

TB is curable!



Institutul de
Pneumoftiziologie
"Marius Nasta"



LHL International



I have TB and I will be cured

TB is curable!

If you follow the advice of your doctor or health worker and take your medication regularly you will be cured of tuberculosis.

Remember: Anyone can be infected with tuberculosis!

Dear patient!

This booklet is for patients with tuberculosis (TB). Here you will find information about TB and TB treatment, and advice on how to cope with the disease.

The material has been developed jointly by patients, health care workers, ASPTMR and LHL International Tuberculosis Foundation. Funding has been granted by Norway Grants and Marius Nasta Institute is overseeing the project.

During the elaboration process we asked TB patients what they would like to know about tuberculosis. Their input has been instrumental in defining the content of the booklet. Together we have found answers to the most common questions. The result of the whole process is this booklet which has been designed to meet the need for information about TB among patients.

If you want to learn even more about TB, you can also read more on the web site of Marius Nasta, ASPTMR, WHO¹ or Stop TB partnership².



To develop this booklet, we talked to many TB patients.

¹ World Health Organization (<http://who.int/tb/en/>)

² A global partnership to combat TB (<http://www.stoptb.org>)

CONTENT

How can you use this booklet?	4
Chapter 1: Facts about TB	5
What is TB?	5
How is TB spread? How do you get infected with TB?	5
Questions from patients	6
How do you know you have TB? What are the symptoms?	9
Will your TB make others sick?	10
Question from patients	10
How is TB detected and diagnosed?	11
TB in children	12
Chapter 2: How is TB treated?	13
Questions from patients	15
Most common side effects of treatment	16
Questions from patients	19
Chapter 3: Drug resistant tuberculosis (also called MDR and XDR TB)	21
What is resistant TB?	21
How is resistant TB treated?	22
Questions from patients	24
Chapter 4: Keeping body and soul well when having TB	26
Keeping yourself active	27
When can you get back to your usual daily activities?	28
Questions from patients	30
Stories of patients	31
Acknowledgements	35

How can you use this booklet?

Read this booklet to learn the main facts about tuberculosis and how to cope with the disease, and deal with problems you may face. You can give this booklet to other people and discuss it with health care workers, your friends, family and other patients.

When you learn what tuberculosis is, how it is spread and how it is treated, you will feel safer. Also you will be able to discuss different questions related to TB with other people. More openness about TB makes people better informed about the disease. When people around you understand more about TB, they will feel safer.



You can read this booklet alone or with a health care worker.

This is how the booklet is designed:

- In the beginning of each section you will find facts and information
- In the end of each section there are questions from patients and answers to them

If you do not understand something or want to learn more, contact your doctor or nurse.

Chapter 1: Facts about TB

People should look for information, about what tuberculosis is and how it is treated. Knowledge is needed, both for the patients and for the society. Negative reactions come only from people who do not know what the illness involves. The less they are informed, the more brutal people are. To be informed about tuberculosis is the best way to cope with it. Silviu, 38 years old

What is tuberculosis (TB)?

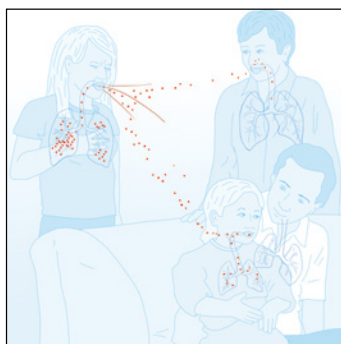
TB is a disease that is caused by TB bacteria. Bacteria are small, invisible organisms which are found everywhere, including inside people's bodies. Most bacteria are harmless, and even useful. But some bacteria are harmful and may cause diseases that we call infections. The bacteria that can cause TB are bacteria of this kind. If the bacteria attach themselves to an area in the body and multiply, and the body doesn't manage to defend itself, you can get the TB disease.

The bacteria that can cause TB is called *Mycobacterium tuberculosis*, or the Koch bacillus.

Generally, it is most common to get TB in the lungs, but you can also get it in other parts of the body, for instance in the bones, the lymph nodes, or the brain. TB outside the lungs is called extra-pulmonary TB.

How is TB spread? How do you get infected with TB?

TB is spread through the air by small droplets (which you cannot see). The droplets come from the nose and mouth of a person who has TB, and get into the air when this person talks, coughs or sneezes. The TB bacteria are inside some of these droplets. When other persons breathe in this air, some droplets with TB bacteria can enter their body and reach their lungs.



Tuberculosis is spread when a person breathes in bacteria from the air.

**It is only lung TB that is infectious,
not extra-pulmonary TB.**

People who have had close contact over some time with someone with infectious lung TB can get the disease. The TB bacteria are not spread easily, so infections generally occur between persons who live, or spend a lot of time indoors, together.

People who are infected by TB bacteria don't necessarily get sick. It is estimated that 1/3 of the world's population carries TB bacteria in their bodies, but only a few - approximately one out of 10 - develop the disease.

The risk of developing TB differs. People with a weakened immune system have a greater risk of falling ill from TB. Reduced immunity can be caused by other diseases such as HIV or diabetes, or conditions such as stress, poor nutrition, alcohol and drug consumption or other reasons.

Questions from patients:

- Why I do have to wear a mask?

Using masks is a way of preventing the spreading of tuberculosis in a hospital. Both infectious patients and the health personnel should use masks, but the type of masks differ. Patients will wear a simple surgical mask that stops the bacilli from entering the air. Health personnel will wear a mask with a special filter which protects them from breathing in the TB bacilli. Patients will wear the mask in the common



spaces of the hospital (halls, bathrooms etc.) and when they go to be medically examined or when a health worker enters their room. It is very important to use the correct type of mask. If a TB patient wears the mask with the special filter TB bacilli will be spread in the air. If the health worker wears a simple surgical mask, he or she can breathe in the bacilli.

Mask used by
patients



Mask used by the
health personnel

- Not everyone who has contact with a TB patient gets infected. Why does that happen?

Most often you get infected when you have close contact over time with someone with lung TB. But even if you breathe in the droplets with the bacteria, the bacteria might not be able to reach the lungs or the immune system is able to kill the bacteria immediately. So not everyone that has close contact with TB patients gets infected.



