Resistant TB is curable!

LHL International

Dear patient,

You have recently been diagnosed with resistant TB. For many, getting the diagnosis can be tough. First, it is important to know that **resistant TB is treatable**, and that **the treatment is free of charge**.

The treatment usually lasts for 6 months, but sometimes longer. It can be hard, especially in the beginning. Most patients have to stay at an isolation ward at the hospital in the beginning, usually a few weeks.

To cope with resistant TB, it is important to have reliable information about the disease. There are many misconceptions about TB and resistant TB that can create fear. We have made this booklet to present reliable information and advice from patients who have been cured.

The booklet has been developed by LHL International Tuberculosis Foundation, with input from former patients and health workers. We hope the booklet will be useful for you!

«When I was diagnosed with resistant TB, it was a shock. I knew very little about the disease, I was afraid, and felt that my body and my life were out of my control.

But after a while, things got better. I got information, and after I had taken medicines for some time, my physical condition improved. The treatment was long, but now I am cured.

I realise that something positive has come out of this. I have become aware of how many people in the world get TB and resistant TB , and that I was lucky to get the medicines I needed. I now work in healthcare and believe that my experience with resistant TB has given me a commitment that I would not otherwise have had.»

We wish you good luck with the treatment and recovering!

Content

How can you use this booklet?

You can read this booklet to learn the main facts about resistant TB and how to cope with the disease. When you learn what resistant TB is, how it is spread and how it is treated, you will feel safer.

You will also be able to discuss with friends, family, and other patients. When they understand more about resistant TB, they will also feel safer.

The booklet is not meant to be read from beginning to end. You can for instance start reading about the topics you have most questions about, or you can read about the different treatment phases as you are going through them. Use it as you like! The table of contents on page 3 can be useful for looking up topics you want to learn more about.

Much of the information in the booklet applies to all forms of TB. But since you need different medicines for different types of TB, we have made this booklet which is specifically about resistant TB.

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

You can use this booklet to ask health workers about different topics related to resistant TB.

Chapter 1

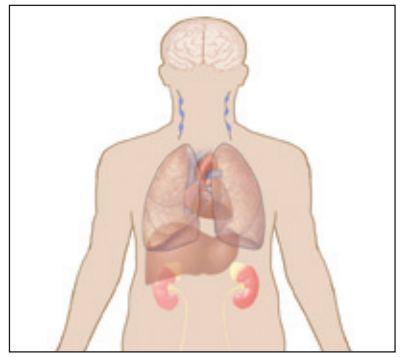
Facts about resistant TB

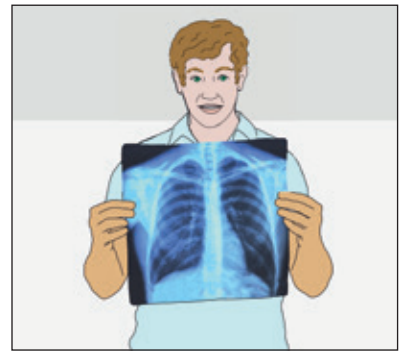
«It is very important to have good knowledge about the disease, and to know that it is curable. Information is part of the treatment.»

What is TB?

TB (short form for tuberculosis) is a disease that is caused by 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 these 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*. TB which can be treated with the most common TB medicines, is often called sensitive TB.





It is most common to get TB in the lungs.

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 extrapulmonary TB.

What is resistant TB?

The term resistant TB refers to TB that must be treated with other medicines than those used for sensitive («regular») TB. The treatment sometimes takes longer.

Resistant TB is caused by TB bacteria that do not respond to either one or several of the most common TB medicines. There are several forms of resistant TB.

TB is often categorised and named after which medicines that are used to treat it:

Sensitive TB:

Sensitive TB is TB that can be treated with all of the most common TB medicines. When we use the term «TB» in this booklet, it refers to sensitive TB.

Mono-resistant TB:

Mono-resistant TB is TB that is resistant to one of the most common TB medicines.

MDR-TB (multidrug-resistant TB):

MDR-TB is TB that is resistant to both of the two most common TB medicines. (These medicines are called Isoniazid and Rifampicin.)

XDR-TB:

XDR-TB (extensively drug-resistant TB) is TB that is resistant to more medicines than MDR-TB is. In addition to being resistant to the most common TB medicines, XDR-TB is resistant to medicines used to treat MDR-TB. So, to treat XDR-TB, you must use yet other medicines.

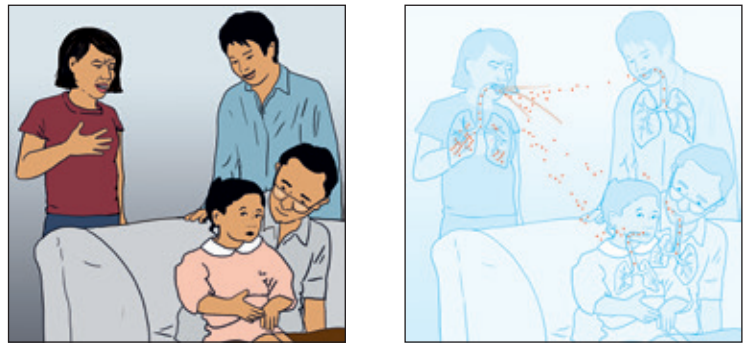
How do you get sick with resistant TB?

You can get resistant TB in two ways:

1. You have been infected with TB bacteria that are already resistant to the usual TB medicines.
2. You have had TB before but have not been successfully cured. This may have happened because of interruptions in the treatment or because the various medicines you took were incorrectly combined or not strong enough to kill all the bacteria.

How is resistant TB spread?

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



Both resistant TB and TB are spread when a person breathes in bacteria from the air.

