

You will be cured of

# tuberculosis



“At first, when I was told that I had TB, I was not that upset. At least I knew what was wrong with me. But as time went by, the seriousness of the disease began to sink deeper into my thoughts. And when I also had to undergo many tests, it was tough. The situation was even more difficult as I was living alone in a foreign country.

But, little by little, I began to feel better. Luckily, the hospital that I was admitted to had really good people working there. In particular, one of the nurses played a big role in guiding me towards a positive path. She helped to bring me back to my senses, and she was an example to me that there is hope and that life can indeed become better.

This disease has changed me a lot. It has changed me in a positive way. You can't take life for granted. I feel that I have been given a new chance in life – and I have to make the best of that chance!”

*Man, 35 years*

# TB patients and health workers sharing experiences and advice

This booklet is for patients with tuberculosis (TB). In this booklet, you will find information about TB and TB treatment, and advice on how to cope with the disease. To develop this booklet, we at LHL (the Norwegian Heart and Lung Patient Organisation) have asked TB patients what they want to know about TB and what advice they want to share with others. Together with health workers and patients we have found answers to common questions.



To develop this booklet, we have talked with TB patients in Norway about their experiences.

Health workers have good professional advice about your disease. Many TB patients also have good advice based on living with the disease and finding ways of dealing with problems they experience.

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## How you can use this booklet

Read this booklet to learn the basic facts about TB and how you can cope with the disease and deal with problems you may face. You can share this booklet with others and discuss it with health workers, friends, family, or other patients. More openness about TB makes people better informed about the disease. When people around you understand more about the disease, they will feel safer from it.



You can read the booklet together with a health worker...



...or alone.

The booklet is structured in the following way:

- In the first part of each chapter or sub-chapter, you will find facts and information
- At the end of each chapter or sub-chapter, you will find questions from patients with answers
- You will also find advice and contact information related to the topics in each chapter

**When there is something you do not understand or want more information about – ask your TB coordinator, your doctor, or a nurse.**



# Chapter 1: Facts about TB

“I think it is important that people learn about TB; about the symptoms of the disease and how it is transmitted. Many people are afraid of TB because they have too little knowledge about it. To learn about the disease is the best way to handle it. Information is powerful.”

*Man, 55 years*

When you learn the basic facts about TB, and you know how the disease is transmitted and how it is treated, you will feel safer. You will also be able to inform others about the disease and discuss it with them. When people around you get more knowledge about TB, they will feel safer from the disease. People who feel safe can be more supportive to people with TB.

In this chapter you will find facts about TB and questions from patients with answers.

## What is TB?

TB 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. Examples of useful bacteria are intestinal bacteria which contribute to digesting the food we eat.

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.

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 skeleton, the lymph nodes, or the brain).

The bacteria that can cause TB is called *Mycobacterium tuberculosis*.

## How do you get infected with TB

TB spreads 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 they 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.



TB is spread by breathing in bacteria from the air.

**People who are infected by TB bacteria don't necessarily get sick.** It is estimated that about 1/3 of the world population carries TB bacteria in their bodies, but only a few develop the disease. The reason why some of the infected persons get sick is that they have reduced immunity. The reduced immunity might be due to other diseases, stress, changing climate, poor nutrition, or other reasons. It sometimes takes years after infection with TB bacteria before the disease breaks out.

## How do you know you have TB?

Someone who has a cough for 2–3 weeks or more could have TB in the lungs. The most common signs of lung TB are:

- Pain in the chest
- Coughing up phlegm from deep inside the lungs, sometimes with blood



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

- Loss of appetite
- Weight loss
- 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  
Weight loss



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

These are also common signs of some other diseases. So, to be sure that it is TB you have, 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.

## Who can get TB?

People who have had close contact over some time with someone with infectious lung TB who has not yet started treatment can get the disease. The TB bacteria don't spread easily, so infections generally occur between persons who live together.

There are people with TB in every country. TB is most common in Asia, Africa, Latin America, and Eastern Europe; therefore, it is most likely that people from these areas get infected and ill.

About eight million people in the world get TB every year. In Norway, during the last few years, there have been about 300 cases of TB discovered every year.

If you want to read more about TB in the world, you can visit the web sites [www.lhl.no](http://www.lhl.no), [www.fhi.no](http://www.fhi.no) or [www.stoptb.org](http://www.stoptb.org).