- I want to know where I got the disease?

You cannot always know who you got the infection from. Maybe that other person also never knew he or she had TB. Remember it can take years after infection with the TB bacteria before the disease breaks out. It could even be that you got infected when you were a child.



- My father and uncle had TB. Did I get it from them? Can TB be inherited?

You cannot inherit this disease. Tuberculosis is a contagious disease spread through the air. There is a good chance you got TB from your father or your uncle, as close family, friends and people living together are more at risk.



- My son got TB many years ago. I was then checked and told I was not infected. And now I have TB. What happened?

You probably got infected by your son at that time. You got something called latent TB infection, meaning the TB bacteria are in your body but they are "sleeping". You cannot see these sleeping bacteria on the x-ray. What they could see on the x-ray, when they checked you that time, was that you were not sick with TB. The sleeping bacteria, might never wake up, or as in your case, wakes up after many years and then makes you sick.



- Is it true that as long as we are positive we can transmit disease

Yes, as long as your sputum examination is positive you can transmit the disease. As soon as you have started effective treatment your infectiousness will be reduced. But to be on the safe side you will be classified as "contagious" until there are no more live bacteria in your sputum.



- How can I protect my friends? And what should my friends do? What should they do to prevent the illness?

You can protect your friends by taking the treatment as prescribed. After a while of effective and complete treatment, you will no longer be contagious. This need to be confirmed by sputum examination. When your sputum is negative, meaning they can't find bacteria in your sputum, you can no longer transmit the illness. You have to take the full course of treatment to get cured. If you stop the treatment before you should, you get positive and contagious again. If you feel comfortable, you can also speak to your friends about TB. Maybe they should go for a medical check up to find out if they have been infected. Early diagnosis and effective treatment are important to prevent the spread of TB.



- What is a direct contact?

A direct contact is someone who has spent time in the same room near someone with infectious TB.



- How is TB not spread?

TB is NOT spread through sex, physical contact, drinking of the same cup, using the same plate or eating utensil, using the same toilet, clothes or bedsheets.



TB is only spread by air, by breathing in the bacilli.

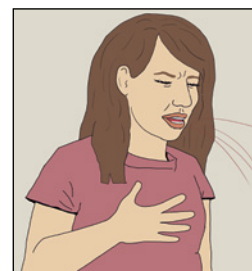
How do you know you have tuberculosis (TB)? What are the symptoms?

Common signs of lung TB are:

- Persistent cough for more than 2-3 weeks (sometimes coughing up phlegm or blood)
- Pain in the chest

Other common signs of both lung TB and extrapulmonary TB (TB in other parts of the body) are:

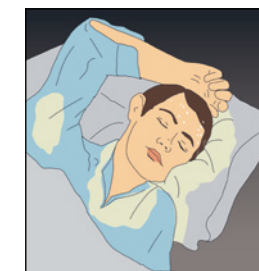
- Loss of appetite
- Weight loss
- Feeling weak and tired
- Having fever over some period of time
- Night sweats
- Swelling on the neck, under the arms, or in the groin



Persistent cough for more than three weeks



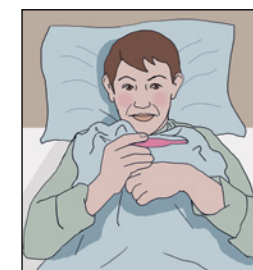
Weight loss



Night sweats



Loss of appetite



Fever over a period of time



Weakness, fatigue and shortness of breath

These symptoms are also common signs of some other diseases. So, to be sure that it is TB, you have to take different tests. Someone who has one or more of these symptoms should go and see a doctor!

A person with TB often do not have all of these symptoms. Some people only have mild symptoms.

"It is an illness which bites you in silence, without symptoms, maybe a bit of tiredness that's all. I haven't felt anything. I went to the hospital for a medical examination and my TB was identified there, but I did not have any problems. I didn't get tired, I didn't perspire, I had nothing. And that was it!" Gheorghe, 43 years old

Will your TB make others sick?

Most TB patients have TB in the lungs. It is only lung TB, and not extra-pulmonary TB, that can be transmitted to others. But lung TB is not always infectious. If you have an infectious form of lung TB, most of the TB bacteria will be killed after approximately 2-3 weeks of taking effective TB medicine, and you can no longer transmit TB to others.

In Romania, you are usually isolated at a hospital ward if you have lung TB or if it is suspected that you have it. You stay there until your TB cannot infect others anymore. To be sure that your TB is no longer transmittable, the health personnel will take some tests and analyze this in a laboratory, to find out if you are "negative".

This means when you are discharged from the isolation ward, the disease is not infectious anymore.

The health service in Romania is obliged to assure that all persons who have TB get treatment, and it is for free. In order to find all persons who may be infected, patients are asked to give the names of people they have had close contact with. These persons are being contacted by health personnel and asked to test themselves for TB-without being told who they may have been infected by.

If you have children, or if you have had close contact with children before it was discovered that you have TB, the children may have to take medicines against TB for a period of time (usually six months), but this is the doctor's decision. This is done to make sure that the children don't get sick later.

Question from patients:

- What is latent tuberculosis infection?

Latent tuberculosis means you are infected by TB bacteria but you are not ill. When the TB bacteria enter a human body, they encounter the body's immune system, which in the majority of cases does not allow tuberculosis to develop. For most people who are infected with TB bacteria, the bacteria remain latent, "sleeping", in the body. As long as the bacteria are sleeping, you do not become ill. The immune

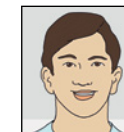


system ensures that the bacteria do not "wake up" so that you remain well. You can have TB bacteria in the body for your entire life without becoming ill. Latent TB is not contagious.

If you have latent TB infection you can get preventive treatment. This treatment will kill the sleeping bacteria in your body. Preventative TB treatment entails taking one or two TB drugs over a period of time. The dosage and the length of treatment course differ and they are the pulmonologist's decision.

- I am scared that I have transmitted TB to my family. How can I protect them?