It is only TB in the lungs (sensitive or resistant) that can be spread from one person to another. People who have had close contact over some time with a person with infectious, resistant TB in the lungs can get the disease.

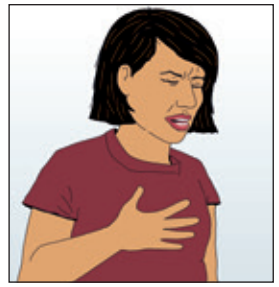
The bacteria do not spread easily, so infections generally occur between persons who live together, or spend a lot of time indoors together.

Most people who are infected by TB bacteria don't get sick. It is estimated that 1/4 of the world's population carries TB bacteria in their bodies, and a small proportion of them carries resistant TB bacteria. Only a few – approximately 5–10 per cent – develop TB disease. **Being infected with TB or resistant TB bacteria without being sick is called having latent TB (sensitive or resistant).**

The risk of developing TB disease – both TB and resistant TB – differs. People with reduced immunity have a greater risk. Reduced immunity can be caused by other diseases such as HIV or diabetes, or conditions such as stress, poor nutrition, alcohol or drug consumption, or other reasons.

How do you know you have resistant TB? What are the signs and symptoms?

The common signs of resistant TB are the same as those of sensitive TB. Common signs of resistant TB in the lungs are:



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

Other common signs of resistant TB – both in the lungs and other parts of the body – are:

- Loss of appetite
- Loss of weight
- Feeling weak and tired
- Having fever over some period of time
- Sweating at night
- Swelling on the neck, under the arms, or in the groin

Loss of appetite
Loss of weight

Feeling weak and tired

Having fever over some period of time

Sweating at night

Swelling on the neck under the arms, or in the groin

Resistant TB outside the lungs usually gives pain or other symptoms in affected body parts.

How is resistant TB detected and diagnosed?

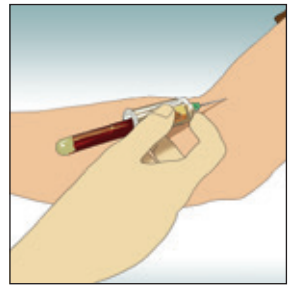
To diagnose resistant TB in the lungs it is necessary to take a chest x-ray and sputum tests. A sputum test implies coughing up phlegm into a small cup or container. Then different methods, for example looking for bacteria in a microscope, cultivation of bacteria, or taking a genetic test, can be used to identify bacteria in the sputum.

A blood test is also often used. This test cannot diagnose TB, but it can show if a person has come into contact with TB bacteria and has developed some immune response. However, the blood test cannot distinguish between latent TB infection (the person not being sick) and TB disease. Therefore, it is also necessary to take chest x-ray and sputum tests to distinguish between latent TB and TB disease.

When TB bacteria have been identified in the sputum, the laboratory will perform a drug sensitivity test. This means finding out what medicines your TB bacteria may be resistant to, and which medicines are needed to kill the bacteria. In this way, an individual treatment will be identified for you.

Chest x-ray

Sputum test



Blood test

Resistant TB outside the lungs is diagnosed by means of special observation methods, for example a physical checkup, x-ray, or biopsy (extracting a sample from the affected organ or body part).

How is resistant TB treated?

Treatment for resistant TB consists of several medicines, and it usually lasts for 6 months or more. **The treatment and all expenses related to the treatment (hospital stay, testing, medicines against side effects, travels, follow up consultations) are free of charge.**

In the past, resistant TB was difficult to cure, and unfortunately, it is still so in some countries. But in Norway today, we have effective medicines, and resistant TB is a curable disease.

In chapter 2, you can read more about the treatment for resistant TB.

Will your resistant TB make others sick?

It is only resistant TB in the lungs that can be transmitted from one person to another (meaning that the disease is contagious). It varies how contagious the disease is, depending on how many bacteria the person has in the lungs. Sputum tests will tell how contagious your disease is.

Effective medicines will kill the resistant TB bacteria and improve coughing after some weeks of treatment. Your disease becomes gradually less contagious and finally you can no longer transmit it to other people. However, how long time it takes, will depend on the extent of the disease and the medicines that can be used.

Testing of contacts

The health service in Norway is obliged to assure that all persons with TB and resistant TB get treatment. In order to find all persons who may have become infected, patients are asked to give the names of people they have had close contact with. These persons will be contacted by health personnel and asked to test themselves. If you want the health personnel not to mention your name, you can inform them about this. **You have the right to be anonymous when persons around you are asked to test themselves.**

Patients are asked to give the names of people they have had close contact with.

If some of the contacts have become infected and ill with resistant TB, they will get proper medical treatment and follow up from the health system. If there are contacts who have become infected, but not ill (they have latent infection), they might be offered preventive treatment. It is the doctor who decides if they are offered preventive treatment, based on the probability that they will develop disease at a later stage (if they for instance have reduced immunity).

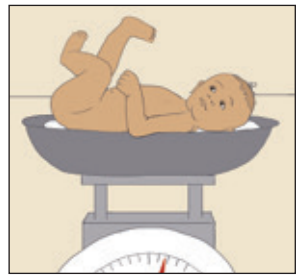
Resistant TB in children

Children, and especially children under 5 years, are more vulnerable to TB and resistant TB than adults. They develop disease more easily and can also get more seriously ill. The disease can also progress more quickly in children. Especially babies, children with reduced immunity or malnourished children have increased risk of falling ill.

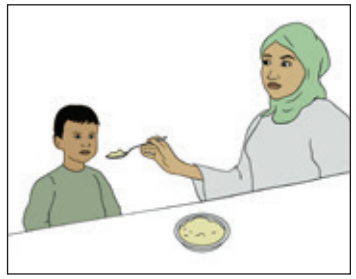
Because of this, children who are close contacts of a patient with contagious disease are often given preventive treatment.