## Will your TB make others sick?

It is only lung TB and a rare form of TB in the throat that can be transmitted to others. If you have a transmittable form of lung TB, or if it is suspected that you have it, you will be brought to an isolation ward at a hospital. You will have to stay in this ward until it is determined that your TB is not transmittable anymore. This often takes about two or three weeks, but sometimes it takes longer.

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

The health service in Norway is obliged to assure that all persons who have TB get treatment. In order to find all persons who may be infected, patients are asked to give the names of the persons they have had close contact with. These persons are contacted by health personnel and asked to test themselves for TB – without being told who they may have been infected by. This means that nobody will know that you are the one who has given his/her name.

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 three months). This is done to make sure that the children don't get sick later.

**When TB patients are discharged from the isolation ward, the disease is not infectious anymore:**

- It is safe to share cups, plates, knives, forks and spoons with TB patients
- It is safe to use clothes or bedding (bedclothes) that TB patients have used
- It is safe to have normal, social interaction with TB patients

## How do you treat TB?

TB is treated with medicines, in most cases tablets. In Norway, these medicines are free of charge. Most patients have to take medicines every day for six months, but sometimes the treatment is longer. A health worker will come and give you your medicine every day.



This man has TB. The disease has made him weak, and he has to stay at a hospital in the beginning of the treatment...



After a short period with medicines and care from the health personnel at the hospital, he is better...



...and can continue the treatment at home. The home nurse comes to his home and helps him take the medicine every day. His health continues to improve...



... and after having completed the treatment, he is cured!



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 can get sick again. The TB bacteria can also become resistant, and, as a result, the medicine may then work less well if you have to start taking it again after having stopped too early.

In chapter 2 you can read more about TB treatment.

### **The most important action to get cured is:**

- **Take your medicine every day as long as the doctor has told you to**
- **Continue taking the medicine, even when you feel much better.**  
**Some TB bacteria are still in your body, even when you don't feel them.**  
**The bacteria die slowly!**
- **Talk with your doctor, TB coordinator, or a home nurse if you have any problems**

## What is resistant TB?

Resistant TB is TB that is caused by TB bacteria which survive the ordinary TB medicines. Because the bacteria survive the ordinary TB medicines, they are called resistant bacteria, and TB that is caused by such bacteria is called resistant TB. Resistant TB spreads the same way as other TB. Patients get cured from resistant TB, but it takes longer to get cured from resistant TB than from ordinary TB.

Resistant TB is a world-wide problem. Resistant TB has developed because the various medicines taken by patients to treat their TB sometimes have been incorrectly combined or not strong enough to kill all the bacteria. This can have happened because patients have not taken all their medication doses; there have been long interruptions in treatment; or there has been too little control over the medicines or treatment. This is not a problem in Norway, where the control over medicines and treatment is good. Patients who have resistant TB have usually become ill in countries other than Norway.

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 two years. Unfortunately, the medicines that are used against resistant TB can have many unpleasant, strong side effects on the body.

# Questions from patients about TB

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## **Why does it take so long to find out if a person has TB?**

In some cases, TB can be diagnosed quickly, but often it takes several weeks from when a patient first visits the doctor until the TB diagnosis is ready. The most important reason for this delay is that the symptoms of TB are the same as for many other diseases, so the doctors must take several tests to find out if TB is the cause of the patient's illness. It may take a long time to get the results of these tests. And because TB is rare in Norway, the doctors often don't suspect TB right away.

## **I don't know anyone with TB – why did I get the disease?**

Many patients wonder about this. You may have been infected by someone who didn't know that he/she had TB, and it may have been a long time ago. It sometimes takes years after infection before the disease breaks out.

## **I have always lived a healthy life – why did I get TB?**

Anyone can get TB, even people who have lived a healthy life. As the TB bacteria are spread in the air, anyone can be exposed to the disease.

## **Why am I not cured after such a long time?**

Some patients feel unwell even after a period of treatment. The reason for this is that it takes a long time to kill all the TB bacteria in the body. TB bacteria die slowly.

## **Will my lungs stay weak forever?**

Most patients are cured without getting any permanent damage. However, some patients may have lasting lung weaknesses, and some get lung diseases like asthma or COPD (chronic obstructive pulmonary disease). This especially applies to patients who were ill for a longer period of time before they were diagnosed and started treatment.