The best way you can protect your family is to continue with the treatment and get well. When your sputum is negative you are no longer infectious. And if you take the whole treatment as prescribed, you will get cured. Family members and close contacts, especially children, should be checked to see if they got infected. If you have transmitted TB to them they can get preventative treatment. Or they should be followed up by health personnel once every six months for one or two years.



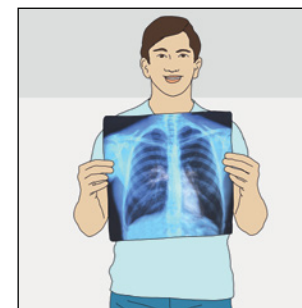
- What does Positive and Negative mean?

Positive means that your sputum contains live bacilli and you are contagious. Negative means that there are no living bacilli in your sputum and you are no longer contagious.



How is TB detected and diagnosed?

A skin test (IDR or PPD), or a blood test can show if a person has been infected with the TB bacteria. But these tests cannot distinguish between latent TB infection or being sick with TB. To diagnose lung TB there is a need for sputum tests and a chest X-ray.



A sputum test means coughing up phlegm into a small cup or container. Different methods can then be used to look for TB bacteria in the sputum; for example Smear Microscopy or Gene Xpert. Once the TB bacteria have been identified in the sputum the laboratory will perform a drug sensitivity test.

Extrapulmonary TB is diagnosed in TB pulmonology hospital by means of special observation methods, for example through clinical assessments, x-ray or biopsy (extracting a sample from the affected organ or body part).

TB in children

Children are more vulnerable than adults to TB disease. They develop TB more easily and can get more seriously ill from the disease. The disease can also progress more quickly in children. Especially very young children, HIV+ children or severely malnourished children have increased risk of falling ill. If children are close contacts of an infectious TB patient they are often put on preventative treatment for TB immediately.

The BCG vaccination can protect your child against TB. Even if BCG is not giving full protection - you can still develop TB if you have been vaccinated - the BCG protects children against the worst form of TB like TB meningitis.

Romania has the highest incidence of TB in EU. Therefore it is recommended that all newborns in Romania receive BCG vaccination.

TB in children can be more difficult to diagnose. This is because it can be difficult for children to produce a sputum sample. Also their symptoms might be more diffuse. Children might not have the classical TB symptoms as mentioned above, often only vague and non-specific symptoms like feeling tired and weak, weight loss or not gaining weight and lack of appetite.



Chapter 2: How is TB treated?

"First, when they told me I had tuberculosis I was scared. After I talked with medical staff about TB and HIV, my chance to be cured and treatment possibilities, I calmed down"
- Maria, 27 years old

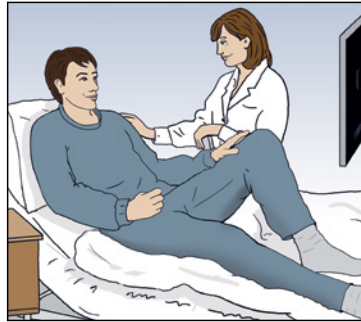
TB is treated with a combination of different kinds of drugs, called tuberculostatic drugs mostly tablets. Treatment course and observation are free of charge. Most patients have to take drugs for 6 months, but sometimes the treatment is longer. If you have resistant TB, the treatment can be as much as 2 years.

It is very important that you take medicines for as long as the doctor tells you to. If you stop taking medicines too early, you may get sick again. The TB bacteria can also become resistant, and, as a result, the drugs may then work less well if you have to start taking it again after having stopped too early.

In most of the cases the patients start treatment in hospital and then continue at home. If you have a contagious form of tuberculosis, you will have to stay in the hospital, until you are not contagious any more. Some people stay in hospital about 1-3 months, others stay longer. In the hospital the health workers can closely monitor how you tolerate the medication, ensure that the medicines are effective and that you are feeling better. You as a patient have a right for support and consultations during the whole treatment period. Your doctor and other health care workers can assist you in different ways. Your health and your well-being is their responsibility and yours too.



This man has tuberculosis. In the very beginning of treatment he has to stay in hospital.



After he has taken the medicines and received care for some time, his condition improved...



...and he could continue treatment in ambulatory while staying at home.



The treatment course is finished. He is cured!

Questions from patients:

- Do I really have chances to cure completely?

Yes, absolutely. In most cases TB is fully curable, and most people have TB only once in their life time. Having had TB does not make you immune, so there is the possibility of getting re-infected at a later stage. Also, if the treatment prescribed was not correct or not taken fully, there is a chance for relapse. But most people do not experience relapse and are fully cured.



- How long is the treatment? What factors determine the treatment terms?

First a drug sensitivity test is done. If the test shows that the TB bacteria are sensitive to all the drugs, treatment terms will be 6 months. If the drug sensitivity test shows that the bacteria are drug-resistant then treatment terms will increase up to 2 years. Treatment terms depend on the immune system as well. If the immune system is very weak the bacteria may remain active longer and the treatment must be extended, this extension is always the doctor's decision.



- Why do I have to stay in hospital for so long?

You should stay in hospital until you are no longer infectious, tolerate the treatment well and you are healthy enough to go home. There is a shift towards shorter hospitalization when it comes to TB. If you feel well enough to go home, you should discuss the option with your doctor.



- Can I get tuberculosis if I had a BCG vaccination?

Yes, it is possible to get sick with TB even if you have had the BCG vaccination. BCG, (Bacille Calmette-Guerin) is currently the only vaccine against TB disease. The BCG vaccination only gives some level of protection, especially for small children, but does not give full protection. It is important to note that HIV-positive children should not be vaccinated with the BCG as it can make them seriously sick.



- Can I develop TB disease again?

Yes, it can happen. This is called a relapse of tuberculosis or recurrence: When patients who have previously been treated for TB, were declared cured or treatment completed at the end of their treatment, and are now diagnosed with TB again. This can occur either because the first TB was not sufficiently treated or it could be caused by a new TB infection.



- Why can the relapse happen? Does it prove that tuberculosis is incurable?



TB is curable, but in some cases the drugs cannot achieve complete eradication of TB bacteria and some “sleeping” bacteria may still be present in your body after completion of the treatment. These bacteria might wake up and cause TB disease again. Relapse can also occur if, a cured person is infected with TB again, for the second time, from another person with active TB.

