TB** response, so you will always have us protecting you. You can help others — become an activist, a fighter and supporter. Bacteria cannot be stronger than us, together we will defeat it. I will be there with you, and we will not give up!”

PARTNERS IN HEALTH: WWW.PIH.ORG

THE STOP TB PARTNERSHIP is leading the way to a world without tuberculosis. Founded in 2001, the Partnership’s mission is to serve every person who is vulnerable to **TB** and ensure that high-quality diagnosis, treatment and care is available to all who need it.

For more than two decades, **PIH** has treated and prevented tuberculosis (**TB**), multidrug-resistant **TB (MDR-TB)**, and **HIV/TB** in some of the poorest and most vulnerable communities in the world. Their community-based approach to care has resulted in some of the highest cure rates and lowest treatment default rates ever recorded.

“Our goal is to share the success of our approach on a broad scale.”

THE INTERNATIONAL TREATMENT PREPAREDNESS COALITION: ITPCRU.ORG/EN

The **ITPC** monitors available treatment options for **HIV**, **TB** and hepatitis in different countries, and makes sure that people get uninterrupted care. They also monitor treatment protocols to ensure they include the newest and best available drugs.

TREATMENT ACTION GROUP (TAG): WWW.TREATMENTACTIONGROUP.ORG

TAG is an independent community-based think tank working for better treatment, prevention, a vaccine, and a cure for **HIV**, tuberculosis, and **HEPATITIS C** virus.

TAG works to ensure that all people with **HIV**, **TB**, or **HCV** receive the right treatment and correct information.

THE TB EUROPE COALITION: WWW.TBCOALITION.EU/RU

There's a map on the website of our partner civil society organizations in different countries of Europe and Asia.

MEDICINES SANS FRONTIERES (MSF): MSF.ORG

Médecins Sans Frontières (Doctors without borders) is an international, independent, medical humanitarian organisation that delivers emergency aid to people affected by armed conflict, epidemics, natural disasters and exclusion from healthcare. They offer assistance to people based on need and irrespective of race, religion, gender or political affiliation.

MSF has been involved in TB care for 30 years, often working alongside national health authorities to treat patients in conflict zones, urban slums, prisons, refugee camps and remote areas.



“AFTER A COMPLETED COURSE OF TB TREATMENT, YOU MUST COME BACK FOR SEASONAL THERAPY TWICE A YEAR (IN AUTUMN AND IN SPRING) TO PREVENT RELAPSE”

“**RELAPSE**” is when TB becomes an active disease again, in previously treated patients who were cured. The WHO guidelines do not mention any preventive treatment courses. The only thing that really matters is to complete your treatment until you are cured. But stick to your prescribed medication. Interrupted treatment, or wrong doses, can lead to the development of resistant TB.

DR SVETLANA DOLTU explains:

In the Republic of Moldova, the system of TB care is based on international guidelines, and anti-relapse therapy is not part of them. Preventive therapy is recommended for people from certain risk groups, like HIV patients, and young children (aged 0–5) who came into contact with a known TB patient. People from risk groups are invited for annual screening. The best anti-relapse strategy is to strengthen your immune system.

Eat healthy, exercise, don't smoke, and treat any other disease that weakens your immune system.

LIFE AFTER TB

When your treatment is over and you are finally cured, you may feel overwhelmed with joy. Many **EX-TB** patients can tell you this. You're healthy, you have won, you feel like dancing and celebrating your life. Some people completely re-invent themselves after recovery. Realizing they have to do what makes them happy, they quit their jobs and started doing what they always dreamt of. Like they say; what doesn't kill you makes you stronger.

BACK TO REALITY

Unfortunately, it doesn't always go like this. After the initial euphoria wears off, a feeling of loneliness can remain. The problems of your friends seem so small, while your struggle was too big for them to understand. It feels like they don't care. Sometimes it seems like the only way out is to just try and forget everything that happened. Trying to ignore the existence of TB altogether is a common mistake that may lead to severe depression.

In situations of grave danger, it is in our nature to be constantly on edge. This hypertension can be released temporarily by crying or laughing hysterically. But once we are safe again, all the subconscious fears and anxieties we never knew we had, slowly reveal themselves.

It doesn't have to be like that! If you are feeling depressed and you're losing hope, please find someone to talk to. I bet someone from **TB-PEOPLE** will understand you. It helps to share. It helps even more to help others. Sharing your story can **REALLY** help change things for the better for all of us, and it will give you new strength and courage, and a purpose in life.

I hope our guidebook has inspired you and given you faith in your recovery.

Now you know what you are fighting, and that you don't have to be scared. Don't give up, follow your treatment and remember: It's not your fault to be sick. Don't be afraid to speak out about it!

TUBERCULOSIS IS A CURABLE DISEASE, AND IF WE UNITE TOGETHER, WE CAN MAKE IT DISAPPEAR COMPLETELY.



SP

This brochure is made possible by:

**LILLY PARTNERSHIP
INTERNATIONAL FEDERATION OF RED CROSS
AND RED CRESCENT SOCIETIES
WORLD HEALTH ORGANIZATION**

Author of the project : **PAULINA SINIATKINA**

Authors of the texts : **KSENIA SHCHENINA,
MARIA TSELOVATOVA, PAULINA SINIATKINA**

Illustrations: **PAULINA SINIATKINA**

Translation: **ELENA PLÖTZ, PAULINA SINIATKINA,
JOHANNES HOGEBRINK**

Editors: **JOHANNES HOGEBRINK, CHRIS DELL,
KARA FULLER, KARABO RAFUBE, NEVENA CIRIC,
TIMPIYIAN LESENI.**

Medical editor: **MICHAEL RICH**

Design: **OLGA CHURYUMOVA**

Thanks for help **TB PEOPLE** members:

**TIMUR ABDULLAEV, TSIRA CHAKHAIA, VITALY OSETINSKY,
OLGA LETVINOVA, SVETLANA PROSVIRINA,
KATERINA EMELYANOVA, PAVEL ZHURAVLEV.**

Doctors participated in the project “**MYTHS ABOUT TB**”:

MICHAEL RICH, USA

SVETLANA DOLTU, MOLDOVA

JANE E. CARTER, USA

VERA ZIMINA, RUSSIA

LEE B. REICHMAN, USA

GRIGORY VOLCHENKOV, RUSSIA

NATALIA BOROVOK, RUSSIA

ALEXANDRA SOLOVYOVA, RUSSIA

ANDREY MARYANDYSHEV, RUSSIA

ALEXANDR PANTELEEV, RUSSIA

ANASTASIA SAMOYLOVA, RUSSIA

TATIANA PYANZOVA, RUSSIA

And yes, you can always write us:

TBPEOPLE.INFO@GMAIL.COM

SP