## **I have TB in the lymph nodes, and sometimes a liquid comes out from the wound on my neck. Can others get infected if they touch this liquid?**

No, the liquid that is coming from the wound cannot make others sick. If you are told to clean the wound yourself, a home nurse or another health worker will give you instructions on how to do it. According to general hygienic rules for cleaning wounds, you should throw the bandages directly in the garbage can and wash your hands immediately afterwards.

**Is it possible to get TB if you sleep in the same bedding that a TB patient has slept in, or wear the same clothes that a TB patient has been wearing?**

No, TB doesn't spread this way. TB spreads by breathing in TB bacteria from the air (see page 6). It is safe to sleep in the same bedding (bedclothes) as a TB patient or to wear clothes that a TB patient has been wearing.

**Can TB be spread by drinking from the same cup?**

No, TB doesn't spread this way. TB spreads by breathing in TB bacteria from the air (see page 6). It is safe to drink from the same cup as a TB patient.

**Can I get TB even if I have been BCG-vaccinated?**

Yes, unfortunately the vaccine does not give 100 % protection. The BCG-vaccine can give adults some protection against TB, but it is only proven effective against serious forms of TB in children.

From 2009, the BCG-vaccine will only be given to children who are at particular risk of getting TB.

**What is extrapulmonary TB?**

TB in parts of the body other than the lungs is called extrapulmonary TB. It can occur in any part of the body, for instance: in the kidneys, the lymph nodes, or the brain. If you have TB outside the lungs or throat, you can not infect others.



# Chapter 2: TB and treatment

“When they told me I had TB, I was scared. I asked if it was treatable. They said that I would be cured, and I was relieved. But I realized that it would take a long time”.

*Woman, 20 years*

TB is a treatable and curable disease. But because the medicines kill the TB bacteria slowly, the treatment lasts a long time – at least six months. In most cases, the treatment starts at a hospital and continues with the patient staying at home.

As a patient, you have the right to get support and advice during the whole treatment period. Your doctor, TB coordinator, and other health personnel will assist you in different ways. Your treatment and your well-being is their responsibility too.

In this chapter we describe the treatment that is given to TB patients in Norway. We also present questions from patients regarding the treatment and the medication, and answers to these questions.

When TB is diagnosed early, the patient can start effective treatment before the body gets very weak. Therefore, it is important that all persons who do not feel well go and see a doctor so that the disease can be discovered and treatment can be started early.

## The different phases of the treatment

Usually, TB treatment is divided into the following three phases:

- 1. Treatment with medicines at hospital**  
(usually the first two weeks or more)
- 2. Treatment at home, observed by health personnel**  
(at least six months – until you are cured)
- 3. Medical check-ups**  
(sometimes up to two years after you have been cured)



## Treatment at hospital

Many patients have to stay in a hospital at the beginning of the treatment period. Patients who are suspected to have TB that can be transmitted to others have to stay in an isolation ward in the hospital.



Most patients stay in a hospital at the beginning of the treatment period.

More than one medicine is needed to kill the TB bacteria. At the hospital, the health personnel can observe if the medicines are working well and that you get better. They also take tests to see if the bacteria are resistant. This may take some time to find out. If the bacteria are resistant, you will need different medicines, and the treatment will be longer.

When you are well enough and the health personnel are certain that the medicines are effective against the bacteria, you can leave the hospital and continue the treatment at home.

## Treatment at home observed by health personnel

According to the Norwegian regulations for tuberculosis control, a health worker has to be present when TB patients take their daily medicine. This treatment method is called Directly Observed Treatment, or DOT. DOT is a method that has been proven to give good treatment results, and the World Health Organization therefore aims to introduce it all over the world.

The DOT system is used to assure that patients complete their treatment and that resistance to TB drugs does not develop. When you are sick with TB, you may not always feel like taking your medicine every day, especially if you have some reactions to the medicine. It may also be easy to forget to take the medicine. Therefore it is important that a health worker is there to help you get through the whole treatment period. The health worker will also observe how the medicine works, see if you have any side effects, and give you advice related to the treatment.



All patients shall have an individual treatment plan which states where and when they will meet the health workers to take the medicines. This plan is worked out by the patient and the health workers together (see page 20). Many patients want the health workers to come to their homes, but it is also possible to take the medicines at the hospital or in another public health centre.