Most common side effects of treatment

At the beginning I felt sick, I had headaches after taking them pills. I have got used to the in the meantime. Now I feel better.
- Doru, 43

Medicines can sometimes cause problems in your body – these are called side effects.

People react differently to medicines. Some patients don’t experience any side effects, and some do. Generally, side effects get milder or disappear when the body gets used to the medicines, often after 4 weeks.

Serious side effects are rare but can occur. Therefore it is important that you inform your doctor or the nurse if you experience any problems or side effects.

If the white part of your eye becomes yellow, if you have serious stomach pains, skin rashes (urticaria, spots on the skin, small bumps etc.) over big parts of your body or if you experience problems with your eyesight – see your doctor immediately.

Most side effects are mild and even if they are unpleasant and annoying, they are not dangerous. We remind you that it is important that you should tell the doctor about any change of your health condition.

The most common side effects of TB medicines are:

- Nausea and vomiting
- Digestion problems – hard stools or loose stools
- Itching and rashes
- Joint pain and other pain and swelling

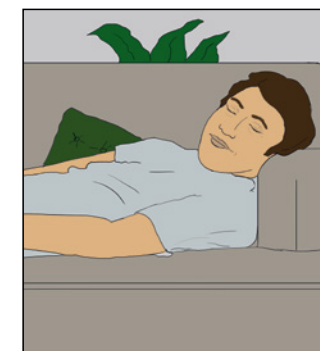
Nausea and vomiting

Many medicines might cause nausea and vomiting. If you have nausea, it can help if you eat something small, like a biscuit, a piece of fruit or some natural yoghurt. It is important to continue to eat regularly; this will help you to recover faster, and it can also help prevent or relieve nausea. An empty stomach might increase the nausea. If you are still bothered with severe nausea, your doctor can prescribe you the medicines to relieve it.



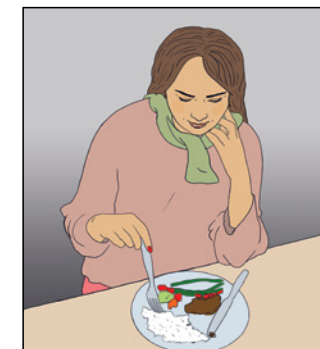
Drowsiness and fatigue

Drowsiness and fatigue can be both a symptom of your disease and a side effect of the medication. So it is very important you get enough rest. When you rest, your body fights the disease better.



Loss of appetite, weight loss

You may not feel hungry because of the disease or due to the medication. It is very important that you continue to eat; try to eat well to help your body fight with the disease. A weak and exhausted body does not have strength to fight the disease.



Itching and rashes

Some of the patients face itching and rashes. Itching is the result of the allergy to drugs. If itching and rashes do not pass off, please contact your doctor or nurse. The doctor may prescribe you some medicines to reduce itching.



Red urine

When you take anti-tuberculosis medicines all your body fluids can become red, pink or orange. This is not dangerous; the red coloring is not caused by blood. It is because of the red coloring that the medicines contain. Some tuberculosis medicines can cause red urine.



Joint pain, headaches and other pain in the body

Some patients experience joint pain, headaches or other pain in the body. If you experience this too, talk to your doctor. The doctor can prescribe you some pain-killers.

Swollen feet may also occur. When you sit or lie down, try to put your feet up high, for example, on a pillow; it can also help if you wrap a wet towel around your legs. Light physical exercises can also help.



Constipation and loose stools

The antibiotics used to treat TB, besides killing tuberculosis bacteria, also affect normal intestinal bacteria. Because of this you can get digestion problems. Some patients have constipation, others – loose stools or diarrhea.



Advice for patients on how to relieve constipation:

- Eat fruit and vegetables;
- Eat dried fruit, especially raisins and prunes;
- Eat soaked flax seeds;
- Drink more water;
- Drink zeama de varza (fermented cabbage juice),
- Do light physical exercises;
- Consult the doctor in case of long-term constipation.

Advice for patients on how to prevent loose stools:

- Don't drink milk
- Don't drink beverages which contain a lot of sugar
- Cut down on vegetables and fruits consumption
- Eat mainly dry toasts, low-fat meat or fish, rice, fasting soup, baked apples, fresh cottage cheese, strong tea, jelly drinks
- Eat blueberries, bananas or drink mint tea
- Take anti-diarrhea medicines

If the side effects become serious or unbearable, there is the possibility for your doctor to change your treatment regimen.

Questions from patients:

- Some patients face long-term side effects while taking the treatment. Do they remain after the treatment is finished? For example, liver functional test deviations.

Most side effects will disappear when treatment is finished. There are a few exceptions, especially when it comes to treatment of resistant TB. Some patients might experience hearing problems. Such side effects may be permanent. That is why close monitoring by health personnel is so important.



- Pain in the joints, does everyone experience that?

No. Pain in the joints is a common side effect of anti-TB drugs. But not everyone experience side effects, and of those who experience side effects, not everyone have pain in the joints

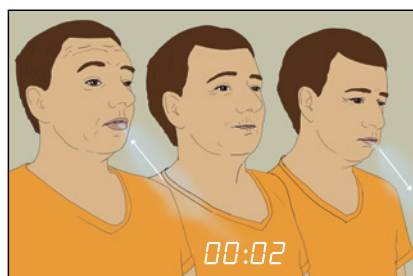


- Medical examination during the treatment

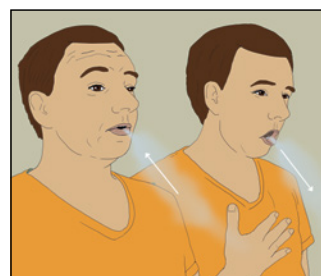
During the treatment against tuberculosis the patient will undergo a medically examined every two months. In the case of resistant tuberculosis the medical examination has to take place every month. The examination normally consist of blood tests, X-ray and sputum sample. The frequency of medical check-ups and the kind of test patients will do is the doctor's decision.