TB (both sensitive and resistant) can be more difficult to diagnose in children. This is because it can be difficult for children to produce a sputum sample. Also, they often have only vague and non-specific symptoms like feeling tired and weak, not gaining weight or losing weight, and lack of appetite. **Many children with TB don't cough.**

Tiredness



Not gaining weight



Lack of appetite

Normally, the treatment for children with resistant TB lasts for 6–9 months.

To reduce the risk of TB in children, all newborns in Norway who have one or two parents from a country where TB and resistant TB is common, are offered a BCG vaccine. The vaccine is usually given when the baby is about 6 weeks old.

Where does resistant TB come from originally?

Resistant TB has developed because TB-bacteria have mutated and become resistant to one or more of the most common TB-medicines.

Mutations of bacteria occur naturally, but can occur more often if medicines are used in an inadequate way. Resistance can develop if the medicine doses are not high enough, if all the medicine doses of a treatment are not taken, or if there are long interruptions in a treatment.

Therefore, it is important to have good health systems with good treatment surveillance and follow up of patients.

Question from patients

- I have heard that resistant TB is not curable – is that true?

No, with the medicines available today, resistant TB is curable. But you need other medicines than the medicines used for sensitive TB, and it sometimes takes longer to treat resistant TB than sensitive TB.

- How did I get resistant TB?

There are two different ways of getting resistant TB:

1. If you have had close contact with someone with infectious resistant TB, you might have been infected.
2. If you have had sensitive TB before, and the treatment was interrupted, wrongly combined or too short, the bacteria can have become resistant to the medicines for sensitive TB.

- I did not have anyone with resistant TB in the family – how did I contract the disease?

It is fully possible to be infected by someone outside the family, but it is most probably someone you have had close contact with. It may also be someone who did not know he or she had resistant TB, and it could be long time ago (it can take years after infection until the disease breaks out). Unfortunately, you cannot always know how you became infected.

- Can resistant TB be inherited?

No. Resistant TB is a contagious disease that spreads through the air. But if you have close family members who have had resistant TB, it is possible that you were infected by them, as close family, friends and people living together are more at risk of infection.

- Can resistant TB be transmitted in other ways than by breathing in bacteria from the air?

No. Breathing in bacteria from the air is the only possible way for resistant TB to be transmitted. It is NOT spread through sex, physical contact, drinking from the same cup or using the same things such as plate, eating utensil, toilet, clothes or bedsheets.

- What is latent TB infection?

Latent TB infection means that you are infected by TB bacteria (sensitive or resistant bacteria), but you are not ill (you don't have symptoms, and you can't transmit the bacteria). When TB bacteria enter a human body, they encounter the body's immune system, which in the majority of cases prevents TB to develop. For most people who are infected with TB bacteria, the bacteria remain latent, or «sleeping», in the body. As long as the bacteria are sleeping, you do not become ill.

- What is preventive treatment for resistant TB?

If you have latent TB infection and it is supposed that you have been infected by someone with resistant TB, you will in some cases be offered a preventive treatment for resistant TB. This treatment will kill sleeping bacteria in the body. Preventive treatment for resistant TB usually consists of one or two TB medicines that you commonly will have to take for 6–12months.

- Not everyone who has contact with a person with resistant TB becomes ill. Why is that?

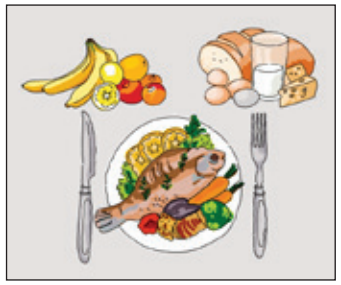
Generally, only those who have close contact over time get infected. And often, when people breathe in bacteria, their immune system fights the bacteria and makes them stay healthy. So, whether different people around a person with resistant TB will get infected will depend on the closeness of the contact and the time spent, how contagious the disease was, and the immunity of the different people.

- Why do some patients with resistant TB get very sick and weak, while others don't?

This depends on both how «strong» the bacteria are, how early treatment was started, and the general health condition and effectiveness of the immune system of the person infected.

- Can I get resistant TB again?

You will not be immune after having had resistant TB. But the probability to get ill again is low. The best way to keep yourself healthy is to eat healthy foods, be physically active and avoid smoking and drinking much alcohol. This will strengthen your health and immune system.



- Is resistant TB caused by poor hygiene?

No, resistant TB is caused by bacteria that are resistant to the most common TB medicines, and not by poor hygiene. Resistant TB has developed from sensitive TB. Both sensitive TB and resistant TB are contracted by inhaling bacteria from the air.

- Is resistant TB caused by poor living conditions?

No, resistant TB is caused by bacteria, but poor living conditions can make people more vulnerable to the bacteria. People who have poor living conditions generally get their immunity reduced, and if they have latent («sleeping») bacteria in the body, it is a higher chance that the bacteria wake up and make them sick.

Also, people with poor living conditions often live more crowded, and such circumstances make it easier for bacteria to spread. The bacteria spread more easily in crowded rooms with poor ventilation.

- How can you prevent resistant TB?

Several factors will reduce the prevalence of resistant TB: Better living conditions, which will improve people's health and immune systems, is important. Also, good health systems with access to care for all people, good follow up and patient support, are very important. This will make it easier for all patients to complete their treatment, so that interruptions in treatment don't create resistance to TB medicines.

Good follow up makes it easier for patients to go through the treatment period.

A general advice on how to reduce the risk of diseases caused by bacteria or virus is to cover your mouth when you cough and keep a window open for good ventilation.