A health worker delivers the medicine to the patient every day.

On page 20 you can read more about patients' rights with respect to DOT, and how you can make DOT fit into your daily life.

You have to continue to take the TB medicines every day for at least six months, until tests show that all the TB bacteria in your body have been killed. Even if you feel healthy again before this, some bacteria are still alive, so it is important that you continue to take all the medicines until the treatment is completed.

## Medical check-ups

Usually, the doctor will follow you up with regular medical check-ups after you have completed your treatment, sometimes for up to two years after you have been cured from TB. Your body has been under heavy strain; therefore it is important that the doctor follow you up for some time.



Most patients are followed up by their doctor after they have been cured.



# Questions from patients about TB treatment



## **Why do I need many different medicines?**

You need many different medicines because the medicines work together and support each other in killing the bacteria. The use of different medicines together helps make sure that the bacteria do not become resistant. If you take only one type of medicine, the bacteria may survive, but when you take several different medicines, the bacteria will not survive.

## **Can I share drugs with family members or other persons?**

No, you cannot share drugs with anyone! This can make both of you very ill. All patients have to take the medicines that their TB doctor has prescribed to them, and no other TB medicine. It is important that all patients are followed up by a doctor during their sickness period.

## **Do I have to take drugs in the morning? Why do I have to wait to eat after taking the tablets?**

Some of the medicines work best on an empty stomach, so you can either take them in the morning or two hours after you have eaten. After you take these medicines, you can eat something again after half an hour has passed.

## **Why do I have to take medicines for so long? Why can't I stop taking medicine when I feel better?**

When you start to feel better, some TB bacteria are still alive in your body. You can think of it as if the bacteria are sleeping. If you stop taking medicine, they can wake up and make you sick again. You have to take medical tests to prove that all the bacteria have been killed.

## **Can I use a traditional healer or take herbal medicine?**

Usually, this is no problem as long as you continue to take the medicine that your TB doctor has prescribed to you. But, to be on the safe side, you should ask your TB doctor if you plan to take herbal medicine – there might be some such remedies that should not be taken together with TB medicines.

### **TB medicine influence on other medicines**

TB medicines can make other medicines less effective. It is important to note that family planning pills don't protect against pregnancy when you are taking the TB medicine Rifampicine. Therefore you need to use other family planning methods, for example, condoms or the loop.



## How to cope with hospital isolation

If you have TB that can be transmitted to others, or if it is suspected that you have such TB, you have to stay at an isolation ward at a hospital. You have to stay there until the medicines have made your TB non-transmittable. This often takes about three weeks, but sometimes longer.

In the isolation ward, all persons who have contact with the patients have to wear masks. The masks cover the mouth and nose and protect those who wear them from being infected by bacteria in the air. (The bacteria may get into the air when the patient talks, coughs, or sneezes.)



People who work in the isolation ward have masks on.

All persons who have contact with the patients also have to wear a special cap and gloves as well as a coat or gown when they are in patients' rooms.

When tests prove that your TB can no longer be transmitted to others, you can leave the isolation ward. If you need more hospital care, you will be moved to another hospital ward. If you are well enough, you can go home.

We know that many patients find it difficult to stay in the isolation ward. One patient said:

The hardest part was when I was in the isolation ward. There, they had to dress up and wear masks. When you see somebody cover up, it is scary. But I knew that they had to.

*Woman, 25 years*

Many patients find it difficult that people around them have to wear masks. Some say they feel worthless and “bad” when others have to cover themselves to be close to them. But it is the 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 to others, others can be close to you without wearing masks.

It is hard when you don't see the whole faces of the people who are treating you. It may be difficult to recognize the different persons who are working in the isolation ward, and many patients feel that the communication becomes very impersonal and cold when people wear masks. You can ask the people treating you what their names are, and you can ask them 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.



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

During the stay in the isolation ward, you are also deprived of many things in your ordinary daily life. Many patients say they find it difficult that they cannot move freely and that they are dependent on others for almost all of their needs. The fact that they spend most of their time alone and that “nothing happens”, is also difficult for many patients, and it may make them lose sense of time. Most people would find this hard.