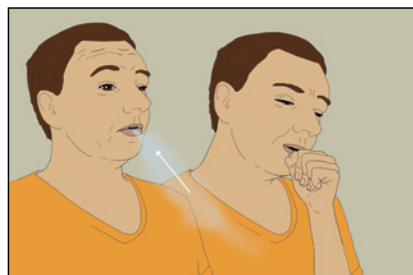
After a period of treatment most patients find it difficult to produce a sputum sample. Here we present you useful tip on how to do it.



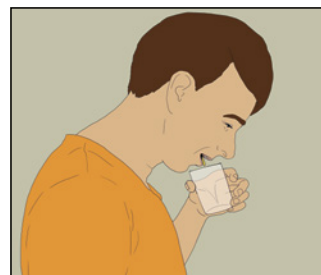
- Breathe in and hold your breath for a few seconds, then breathe out slowly. Do this twice.



- Breathe in for the third time and breathe out strongly.



- Breathe in again and cough in the container.



- Hold the container close to your mouth when expectorating.

Chapter 3: Drug resistant tuberculosis (also called MDR-TB and XDR-TB)

What is resistant TB?

Resistant TB is TB that is caused by TB bacteria which is not killed by the ordinary TB medicines. Resistant TB spreads the same way as other TB - from a contagious person by droplets in the air.

People get cured from resistant TB, but it takes longer. To get cured from resistant TB, you need other medicines than the medicines used for ordinary TB. Because it takes longer for the medicine to kill these bacteria, patients have to stay on treatment for up to 18 or 24 months. Unfortunately, the medicines that are used against resistant TB can have many unpleasant, strong side effects on the body.

MDR-TB (multi-drug resistant TB) is TB that is resistant to the two most important common TB drugs: isoniazid and rifampicin. **XDR-TB** (extensively drug resistant TB) is in addition to being resistant to the two most important common drugs, also resistant to any of the second-line injectable used to treat MDR-TB.

As in the case of sensitive tuberculosis, in order to treat resistant TB hospitalization is necessary until the patient is no longer contagious. Generally, the patient can leave the hospital after receiving two consecutive negative results of the culture, which means that the hospitalization period will be longer than in the case of sensitive tuberculosis. Generally, the medium duration of the hospitalization for patients suffering from MDR-TB is 3 months, but may vary as the pulmonologist will decide.

Being hospitalized for a such long period can be difficult for many people. It is important to observe the internal rules of the hospital and listen to the recommendations of the health personnel. Try to establish a good daily routine and ensure you get enough sleep and proper nutrition (for more information see chapter 4). In a hospital setting it is very important to observe the general hygiene rules and the hygiene rules of coughing.

Cover your mouth with your elbow when you cough, if you expectorate spit out in a disposable handkerchief which you will throw into the toilet. Under any circumstances do not spit on the floor.

How is resistant TB (MDR and XDR) treated?

I notice that I feel better and have more courage. I am trying to think of only beautiful things, I talk a lot with the patients in my room so that time could pass by more quickly
– Ion, 55

At the beginning I took various symptomatic pills, according to the side-effects of the pills which I took, but since there were too many pills, I wasn't able to take new pills any longer and I tried to use other methods. Because of my doctor's advice, I divided the pills into two sections: I take the pills which have more aggressive side-effects in the evening, before going to bed. I spend time with the child who is very little and who makes me no longer think of the illness. I read relaxing things. I talk on the phone with the people who understand me. I have also adapted the daily menu according to my psychological and physical state.
– Vera, 38

First of all, a special laboratory test, drug susceptibility test, is done to find out, what medications your tuberculosis bacteria are susceptible and resistant to. This is called an antibiogram. This means finding out which medications are necessary to kill the TB bacteria that you are infected with. Based on this result, an individual treatment regimen is identified.

Treatment for resistant TB consists of several medications and is normally treated for about two years. Unfortunately, some of the medications can be quite toxic for the body. In addition to the side effects mentioned earlier (like stomach problems, nausea, joint pains or hearing loss), some psychiatric problems can occur (like anxiety, paranoia, depression) and more seldom epileptic seizures. Normally, a MDR-TB treatment will include an injectable drug.

If you experience problems with your hearing it is important to alert your doctor immediately as this may lead to permanent hearing loss if not dealt with correctly.

Medicines for resistant TB are classified in different categories. Treatment for resistant TB is a combination of drugs from different categories, depending on your antibiogram and health condition.



Group 1 (first-line oral agents) Also called first line treatment is for sensitive TB. Some of the drugs from this category can be used for resistant TB depending on your antibiogram.

Group 2 (injectable agents) These drugs are delivered by injection. Normally MDR-TB treatment includes an injectable drug.

Group 3 (fluoroquinolones) These pills are broad-spectrum antibiotics currently used in the treatment of MDR-TB.

Group 4 (oral bacteriostatic second-line agents) These drugs are used in the treatment of MDR-TB. Although they do not have strong TB-killing activity, they can prevent the development of resistance to other drugs used in the regimen.

Group 5 (drugs still under development) In this group there are drugs recently approved and further research is needed. But for now they are used to support regimens for MDR-TB or XDR-TB that are resistant to other drugs.

It is important that you take all the medicines, which your doctor prescribed. As taking the medicines does not come naturally to your body, it takes time until the body gets used to them. So some side effects will disappear after a while and some might get milder. If this is not the case, there can be some medication that can reduce side effects. And if nothing else works, it is sometimes possible to change the treatment regimen by your TB doctor.

Resistant TB is a world-wide problem and it is increasing. According to the WHO report in 2016, 3 % of all new TB cases and 12 % of relapse cases in Romania were MDR-TB. In the past the treatment success for resistant TB in Romania has been very low. This has changed, now the necessary drugs are available, and test results come faster. More and more people are being cured of resistant TB.

Multidrug resistant TB can be cured!

Questions from patients:

- How can one get drug resistant TB?



There are two different ways of getting resistant TB:

1. If you have had close contact with someone who has infectious resistant TB you might have been infected
2. If you have previously interrupted your treatment for sensitive TB. Wrong or too short treatment can cause the bacteria to become resistant.

Lack of supervision by the health care worker or a volunteer increases the risk of resistant TB development.