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

After some weeks of effective treatment, your resistant TB is no longer contagious. This will be confirmed by a sputum examination. When you cough less and your sputum is negative (which means they can't find bacteria in your sputum), you can no longer transmit the disease. It is important to finish the whole treatment as prescribed by your doctor; if you stop earlier, your disease can become contagious again.

Family members and close contacts, and especially children, will be checked to see if they have become infected. If they have become infected, they might get preventive treatment. Alternatively, they will be followed up with regular check-ups.

- What should my friends do to prevent getting ill?

When you take your treatment as prescribed and become sputum negative after a while, you can't infect anybody. And if you feel comfortable, you can speak to your friends about resistant TB and tell them about symptoms to be aware of.

You can talk to your friends about resistant TB and its symptoms.

If you have had close contact with your friends before you were diagnosed, they should have a medical check up to find out if they have become infected. You will be asked to give the names of people you have had close contact with, and these people will be contacted by health personnel so that they can be tested. **This is confidential and you can tell the health personnel not to mention your name.**

Early diagnosis and effective treatment are important to improve the disease prognosis and to prevent the spread of resistant TB.

Chapter 2

Treatment of resistant TB

«The treatment is long, and it can be hard. But if you see it in a lifetime-perspective, it feels less long. There is a life after resistant TB!»

How is resistant TB treated?

To get cured from resistant TB, you need other medicines than the medicines used for sensitive TB.

If it is suspected that you have contagious resistant TB in the lungs, you will be admitted to an isolated ward at the hospital. Here, health personnel will take tests to assess the contagiousness of your disease.

You will usually have to stay at the isolation ward until your disease is not infectious anymore. This often takes 2–6 weeks, but it may take longer.

In some cases, patients can be isolated in their homes, but this requires that the disease is only mildly contagious. It is the doctor who decides how long and where you have to be isolated, based on the tests taken.

After the isolation period, you will continue the treatment at home, with home nurses delivering your daily medicines.

This patient has gone through all the treatment, and is cured!

The isolation ward

At the isolation ward, all patients will have a room of their own. This is done to avoid possible infections between patients: Because patients most often are infected by different strains of bacteria, infections could potentially occur if they spent time close together in the same room.

Both health personnel and visitors at the isolation ward have to wear a mask and a special cap, gloves and a coat or gown when they are in the patients' rooms. This is according to the infection control routines at the hospital.

Many patients find it difficult that people around them wear masks. Some say they feel worthless and «bad» when others have to cover themselves to be close to them. But remember that it is the resistant TB bacteria, and not you, they have to protect themselves from. As soon as the bacteria are controlled enough that your TB is not transmittable, others can be close to you without wearing masks.

You can ask health workers to show their faces before they enter your room.

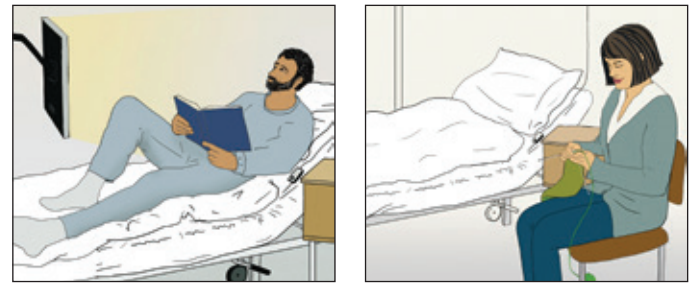
It can be hard when you don't see the whole faces of the persons treating you. It may be difficult to recognize the different persons, and you may feel that the communication becomes impersonal and cold when they wear masks. You can ask them their names and to show their faces through the window in the door before they enter your room – then you will probably feel like you get to know them better. If there is no window, you will have the opportunity to look at an ID card with a picture of the health worker.

To cope with the stay at the isolation ward

During the stay in the isolation ward, you are deprived of many things in your ordinary daily life. Many patients say they find it difficult that they cannot move freely and are dependent on others for almost all their needs. To spend most of their time alone is also difficult for many and may make them lose sense of time. Most people would find this hard.

To keep in touch with friends and relatives through telephone or computer will make you feel less alone. And your friends and relatives can visit you, as well! If you meet with them outdoors, they won't have to wear any protective equipment, but to enter your room, they will have to wear masks and other protective equipment. Unfortunately, children are not always allowed to enter the isolation ward.

To cope with the isolation, 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 you like when you stay in the isolation ward.

There are different possibilities for activities at the isolation ward, but these may vary at different hospitals. Commonly, you will have the opportunity to go out for walks (wearing protective equipment if you have to pass through corridors), to meet with family and friends, have visits organised by the hospital with a priest or imam, a visitor friend or a former TB patient (where this is available), or exercising with an ergometer bike. Examples of things to do include reading, writing, listening to radio, watching television, playing games, doing needlework, or doing exercises.

If there are activities you want to do, ask the health personnel at the ward if it is possible!

De-isolation

Before you leave the isolation ward, the things you have brought with you to the isolation room will be disinfected. Your clothes will be washed, and your things, such as a mobile phone or pc, will be wiped over with a cloth with disinfectant. It is the health personnel at the ward who do this.

Medical examinations during the treatment

During the treatment for resistant TB, you will undergo several medical tests. Sputum tests (a test where you cough up phlegm from the lungs), ECGs (a test to check the heart funcion) and blood tests will be taken regularly, both when you are at the hospital (often weekly) and when you continue the treatment at home (often every 4–6 weeks). You will also have to take x-rays during the treatment period. The doctor decides how often the patient needs to have medical checkups, and which medical test to take.

Sputum samples are often taken at the hospital, but in some cases also at home. After a period of treatment patients may find it difficult to produce a sputum sample. If you find it difficult, and this may especially be the case if you are asked to take a sputum sample at home, this is a useful tip to produce a sample:

Breathe in deeply ...