**Here, we present advice from patients on how to cope with these things:**

- Keep in touch with friends and relatives through telephone or computer. This will make you feel less alone. And, your friends and relatives can visit you in the isolation ward, as well! But they will have to wear masks, gowns or coats, and gloves when they are in your room. Unfortunately, children are not always allowed to enter the isolation ward.
- Bring some of your personal things to your room; this will make you feel more at home. Some things might have to be disinfected; so, to be on the safe side, ask the nurses what you can bring with you.
- Try to establish some daily routine. This will help you to avoid losing your sense of time.





Try to find things to do when you stay in the isolation ward.

- Keep yourself a little “busy” – to focus on things other than your disease, and to make time pass more easily. Examples of things to do include reading, writing, listening to the radio, watching television, playing games, doing needlework, or doing exercises.

I knew what I was supposed to do every day and at what times of the day I should do it. For example, I knew I had to take medicines every morning, and I felt it rather abnormal if I had these at a different time of the day. I made myself feel at home, put on a smiling face, and kept myself busy. Coupled with all the positive results that my doctor delivered, I hardly noticed the days go by.

*Woman, 30 years*

## Questions from patients about isolation



### **Why must I be isolated?**

You have to be isolated until it is proven that your TB is not infectious anymore. This is done in order to ensure that the disease will not be transmitted to others.

### **Why do health workers need to wear masks?**

The masks protect health workers from breathing in TB bacteria in the air.

## How can DOT fit into your life?

All TB patients shall have an individual **treatment plan** which points out where they will meet a health worker to take their medicines, and at what time. The agreement is made to make it as convenient as possible for the patient to get through the treatment period.

The treatment plan is worked out during a meeting between the patient and the health personnel who are treating the patient. This meeting is called “treatment plan meeting” (“behandlingsplanmøte”), and it is held at the beginning of the treatment period, usually before the patient leaves the hospital. The patient, the patient’s TB doctor (specialist), the patient’s TB coordinator, and people from the municipal health service participate in the meeting. The patient can also ask for a translator for the meeting, 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.



Treatment plan meeting.

The purpose of making a treatment plan is to find an arrangement that considers both the patient’s wishes and the health workers’ possibilities. If you want to have the medicines delivered to your home, you have the right to ask for this. If you prefer to take the medicines at the hospital, you have the right to do it this way also.



Many patients want to have the medicines delivered to their homes...



...but some prefer to take it at the hospital.



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 – even if it is very early. If you don't want the health workers to come to your home, and you don't live far from the hospital, it may be a good solution to take the medicines at the hospital.

It is also possible to change the arrangement in the course of 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 we also know that some find DOT difficult. Some patients 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.

## Questions from patients about DOT

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### **What is DOT?**

DOT stands for Directly Observed Treatment. It is a treatment method in which health workers are present and support TB patients when they take their medicines every day.

### **I am an adult – why should I be observed when I take my medicine?**

It is not you, personally, who must be observed, but it must be observed that the medicines are taken the right way and that you don't forget to take them. We know from experience that it is easy to forget to take the tablets, especially for patients who are starting to feel better. DOT is made to help patients get cured from TB.

### **The nurses don't always come on time. Can I ask them to be on time?**

Patients who have the medicines delivered to their homes sometimes experience that the nurses don't come on time. You can ask them to be on time or discuss the problem with your TB coordinator. As nurses usually have many patients to visit in the course of the day, however, it is understandable that they don't always manage to be on time.



# Dealing with side effects of the TB medicines

TB medicines can sometimes cause problems in your body – side effects. The reason why they may cause problems is that it is not possible to make medicines that are so “specialized” that they only affect the TB bacteria. In addition to fighting the TB bacteria, the medicines also have effects on other parts of the body, and this may sometimes cause problems. You could think of it as a war: Your body is fighting the disease with the help of the medicines, and there will be some “wounds” (side effects) because of the fighting. You will win, as long as you keep taking your medicines every day.

Patients react differently to the medicines. Many patients don’t have any side effects, but some experience problems. Generally, the side effects get milder or disappear when the body has got used to the medicines, usually after about four weeks.

Serious side effects from medicines for ordinary TB (non-resistant TB) are very rare, but may occur. Therefore it is important that you inform your doctor, TB coordinator, or home nurse if you experience any problems or side effects. It is also important that you come to the regular medical follow-ups.