- What is MDR-TB?

MDR stands for "multi-drug-resistant" TB and is a form of bacteria that is resistant to the two most important common TB drugs: Isoniazid and rifampicin. This means that these drugs are not able to kill the TB bacteria. Treatment is therefore more complicated and takes longer, but you can be cured after 2 years if you complete your treatment.



- What are my chances of healing from MDR?

Previously the treatment success for MDR-TB has been low. This has fortunately changed and today your chances of being cured from MDR-TB are high. This is because the medical knowledge on how to treat resistant TB has improved and new drugs have been developed. So if you stay motivated and go through your treatment, you will get cured.



- When will they find a shorter treatment with fewer side effects?

A lot of research is ongoing to try and shorten the time and the suffering for those who have resistant TB. There are promising results that might shorten down the treatment in the near future, but for now, this long and hard treatment regimen is the best we have.



- What to do to reduce side effects?



There can be different ways of reducing side effects. Because of their doctor's advice, some people divide the number of their pills, and don't take all of their pills at the same time. Some take the pills they react badly to just before they go to bed. There are some advice in this booklet, you could also ask health workers or other patients for their advice. Remember to always consult with your TB doctor to ensure that what you do does not affect your treatment.

- How can you get XDR if you took all the medication?



This is a difficult question which has not a clear answer. Maybe the first time you had TB you did not have an antibiogram and you did not get the right treatment. Maybe you have been re-infected by resistant bacteria. We cannot always know why someone gets resistant TB.

- Why do some patients get lung surgery?



Some patients get lung surgery if the TB drugs are not able to kill the bacteria in a certain area in the lung and the doctors decide it is better to have that area removed.

- For how long do I have to take injections?



This might differ from person to person, but the common length is 8 months from the first negative sputum culture test. Your TB doctor will decide when you can stop taking the injections.

Chapter 4: Keeping body and soul well when having TB

I told everybody about the illness, I'm neither embarrassed nor ashamed, it is an illness
- Sorin, 36

Some people transformed the TB experience into an opportunity to change their life to the better. One way of using the TB experience is to become a peer-supporter for others or to become an activist fighting for the rights of TB patients.

TB is surrounded by misconception and fear, which leads to stigma. Usually, the reason people discriminate or stigmatize is that they lack knowledge and that they are also afraid, afraid of being infected with TB. Try to learn as much as you can about the disease so that you can explain to your friends and family. There is no need for people around you to be afraid because of misconceptions and lack of knowledge.

Some patients find it difficult or are afraid to talk about their disease, and hide their disease from other people. They usually hide it because they fear that when people learn, that they have or have had TB, they will stay away from them and refuse to talk to them. Some patients are abandoned by their friends and relatives, others by their husband or wife. Some people are aggressive towards tuberculosis patients and refuse to talk to them. For someone who is fighting a disease, it is terrible to experience this. But we have many examples that discussing your disease openly brings a lot of benefits. Being open about your status you can get support from the people around you. If nobody knows you are sick, nobody will know that you need support. And openness can reduce fear: when people are well informed they will feel safe and will no longer be afraid. In this way, openness can counteract fear and loneliness.



Unii pacienți se tem să stea de vorbă cu alții despre boala lor.



Talking to someone who has gone through the same thing as you can also be very helpful. The association for Supporting MDR-TB Patients - ASPTMR - is a patient organisation who provides peer to peer and psychological support to TB patients in order to cope better with illness. For any concern regarding the TB you can contact this organisation for advice or information.

Try and live a healthy life, take care of yourself and be as active as you can. Fresh air, nutritional food, enough rest, medication as prescribed and activities that motivate you can do wonders. In this chapter we present advice from patients and health workers about work and rest, food and drink, sex, and social life during the sickness period.

Keeping yourself active

Keeping oneself a little active or busy can help prevent or reduce feelings of depression. Having too much time to be alone and think can be very tough. Therefore, it is useful to try to stay active and focus on other things besides your disease. You don't have to do things that are very demanding; a couple of small tasks or activities each day are enough.

Of course, you will have days when you don't manage to do anything – this is ok too! Try to establish some sort of daily routine. Structuring your days will probably make daily life more meaningful, even if you are sick and unable to live your normal life. Try to find things to do that make you feel better; things that you can do in spite of your condition, for example: listen to good music; watch TV; read a magazine. Do things that you like!



When can you get back to your usual daily activities?

There are great differences among TB patients as to how weak they are, how much rest they need, and when they can go back to their work or other daily activities. Some patients get better fast, especially those who got treatment early, before the body got too weak. Other patients get better more slowly, especially those who were diagnosed late or have other diseases in addition to TB. Their bodies have become weaker and take more time to build up strength.

When you feel strong enough, you can go back to your work or other daily activities. Try things out to see what you can do. Be careful in the beginning, and start with very light work, like office work or light housework. Some patients feel they must

start to work again as soon as they have a little strength. But your body needs rest to recover. It is important that you listen to your body – don't push yourself too hard. And remember that house work and taking care of children is also work!

If you feel too weak to work, but still want to have something to do, try to find other activities to do. Even if you are on sick leave, you don't have to stay indoors. Being together with others, doing light exercises, or participating in social activities in your local community, are examples of things you can do to add something positive to your daily life. Do as much as you feel is ok for you, and do things that you like.



SMOKING

Lung TB makes lungs sick and weak, but all kinds of TB weaken your lungs and the rest of your body to some degree. Smoking makes your lungs weaker and decrease your immunity. When you smoke, you pull the smoke into your lungs, and they have to work hard, even if they are sick. Smoke irritates sick lungs, and can make you cough more.

Because your body is weakened from TB and from smoking, it can be easier for other diseases to attack you, especially in the lungs. This can slow down your healing. Smoking also makes you less hungry, and makes it more difficult for your body to gain strength and fight the TB well. Therefore, it is best to avoid smoking, especially if you have lung TB.