... and hold your breath for a few seconds ...

... then breathe out slowly. Do this twice (image 1–3).

Breathe in deeply for the third time ...

... cough hard a couple of times, until some sputum from deep inside your lungs comes up into your mouth ...

... and spit the sputum into the cup.

Medicines

To be cured from resistant TB, you have to take many pills each day during the whole treatment period. The treatment is a combination of medicines from different categories, adapted to your TB bacteria and your health condition. This means that you will be given medicines that tests have shown your bacteria will respond to, and medicines that you tolerate.

Most patients with resistant TB are treated with these four medicines: *Bedaquiline, Pretomanide, Linezolid, Moxifloxacin.* In some cases, for instance if your bones or brain are affected by the disease, these medicines cannot be used. Then a combination of medicines from the following categories will be used:

- Group A: Levofloxacin or Moxifloxacin, Bedaquiline, Linezolid, Pretomanide
- Group B: Cycloserine, Clofazimine
- Group C: Pyrazinamid, Prothionamide, Ethambutol, Amikacine, Imipenem-Cilastatine, (+Amoxicilline Clavulanic acid), Meropeneme (+Amoxicilline-Clavulanic acid)

All patients are also given Pyridoxine, which contains vitamin B.

You will have to take most of the medicines daily, except if you take Bedaquiline, which will be taken every day the first 14 days of the treatment, and then three days a week.

You will take medicines daily.

Some patients may feel worse after they have started taking medicines. This can be just a sign that the medicines have started to work in your body to fight the disease. But it might also be a side effect of the medicines, so you should tell your doctor, TB-coordinator or nurse about it, so they can follow you up in the right way.

Some patients find it difficult to swallow all the pills. Here are advice from two patients:

«I tried to take the tablets in different ways, and when I started to divide the pills, it became easier to swallow them.»

«I tried to take them in the morning, then at lunch, and finally, when I started to take them the night before I went to bed, it helped me a lot. I woke up in the morning after, feeling well. I could be human all day.»

Remember that some medicines should be taken at approximately the same time of the day. Also, some medicines should be taken with food, and some on an empty stomach. So, ask your doctor about taking the tablets, to assure you take them correctly.

Side effects of the medicines

Unfortunately, the medicines for resistant TB may have unpleasant and adverse side effects on the body. But people react differently to medicines; some patients experience side effects, others not.

The most common side effects include:

- nausea, vomiting
- loss of appetite
- dizziness and fatigue
- blood problems (reduced production of blood cells or platelets)
- diarrhea and constipation
- itching and rashes
- peripheral neuropathy
- joint pains and headaches

Other side effects that can occur include:

- sleeping problems
- heart problems
- liver problems
- some psychiatric problems (like depression, anxiety, or paranoia)
- in rare cases: sensitivity to sun exposure or skin discoloration

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.

If you experience pain, reduced sensitivity, a sense of having heavy or burning feet, tingling sensations or a sense of having needles under your feet, you should contact your doctor immediately.

Generally, side effects get milder or disappear when the body gets used to the medicines, often after about 4 weeks. In this paragraph we present information about the most common side effects and how you can deal with them, and advice from patients.

It is important that you inform your doctor, nurse, or TB-coordinator if you experience problems or side effects.

Most common side effects

Nausea, vomiting

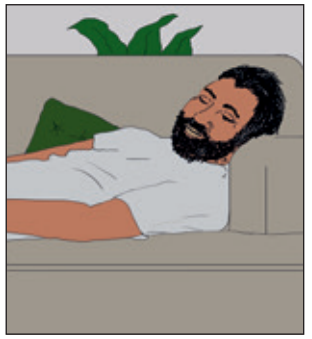
Medicines for resistant TB can cause nausea and vomiting. If you have nausea, it can help if you eat something small, like a biscuit, a piece of fruit or some natural yoghurt. It is important to continue to eat regularly; this will help you to recover faster, and it can also help prevent or relieve nausea.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

Loss of appetite

Both the resistant TB and the medicines may cause loss of appetite. It is very important that you continue to eat; try to eat well to help your body fight the disease. A weak and exhausted body does not have strength to fight the disease.

Dizziness and fatigue

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



Blood problems

Some patients develop blood problems (reduced production of blood cells or platelets) as a side effect of the medicines. Symptoms can be, among other things, fatigue and paleness. If you develop blood problems, it will be detected through routine tests. The doctor will adjust the medication and advise you on what to do.

Diarrhea and constipation

In addition to killing the bacteria, the medicines against resistant TB also affect normal intestinal bacteria. This may cause digestion problems. Some patients have constipation, others have loose stools or diarrhea.

Advice on how to prevent diarrhea:

- Don’t drink beverages that contain a lot of sugar
- Eat something small, often
- Eat blueberries/drink blueberry juice, and eat bananas
- Eat less vegetables and fruits
- Take products which contain «probiotic lactic acid bacteria», for instance Biola
- Take tablets with lactic acid bacteria, for instance Idoform Classic

Generally, food that is often tolerated include dry toasts, rice, pasta, cooked potatoes, white fish and boiled chicken. And boiled food is better tolerated than fried food.

Advice on how to relieve constipation:

- Eat fruit and vegetables
- Eat dried fruit, especially raisins and prunes
- Eat soaked flax seeds
- Drink a lot of water
- Take products which contain «probiotic lactic acid bacteria», for instance Biola
- Do light, physical exercises regularly

Itching and rashes

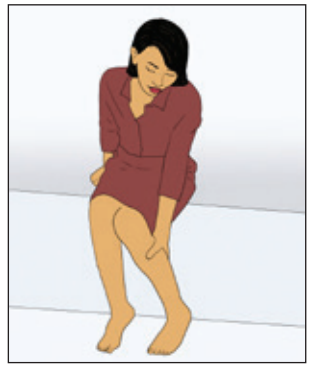
Some patients itch a lot on the body and may get a rash. This can be very annoying. The itching is caused by an allergic reaction to the medicine. If the symptoms are not serious, you can try the advice below. If the itching and rashes do not go away, talk to your TB-coordinator, doctor, or home nurse. The doctor can, in some cases, prescribe medicines to relive itching.