**If the white part of your eyes becomes yellow, if you have serious stomach pain or skin rashes over big parts of body, or if you experience problems with your eyesight – see your TB doctor immediately.**



## Question from a patient

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### **When do the side effects decrease or disappear?**

This is a very difficult question, because patients react differently to the medicines. One patient may have side effects for a short time, another for a longer time. Some don’t have any problems at all. All bodies are different, and react in their own way to the medicines. But most patients feel better after 2–4 weeks.

**If you are unsure about symptoms you have, or they last for a long time, talk to your TB doctor or TB coordinator.**

## Common side effects

The side effects we describe in this section are common, unpleasant, and annoying, but not dangerous. We also present suggestions from patients and health workers on how to deal with them without spending much money. If this advice does not work, talk to your TB coordinator, TB doctor, or home nurse.

You may have additional methods that you or other TB patients have tried out. Please check these out with your TB doctor or home nurse to find out if they are safe – and let them know of good methods they can recommend to other patients.



Talk with a health worker you have contact with if you have side effects.

### The most common side effects of TB medicines are:

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

## Nausea and vomiting

The TB medicines may cause nausea and vomiting. It may help to take the medicines together with some natural yoghurt. It may also help to eat something small, like a biscuit or a piece of fruit, when you have nausea. 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 bothered with severe nausea, it is also possible to get medicine to relieve it.



Nausea and vomiting.

### To relieve nausea, patients suggest:

- Put some ginger in your mouth and suck on it, or add ginger to your tea or food
- Drink black tea before swallowing your medicines
- Drink fresh fruit juice in small amounts from time to time
- Suck on a bit of lime
- Put some sugar in your mouth

## Questions from patients



### **One weekend, when I took my medicines at home, I started vomiting and the medicines came out. If I vomit out the medicines, I need to take some more, but where can I get them?**

Let your home nurse know that you have vomited. If you vomited immediately after taking your tablets, you may get new ones. If you are bothered with nausea and vomiting, the doctor can give you medicine to relieve this.

### **A short time after I take my medicine, I get dizzy. Why? Is there anything that can help?**

You might be getting dizzy because you have taken the medicine on an empty stomach. Try to eat something half an hour after you have taken the medicines, and rest until you feel better. If you need to eat before taking the medicine, it should be two hours before.



## Red urine

All body fluids may become red, pink, or orange when you take TB medicines. This is not dangerous. The reason is that the TB medicines contain red colouring.



The urine becomes red when you take TB medicines.

## Hard or loose stools

In addition to killing TB bacteria, the TB medicines also affect normal intestinal bacteria. Because of this, some patients get digestion problems. Some may get hard stools; others may get loose stools.



Some patients experience digestion problems when taking TB medicines.

### Advice from patients and health workers on how to relieve hard stools:

- Eat fruit and vegetables
- Eat dried fruit, particularly prunes and raisins
- Eat soaked flax seeds
- Drink a lot of water
- Take remedies against constipation, for instance Lactulose, that you can buy at the pharmacy
- Do light physical activity, if you are up to it

### Advice on how to prevent loose stools:

- Avoid drinking milk
- Avoid drinks which contain much sugar
- Take products which contain “probiotic lactic acid bacteria”, for instance Biola
- Take tablets with lactic acid bacteria, for instance Idoform Classic
- Eat blueberries or drink blueberry juice



## 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, your doctor, or your home nurse. The doctor can, in some cases, prescribe anti-allergy medicine (anti-histamine tablets) to relieve itching.



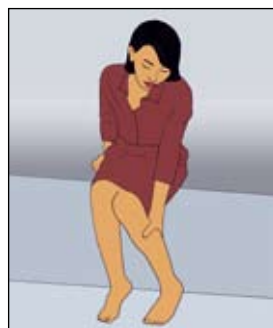
Itching and rash.

### Advice from patients and health workers 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

## Joint pain and other pain and swelling

Some patients experience joint pain or other body pain as a side effect of TB medicines. If this is a problem for you, you should discuss it with your TB doctor. You may try massage or acupuncture, or, if nothing else helps, take pain killers without Paracetamol. (Paracetamol is too hard on your liver when you are on TB medicines.)



Pain in joints and body.

Swollen feet may also occur. It can help to put your feet up high when you sit or lie down – use a pillow. You may also try to wrap a cold towel around your legs. Doing light physical exercise can also help.

