

# Multidrug-resistant (MDR) tuberculosis – preliminary information for people with the disease

Hey,  
you need information  
and support to be cured.  
Catch!



**You have been diagnosed with drug-resistant, MDR tuberculosis. You're probably worried about your illness, treatments, your recovery and how getting ill may affect your life.**

**MDR-TB can be treated even though the usual TB drugs do not work. Treatment is lengthy, but a most patients are cured.**

You are not alone. MDR tuberculosis is found all over the world. Every year, around half a million people worldwide fall ill with this type of TB disease. Half of those affected live in India, China and the Russian Federation. In Finland MDR-TB is rare and only a few cases are diagnosed each year.

You have been infected with MDR-TB through the air you breathe, after a long or repeated indoor exposure to a person with respiratory MDR-TB. You can read more about infection and disease at [www.tuberkuloosi.fi](http://www.tuberkuloosi.fi). It's not your fault you got infected – nor is the person who infected you responsible.



tuberkuloosi.fi





### How will you be treated?

Treatment for MDR-TB starts in the hospital. Because of the risk of transmission, you will be treated in an isolation room at first. This room has separate ventilation. You are not allowed to leave the room without permission. Everyone who enters the room will wear a special respirator which protects them. Your doctor will evaluate when you can be visited by adults close to you. You can keep in touch with your family and friends by phone. As your recovery progresses, ask if it's possible to meet your loved ones outdoors. There is a TV and other entertainment in the isolation room.

Depending on your situation, isolation can last several weeks to a few months. Your doctor will decide when to discontinue the isolation. To do this, a chest x-ray will be redone and sputum samples will be collected. This is done to make sure that the treatment is effective and that there is no longer any risk of transmission. If you are employed, you will receive an infectious disease allowance for the period of isolation. Sick leave depends on your field of work and your condition. If you are worried about your income during sick leave, talk to a social worker.

It may not be easy to accept information about MDR-TB. You may experience many emotions and it can be hard to envision the future. Share your thoughts with the staff at the hospital. Possible depression, anxiety and sleep disturbances can be eased with counseling and medication.

### A few words on drug treatment for MDR-tuberculosis

The main and commonly used TB medicines (rifampicin and isoniazid) will not cure your TB disease. Fortunately, there have been many recent advances in the treatment of MDR-TB. New TB medicines will help you be cured.

You will initially be treated with at least five different medicines. The final combination of drugs will be determined once the effectiveness of the different medicines for your situation has been established. This usually takes several weeks. The combination of drugs chosen will also depend on your other illnesses and medications, and the extent and location of your TB disease. Ask your doctor about these matters.

Modern treatment of MDR-TB is based on the use medications in tablet form. There is no reason to worry if your treatment also requires intravenous antibiotics. These were used to treat every patient with MDR-TB until a few years ago. The most important thing is to be cured.

You will get a large amount of pills to swallow. Some are taken on an empty stomach, others with food. The number of tablets you take depends on your weight, as almost all TB medicines are dosed according to your weight. Weight usually increases as you get better and therefore the number of tablets you take may also increase. An increase in tablets is therefore not a bad sign.

You certainly want to be cured and do everything you can to achieve that. That's why it's good to get used to the idea that treatment will last for a long time. Be prepared for a year and a half to two years of treatment. It is quite possible that in the near future, newer treatments and drug combinations will shorten the length of treatment.

### **What should you know about the adverse effects of TB drugs?**

Each person tolerates medication differently. Adverse effects associated with drug treatment for MDR TB are common. Ask your doctor or TB nurse in the hospital about them. In most cases, the adverse effects can be alleviated so that treatment can be continued. If you experience serious adverse effects, immediately report them to the person supervising your treatment. See the list of concerning symptoms below. In certain situations it may be necessary to discontinue your medication for a while or to change the combination of drugs. If you are taking any other medication or dietary supplements, let the doctor who is treating

you know. Certain things may increase the risk of side effects associated with your medication.

### **Why is the swallowing of tablets observed?**

TB treatment is always given under observation, both in the hospital and after discharge. This means that a trained worker will administer your TB drugs and watch you swallow them. The doctor and nurse in charge of your care will organize the most appropriate practice for your situation.

This is for your own good, because you will only be cured by taking your TB drugs regularly. If drug treatments is interrupted, your TB disease can become more severe. When your TB drugs are administered, you will have the opportunity to tell the staff about your condition, your concerns and

#### **CONCERNING SYMPTOMS. If you experience any of these symptoms contact your healthcare provider:**

- Vomiting and/or abdominal pain
- Whites of eyes or skin turning yellow
- Feverishness and malaise
- Extensive skin rash or blisters on the mucous membranes of the mouth
- Bleeding from the gums or nose
- Dizziness, ringing in the ears or hearing loss
- Reduction in the amount of urine, color of urine becomes very dark
- Changes in vision (monitor your vision on your own. Ask for guidance.)
- Feeling confused
- Irregular heartbeat involving dizziness or loss of consciousness
- Seizure
- Suicidal thoughts, severe mood swings

any symptoms you suspect may be due to your treatment. You will be supported by a member of staff who will monitor your medication during the lengthy treatment period.

### Who can I tell about my illness?

It's up to you to decide who you tell about your illness. Family members living in the same household will inevitably be informed and will be an important support for you. You may also need support from your closest friends or relatives. It is important that you are not left to worry about your situation alone. Talking openly and sharing TB information will allow friends and family to support you during your treatment.

### Ask for peer support

Only someone who has had TB-disease can understand exactly what you are going through right now. The peer supporter will have time to listen and discuss the issues that are occupying your mind. Peer support will help you get through the lengthy treatment process. If you want, you can speak with your peer supporter by phone or text message in Finnish or English at an agreed time. The peer supporter has received training (OLKA – Toivo training). They are bound by the same confidentiality

as healthcare professionals. If you are interested in getting in touch with a peer support worker, please call 044 771 7712.

### Drug treatment alone is not sufficient

Your body needs rest and good food to heal and it is important to pay special attention to these things. You will receive Vitamin D supplements in tablet form to boost your immune system. When you feel up to it, you can start exercising. Daily walks and muscle strengthening exercises improve your mood as well.

Quitting smoking helps lung recovery and also has many other health benefits. Nicotine replacement therapy is effective in relieving withdrawal symptoms.

Sometimes surgical treatment is needed to treat MDR-TB. Removal of infected tissue can help control the infection.

### Tuberculosis treatment in Finland is very good

You can trust that all the healthcare professionals involved in your treatment will help you get better. In Finland, a special team of experts monitors the care of every MDR-TB patient.



tuberkuloosi.fi