Advice on how to relieve itching:

- Use a mild soap without perfume
- Use a body lotion without perfume
- Use a cream to relieve itchiness, for instance Eurax
- Use Aloe Vera (directly from the plant or a skin lotion with Aloe Vera)
- For itching on private parts, wear light, loose, and preferably cotton underwear.

Peripheral neuropathy

Peripheral neuropathy is a side effect of the medicines that patients may experience. The symptoms may be numbness, reduced sensibility or tingling in fingers, toes and feet; burning pain in the affected areas in the body; loss of balance and co-ordination, or muscle weakness, especially in the feet. It can also affect the eye nerve and cause problems with the vision. Physical exercises, physiotherapy or medicines may in some cases help relieve the symptoms. Often, the dose of the medicine that cause the problems will be adjusted.



Joint pain and headaches

Some patients experience joint pain, headaches, or other pain in the body. If you experience this, talk to your doctor about it. The doctor can prescribe painkillers. 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.

If your problems don’t go away, you should talk to your doctor, nurse or TB-coordinator!

Treatment plan and Directly observed treatment (DOT)

All patients with resistant TB shall have a treatment plan which points out where and when to take their daily medicines during the period after the hospital stay. With resistant TB, the intake of medicines has to be observed by a health worker. This is called DOT – Directly observed treatment.

The treatment plan is worked out during a meeting between the patient and the health personnel who are treating him or her. This meeting is called «treatment plan meeting» («behandlingsplanmøte»), and it is held before the patient leaves the hospital. The patient, TB doctor (specialist), TB-coordinator, and often people from the municipal health service participate in the meeting. The patient can also ask for a translator, and/or bring a relative or a friend as support. Your TB-coordinator can also tell you more about the treatment plan and the meeting.

The purpose of making a treatment plan is to find an arrangement that is convenient for the patient, considering both the patient's wishes and the health workers' possibilities. Most patients have the medicines delivered to their homes. If you prefer another arrangement, you have the right to ask for this.

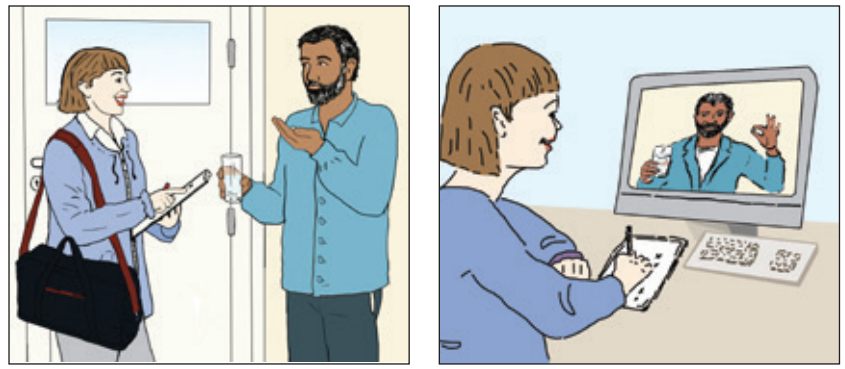
Treatment plan meeting.

Finding the best DOT-arrangement depends on your life situation. If you work, you can for instance ask the health workers to deliver the medicines before you leave in the morning, or in the evening. You can also ask for treatment observation by video (video observed treatment), which is available in some places.

It is also possible to change the arrangement during the treatment period, if you find that your situation or your needs change.

Many patients do well with DOT and perceive it as a supportive system. But some also find it difficult. Some feel uncomfortable about being observed when they take their medicines and feel that the health personnel are controlling them. This is understandable – it is usual for people to want to «govern themselves». But, as one patient put it, «It is not to control me, but to control my disease».

Some patients also find it hard to plan their daily activities during the DOT-period. If this is a problem for you, explain the problem to your home nurses or your TB-coordinator and ask if you can make an agreement that suits you better, for instance video observed treatment.



Many patients get the medicines delivered at home. In some places it is possible to meet the health worker on video.

Questions from patients

- Why is the treatment so long?

This is because bacteria that cause resistant TB are killed very slowly. To kill all the bacteria, you will have to take medicines for a long period.

- Why do I have to take so many different pills?

Because the medicines work together and support each other in killing all the bacteria. If you take only one type of medicine, the bacteria may survive, but when you take several different medicines, the bacteria will not survive.

- Why is it important not to skip taking pills?

To kill all the bacteria, the effect of the medicines in the body should be constant. To achieve this, you should take pills every day.

- What does «positive» and «negative» mean?

«Positive» means that your sputum contains bacteria that can be seen under a microscope, while «negative» means that no bacteria could be seen under a microscope.

The microscopy method is a fast way of monitoring your treatment progress, but it cannot tell if the bacteria are dead or alive, and if your disease is still contagious. Only bacteria culture can tell us that, but because the results of bacteria culture can take several weeks, «positive» results are interpreted as if the disease is contagious, until the doctor gets the culture results.

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

You should stay in hospital until your disease is no longer infectious, or very little infectous (in this case you may be transferred to home isolation), and health personnel have seen that you tolerate the treatment and you are healthy enough to go home.

- Do I really have a chance to cure completely?

Yes, absolutely. The medical knowledge on how to treat resistant TB has improved and new, effective medicines have been developed.

- Do side effects remain after the treatment is finished?