Anyone who has tried to stop smoking knows this is very hard to do. Ask for help from people who have managed to stop or from professionals who have good advice. Some smokers find it is wise to cut down gradually: Count how many cigarettes you smoke per day, and smoke one less each day until you can quit. You may also try to find a substitute for the cigarettes, for instance a (nicotine) chewing gum or a nicotine patch. You can get professional help from www.stopfumat.eu or can call for free to 08008 78673, smoking cessation hotline

However, if you don't manage to stop smoking, remember that people who smoke also get cured of TB.

SEX

While you are being treated for TB, there is no medical reason not to have sex. Having sex with your partner can make you both feel good and optimistic. As one patient put it: "It brings peace to the heart and reduces the tension". Feeling close to your partner can be important for getting well.

However, having sex can also be stressful if you feel pressured to have it or you don't feel well enough. Then it can take away your energy, rather than give you energy. Men should be especially aware that their wives or partners who are on TB medicines may not feel strong enough to have sex and may not dare to say no.



One of the TB medicines (Rifampicine) reduces the effect of birth control pills. You should not stop taking Rifampicine. Discuss with your doctor what other effective birth control methods you can use.

TB AND PREGNANCY

It is best to avoid getting pregnant while you are being treated for TB. The TB medicines are strong, and it might be harmful for you and your child if you take TB medicines during pregnancy. If you are planning to get pregnant, it is best to wait until you are cured from TB.

If you already are pregnant when you get the TB diagnosis, you will be examined by several specialists. Even though it is not recommended to get pregnant in this situation, continuing with the pregnancy usually goes well. Women with TB who are pregnant are seldom recommended to have an abortion. If you are pregnant, it is extra important that you get enough food and proper nutrition.



You will be followed up with many thorough examinations of both you and your child. TB treatment usually starts in the fourth month of the pregnancy, but if the TB is advanced, the treatment starts earlier. Always discuss your options with your TB doctor.

Questions from patients

- *Can I work after healing?*

When you feel strong enough and you are no longer infectious, there is no reason for you not to go back to work. Some people can start work whilst getting treatment for the TB dispensary, others wait until they have finished the treatment.



- *Can I get pregnant after finishing the treatment?*

Yes! It is important to not get pregnant during the TB treatment. You can get pregnant after finishing the treatment! Always ask your TB doctor advice to know when is safe to get pregnant.



- *What are the rights and responsibilities of TB patients?*

TB patient have the right to be informed regarding the medical services available and how to access them. This information should be delivered in a respectful, clear language, adjusting the terminology on the patients' level of understanding.



TB patients have the right to know all personal medical data and have right to ask for a second medical opinion. TB patients have right to confidentiality regarding personal medical data. This right will suffer changes if it is a matter of public health or public safety.

TB treatment is free of charge in Romania, TB patients benefit of free medical care, hospitalization included, even if they do not have a health insurance. TB patients on medical leave can not be fired.

Responsibilities

Patients have to follow all the hospital and ambulatory regulation. TB patient have the obligation to be respectful towards medical staff and other patients. TB patients have the obligation to use in a proper manner medical devices and hospital property.

TB patients must follow the treatment as the Penal Code (Article 652) states that failure to comply with measures for the prevention or combating infectious diseases is a crime and is punishable by imprisonment from 6 months to 2 years or fine.

Law no. 46/2003, Patients' rights law

From this law you can find information about:

- The patient's right for medical information
- Patient's consent regarding medical intervention
- Patient's right for confidentiality about medical information and patient's private life
- Patient's right to conceive
- Patient's right for treatment and medical care

Patients' stories

My name is Georgiana, I am 35 years old and I was diagnosed with sensitive lung TB. I was shocked because I was convinced TB does not exist anymore and is an illness for poor people who have no food and no shelter. I am married, with 2 children, we have almost everything we need, but still I am sick with TB.

I used to work long hours, skip meals, short sleeping hours, drink a lot of coffee to stay awake. In that way I could cope with work and kids and house chores. My husband was doing the best he could, but we were thinking to make more money for the children's studies and a new house.

At first I felt weak and started to sweat in the night. I started to take vitamins because I had to be strong for daily duties. Then I started to cough. I took cough medicines and it was better for a while, but soon it was worse. I went to the doctor and he gave me antibiotics and more cough medicines. After two months he sent me to the pneumologist. I had a lung X-ray and they told me I have lung TB.

In that moment I felt like the sky falling over me. I was thinking about my children: are they also ill? Did I give them the disease? To whom I gave TB? I felt fear, shame and guilt and fear again.

The doctor told me I will be cured, I will not die, I will be fine again. At first I could not process all the information the doctor gave me, but in time I understood and felt better when I found out my children and the rest of the family are healthy, my colleagues and friends have no TB. I never found out from where I got TB.

The next step was to be admitted in to hospital. It was very hard for me to be away from my family. My husband visited me every day, but I saw a lot of patients who had no visitors. It was difficult to take so many medicines every day. It made me dizzy and gave me joint pain. I took every pill thinking of my kids and the moment my doctor will tell me I am healthy.

I talked with people admitted in the hospital and a few of them were there for the second time. I heard stories about being rejected by family and friends, colleagues and employers. I started to think about people who called me or visited me in the hospital and I got sad because they were very few. I started to worry about going back to work. How will I be treated? Am I able to cope with their rejection?

After I went home, I called some of my colleagues and I explained to them about my disease. Some of them visited me at home, some not. I decided to take care of myself and not worry about how people will see me. The hospital psychologist helped me a lot with that.

Now I am cured. I cherish my health, my time with the family, my life. I do eat healthy, I sleep enough, I work wisely. TB knocked me down for a moment, but now I understood what is meaningful for me and what I have to do: I want to live.

My name is Costel, I am 27 year old. I am single and I have MDR-TB. I was very young when I started to work. In time and with effort I began to earn a lot of money and I thought it is time for me to have fun. So, almost every weekend I went to parties, clubs, drunk a lot, slept very little, worked hard during the week. At 21 I started smoking tobacco and soon I smoked 2 packages every day. When I was 25, I began to feel weak and cough a lot. I thought it is because of cigarettes, I tried to lower the amount of tobacco, but my cough went bad, so bad I could not sleep. When I went to parties I felt I could not breathe and felt like I was going to faint.

I decided to go to the doctor and he sent me to a pneumologist. I found out I have lung TB and he told me I have to take more tests because I was a heavy smoker. I panicked. TB and cancer? Too much for any person. I went to the hospital and I was admitted for 2 month. In the first week they told me I do not have cancer, but that the TB is pretty much advanced. I quit smoking at once, and it was not easy, but I got help from the doctors. I was thankful because I did not have cancer, so I was thinking I have to manage the best I can to get rid of the TB. So I swallowed every pill, I slept many hours, I ate everything they told me to and I was very keen to find out about the second month sputum test result. It was positive.

I could not understand: I did everything they told me to do and still I am as sick as at the beginning. They told me I have to wait for another test called antibiogram. I did. Another month of TB treatment, fearing things will go worse. And they did: I found out I have resistant TB and people died because of it, I saw them with my own eyes. I would meet them in the hospital yard and the next day I would hear that they were dead.

I cannot describe my fear in that moment. They told me I have to stay in hospital at least two more months, to start a new treatment, with more pills and an injection every day. I had to go to the ward every TB patient was afraid of: MDR-TB ward. The treatment started and so did the side effects: nausea, dizziness, joint pain, panic attacks. After few weeks I felt much better and started to be optimistic. After two months of the new treatment my sputum test got negative and finally I was able to go home when these two months ended.

MDR-TB treatment was the hardest thing that I had to do in my life. I got a lot of help: from medical staff, from family, from friends and I began to think of the future: The day of the one year medical check-up. The doctor told me it will be better if I have lung surgery and remove half of my lung.

I had to do it. There was no way I could risk to live this nightmare again. So I did it, I had my surgery and it was much easier than I feared. Now I am much, much better, I have one more month and I will finish my treatment. I am keen to start a new life, because the previous one almost killed me. I know now how strong I am, I can do anything I want and I want to be happy.

My name is Anca, I am 38 year old and I had MDR-TB. I had an old cold and a two month old cough, fever and I lost 8 kilos of my weight. My family insisted that I should go to the doctor and I did. I had a lung X-ray and found out I had TB. They told me I have to take the treatment, otherwise I will die. I felt lost. And very angry: why me? I was a very hard working person, always willing to help, trying my best.

I had eight months of sensitive TB treatment, got a negative sputum test, and I was told I am cured. I was happy, until two months later, I started to feel like I did before the treatment. I went back to the doctor and, after more tests, they told me I had MDR-TB.

While I was admitted in hospital for the first treatment and I was crying, a nurse told me: Be happy you are not admitted in MDR-TB ward where people die because of TB. Now I had to go to that ward. I felt devastated. I had to take 16 pills and an injection every day and I had to stay in the hospital another 5 months.

I was depressed and very frightened, I had bad days and I wanted the nightmare to disappear, but they told me if I skip a pill, the illness will get worse. Worse than MDR-TB? Hard to imagine. Until I saw that it is possible. One of the new patients had XDR-TB. So it can be worse, I am lucky I am not there.

I took all treatment as my doctor prescribed it and this is the main reason I am alive now.

This illness taught me who my friends are and what I have to do: none of my friends were there for me. When I returned to work, my colleagues excluded me and I was forced to quit the job.

But MDR-TB was an experience I learned a lot from. I learned that I am very important and I deserve to be healthy, happy and have real friends. I learned my family is amazing because I received a lot of help and love and support from them. I know now that if I beat MDR-TB, I can do anything. I got a lot of help from people I never met before and I decided to help TB patients in return. I am cured from MDR-TB and my life passed with a lot of challenges I know I can face and cope with. It was not easy, but I fight for my life and I am a winner!

Acknowledgement

We are thankful to all patients who make an effort to study booklet draft and give us valuable feed-back and input. Their work made the difference.

We would like to thank to people involved in patients' interview and in booklet pre-testing:

Volunteers: Adrian Dumitrescu, Aida Chicioreanu, Alice Ardeleanu, Alexandra Ioana Gușe, Anca Pruteanu, Camelia Borozan, Catrina Acuța, Corina Coman, Cosmina Dragan, Costina Roșu, Cristian Borozan, Daniela Salomia, Elena Roșca, Florentina Buzea, Larisa Cojocaru, Larisa Șoroagă, Maria Enciu, Mariana Nițu, Mihai Udriște, Oana Stan, Petronela Păvălucă, Răzvan Alexandru Radu, Sorin Neacșu, Ștefania Floricel, Valentina Solomon, Florentina Lică.

We like to thank to people involved in booklet review:

Volunteers: Anca Pruteanu, Andreea Dumitrescu, Bianca Nițoi, Cristina Elena Sima, Larisa Șoroagă, Oana Stan, Raluca Popovici, Sorin Neacșu, Cerasela Gherghina

Special thanks for Marius Nasta Institute management:

Dr. Gilda Georgeta Popescu – Marius Nasta Institute Manager

Dr. Victor Spânu – NTP Coordinator

Many thanks for helping reach the patients involved in reaching patients willing to contribute to booklet:

Dr Cristina Popa – pulmonologist, MDR-TB ward, Marius Nasta Institute

Psychologist Andreea Dumitrescu – Marius Nasta Institute

Team concept:

Mona Drage – LHL International Tuberculosis Foundation, Norway

Cătălina Constantin – The Association for Supporting MDR-TB Patients, Romania

Ștefan Răduț – The Association for Supporting MDR-TB Patients, Romania

Useful links to more information

WHO

<http://www.who.int/en/>

Marius Nasta Institute

<http://www.marius-nasta.ro/>

Ministry of Health

<http://www.ms.ro/>

The Association for Supporting MDR-TB Patients - ASPTMR

<http://www.asptmr.ro/>



ASPTMR

tel. 021 3134363

Material produced under the project

"Improving the health status of the Romanian population by increasing TB control"

financed under the Norwegian Grants 2009-2014, program RO_19 "Public Health Initiatives".

Publishing date: April 2016

For more information about the project, please visit: www.control-tb.marius-nasta.ro .

The content of this material does not necessarily represent the official status of Norwegian Grants 2009-2014.

The entire responsibility for the correctness and consistency of the information presented lies with the authors of the material.