Most side effects will disappear when the treatment is finished, but there are a few exceptions. Loss of sensitivity and unusual or unpleasant feelings in the feet are side effects that can remain after treatment completion. This is why it is so important that health personnel follow patients up closely.

- What can I do to reduce side effects of the medicines?

There can be different ways of reducing side effects. For instance, according to their doctor's advice, some patients don't take all their pills at the same time. And some take the pills they react badly to just before they go to bed. On the pages 22–25 in the booklet, you can find advice related to some of the most common side effects. You can also ask health workers for their advice.

Remember to always consult your doctor to ensure that what you do does not affect your treatment negatively.

Chapter 3

Taking care of yourself during and after the treatment period

«I know it is important to eat well, be positive and active, when I have the energy for it. This will give me strength to cope the disease»

Being sick with resistant TB can affect your daily life during the treatment period and sometimes after. For some patients their life can be challenging or difficult, especially in the beginning. Challenges and difficulties may be due to side effects of the medicines, hospitalization/isolation at hospital, or fear and stigma related to resistant TB (which is usually caused by misconceptions about the disease). But some patients have also transformed their experience with resistant TB into an opportunity to change their life to the better – changes in their own life or a drive towards helping others.

In this chapter, we present information, experiences and advice from former patients and health personnel on how to cope with the situation.

At the hospital

When you have resistant TB, you will usually have to stay at the hospital for some weeks in the beginning of the treatment. Some patients experience the hospital stay as difficult. On page 18–19 you can find advice on how to cope with this.

Daily life during the treatment period

There are great differences among patients with resistant TB as to how weak the disease makes them, 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 resistant 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 housework and taking care of children is also work!

This work might feel ok ...

... but this might be to hard.

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. Try to establish a good daily routine and ensure you get enough sleep and proper nutrition (for more information see page 32).

Sex

Resistant TB is not a sexually transmittable disease, but when you have sex, you often breathe heavily, and this may pose a risk of transmitting the disease through the air. But, when your disease is no longer contagious, 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. So, remember that it is absolutely ok to say no to sex if you feel you don't have the energy or desire.

Having sex with your partner can be good for you both.

Resistant TB and pregnancy

It is best to avoid getting pregnant while you are being treated for resistant TB. The medicines for resistant TB are strong, and it might be harmful for you and your child if you take them during pregnancy. If you are planning to get pregnant, it is best to wait until you are cured. If you already are pregnant when you get the diagnosis resistant TB, 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. You will be followed up with many thorough examinations of both you and your child. Treatment for resistant TB will usually start in the fourth month of the pregnancy, but if the disease is advanced, the treatment starts earlier. Always discuss your options with your doctor.

If you are pregnant, it is extra important that you get enough food and proper nutrition.

Food and drink

Food and drink will help your body fight the resistant TB. But when you are ill, it can sometimes be difficult to eat and drink. In some cases, the medicines for resistant TB also make patients lose their appetite. Here is some general advice on what to eat and drink:

Eating

Some good foods for you are fish, meat, beans, vegetables, fruits, eggs, porridge, rice, and potatoes. Eat what you usually eat, but if you have lost much weight or are undernourished, try to eat a little more fatty foods and foods that are rich in proteins. Fatty fish (for instance mackerel or salmon), chicken or other meat, and foods that contain vegetable oils will be good for you. The main advice on food is to eat what you like.

If you have poor appetite, you can try some of this advice from patients:

- Eat food that you like
- Eat something small often
- Eat fruits or drink fruit juices
- Eat vegetables, especially green, leafy vegetables
- Try to be physically active, if you are up to it

If you don't manage to eat very much, it may be a good idea to take nutritional supplements. Some patients with resistant TB need supplements of vitamin D. Talk to your doctor or other health workers about this.

Your appetite will improve when you start feeling better.
This usually happens when you have taken medicines for about two weeks, but it can also take longer.

Drinking

It is important to drink a lot, about two litres a day if you can manage. Drink water, and also fruit juices. Fruit juices are healthy because they have vitamins.

Alcohol

While you are being treated for resistant TB, your body needs all its strength to fight the disease. Alcohol is a drug that is toxic for body. Both alcohol and TB medicines are digested in the liver, so if you drink alcohol during the treatment, your liver must work very hard. Your liver might not be able to cope with the medicines and alcohol at the same time, and you could develop liver failure. Therefore, it is best to avoid drinking alcohol during this period. If you don't manage to avoid drinking, it will be important to reduce the drinking. If you drink alcohol, you should talk to your doctor about it.

Smoking

TB and resistant TB, especially if it is located in the lungs, weakens your lungs and the rest of your body to some degree. Smoking makes your lungs weaker and decreases your immunity. When you smoke, you pull the smoke into your lungs, and they must work hard, even if they are sick. Smoke irritates sick lungs and can make you cough more.

Because your body is weakened from resistant 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 disease. Therefore, it is best to avoid smoking, especially if you have resistant TB in the lungs.

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 also download the app called Slutta, which is made for helping people quit smoking.

It is also possible to get professional help. Some hospitals have smoking cessation courses, and you can ask your doctor if this is offered at your hospital. Additionally, it is possible to get help at «Frisklivssentralen» where you live, which is a municipal wellness centre. However, if you don't manage to stop smoking, remember that people who smoke also get cured of resistant TB.

Fear and stigma

Some patients are afraid to tell others that they have resistant TB, and hide their disease from others. They usually hide it because they fear that people who know about their disease will stay away from them and refuse to talk to them.

Some patients may feel lonely and stigmatized.

Patients who are open about their disease usually benefit a lot from this.

Some patients experience that people around them withdraw from them. For someone who is fighting a disease, it is very painful to experience this.

Usually, the reason why people withdraw or stigmatize is that they lack knowledge and are afraid of being infected. Try to learn as much as you can about your disease so that you can explain to your friends and family!

We have met many patients who discuss their disease openly and benefit from that. By being open about your disease, 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 no longer afraid.

«Lack of information always make us bad. It would be good to know that everyone can get affected by this disease, not just one social class.»

Feeling of depression and other psychological challenges

Many patients with TB and resistant TB have periods when they feel depressed, anxious or experience other psychological challenges. The psychological challenges may be caused by changes in the body that are related to the disease itself, the medicines (see list of side effects of medicines on page 22) or may be due to the difficult life situation while being sick. If you experience this, you should tell your doctor, nurse, or TB-coordinator so that they can assess if you need follow up for these problems.

Some patients have periods when they feel lonely and depressed.

The majority of patients with TB and resistant TB in Norway are immigrants, and many feel that their situation is especially difficult because of this. Many immigrant patients don't have their family members around them; they may have language difficulties; or they may not be used to the food, the environment, and the society in Norway. Some patients therefore have periods where they feel lonely.

For many patients, the feeling of depression or loneliness passes or decreases when they start to feel better physically, when their bodies have got used to the medicines and/or when they have stayed in Norway for some time and have got used to living here. For others, it takes longer. Negative psychological effects can also arise at a later stage.

It can be very useful to talk to someone who have gone through the treatment:

«It was encouraging to talk to a former patient. It gave me motivation to talk to someone who had been cured and was back in activity.»

You can contact LHL International Tuberculosis Foundation, which is a patient organization that provides peer support to patients with TB and resistant TB. Through the organization you can meet persons who have had TB and recovered.

If you experience serious psychological problems, it is important to talk to your doctor, nurse, or TB-coordinator to get assistance.

Keeping yourself active

«I will recommend other patients to find activities they enjoy and to focus more on these. Having something to do makes the days go easier.»

Having too much time to be alone and think can be very tough.
Keeping oneself a little busy can help prevent or reduce difficult feelings or feelings of depression. 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! 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 music; watch TV; read a magazine. Do things that you like!

Life after resistant TB

The majority of patients get well and don't experience problems after finishing treatment, but this is not the case for all. The most common health problem after finishing treatment is lung problems, such as reduced lung capacity, reduced exercise capacity, pains, cough, or shortness of breath. Another common complication is neuropathic pain (see page 25). Persons who have had resistant TB outside the lungs may experience pain in the body part affected by the disease.

If you experience any health problems after completing your treatment, you should talk to your doctor or nurse about it. In addition, if you experience lung problems, exercises to increase your strength and endurance will in most cases improve your condition considerably. Many simple exercises or activities will be good for you: Examples are walking, running, blowing a ballon or jumping a rope. Dancing and singing are also very effective!

Lung rehabilitation programs with exercises can help people with lung related problems. You can ask your doctor or nurse if such programs are available for you in your area. Remember that although it can be painful to exercise, especially in the beginning, it is good for you and will improve your health.

Questions from patients

- What can I do to improve my social life and emotional well-being while I am sick?

There are many different ways of coping with the social and emotional challenges that sickness can cause. Every person has to find out what works best for him/her. But based on what patients have told us, it seems like eating well, and staying a little active, and sharing experiences with others, are things that have a positive effect on most patients.

- Where can I get more advice on what kind of food to eat when I am on treatment for resistant TB?

You can ask your doctor, nurse, TB-coordinator or a dietician for advice.

- I have been told to eat food, but I have poor appetite. How can I increase my appetite?

Eating frequent small portions of food that you like can help to increase your appetite. You can also try to drink fruit juices and to eat fruits and vegetables, especially green vegetables. Fresh air and physical activity can also help.

- When I come home from hospital, should I stay home and rest, or can I go out and meet people?

If you want to go out and meet other people, and you feel well enough, there is no reason for you to avoid this. It is good for your health to do things that you like. But don't push yourself. Some patients feel that they relax better when they are alone.

- Can I work after healing?

When you feel strong enough and your disease is no longer infectious, there is no reason for you not to go back to work. Some people can start working while they are discharged from the hospital, others wait until they have finished the treatment.

- Can I do sports?

Yes, when you feel strong enough. But don't start doing heavy exercises too early. If you like to do sports, try to go back to your former exercising habits little by little. Sports and exercising in reasonable amounts are good for your health.

- I have come home from hospital, and I am unsure if I can have sex?

Yes, you can have sex. Having sex can make you feel good and comfortable/relaxed. But remember that sex is a kind of physical activity, and as with any other kind of physical activity, it is important that you consider how you feel. You should not force yourself to have sex if you don't feel like it.

- Is it true that TB and resistant TB comes from sexual intercourse?

No, TB and resistant TB is not transmitted through sexual intercourse. TB and resistant TB is transmitted by breathing in bacteria from the air.

- Can I get pregnant after finishing the treatment?

Yes, you can. But it is important to not get pregnant during the treatment for resistant TB. You can get pregnant after finishing the treatment! Always ask your doctor for advice to know when it is safe to get pregnant.

We are thankful to all the patients and health workers who have given us valuable input and feedback on the booklet content. Without their efforts there would have been no booklet!

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«It is very important to have good knowledge about the disease, and to know that it is curable. Information is part of the treatment.»

If you want to learn even more about resistant TB, you can also read on the following websites:

LHL International Tuberculosis Foundation: www.lhl-internasjonal.no
The Norwegian Institute of Public Health (NIPH): www.fhi.no
Stop TB partnership: www.stoptb.org
World Health Organization (WHO): www.who.int
TB People: www.tbpeople.org

LHL International

LHL International Tuberculosis Foundation
E-mail: post@lhl-internasjonal.no
www.lhl-internasjonal.no