**The most important thing is that you continue to take your medicines, even when they make you feel bad. Inform your TB coordinator or doctor about any problems or side effects that you experience.**



# Chapter 3: Keeping body and soul well when you have TB

“For me, getting TB was the beginning of, not just one, but many wars: In addition to fighting to get better from TB, I had to fight to get familiar with Norwegian food, language, social life, and climate. All this impacted greatly on me, until I found out how I could get something positive out of the situation.”

*Man, 28 years*

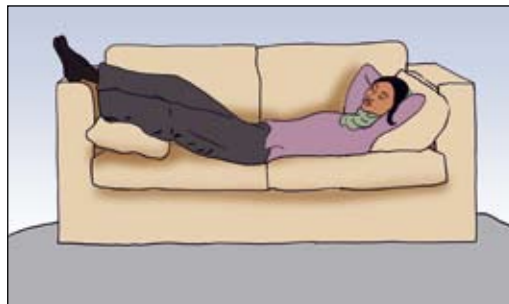
Having TB can be stressful for body and soul. Rest, food, drink, and support from people around you will help you to get better. But during sickness these things can be more difficult than before, and patients have many questions concerning them.

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.

## Work and rest

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.

TB patients should be given time to rest as much as they feel their bodies need. This is especially important during the first two months of the treatment.



Patients can take care of themselves by getting enough rest.

## When can you get back to your usual daily activities?

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 carrying children is also work!



This work might feel ok...



...but this might be too hard.

If you have a job, you can have sick leave (“sykmelding”) as long as you are too sick to work. If you feel strong enough to work a little, but not full-time, you can have partial sick leave (“gradert sykmelding”) or active sick leave (“aktiv sykmelding”). Talk to your TB coordinator or doctor about this.

**Partial sick leave (“gradert sykmelding”):** If you are able to manage to do the work you had before you were sick, but not full-time, you can have partial sick leave. This means that you continue with the work you had before, but that you work less (for instance 50 %). If you work 50 %, you get 50 % of your normal salary and 50 % sick pay (100 % salary in all).

**Active sick leave (“aktiv sykmelding”):** If you are unable to manage the work you had before, but you want and are able to do other work, it is possible to have “work training” while doing other tasks at your usual place of work. Such work training is called active sick leave, and gives you the right to sick pay.

Some patients who are on sick leave or who don't work find it boring to stay home all day. 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 (see also page 39). Do as much as you feel is ok for you, and do things that you like.



# Questions from patients about work and rest



## 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 go back to school when I come home from hospital?

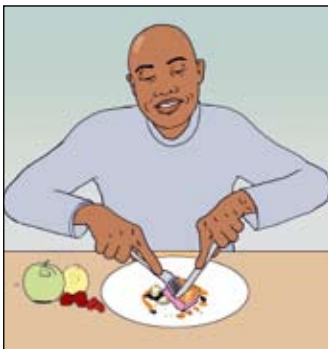
If you feel well enough, you can go back to school. Try it out and see if it feels ok for you. If it does, you can go to school and do schoolwork as before. It will usually be a good idea to talk to your teacher about your situation, especially if you often have to be away from school because of your disease. You may find this booklet useful for informing your teacher about your disease.

## Can I do sports?

Yes, when you feel strong enough. 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.

## Food and drink

Food and drink will help your body fight the TB. But when you are ill, it can be difficult to eat and drink. Sometimes the TB medicines also make patients lose their appetite.



It is important to eat and drink, even when it is difficult!



## Advice on what to eat and drink

Some immigrant patients say that they know what is healthy food in their home countries, but that they are unsure about what is healthy food in Norway. Here is some general advice on what to eat and drink:

**Eating:** Some good foods for TB patients 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 salmon or mackerel), 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.

It is important that you eat well, so that your body gets energy to fight the disease. A weak body has little strength to fight TB.

**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 TB patients need supplements of vitamin D and vitamin B. Talk to your doctor or other health worker 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.

**When you stay at the hospital, you have the right to choose your own menu.**

**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 TB, your body needs all its strength to fight the disease. Both TB medicines and alcohol are digested in the liver, so if you drink alcohol while you are being treated for TB, your liver has to work very hard. Therefore, it is best to avoid drinking alcohol during this period. If you want to drink alcohol, you should discuss it with your doctor.



## Eating alone, or with others?

Sharing a meal with others is usually a good time for being social. Some patients who have poor appetite also say they find it easier to eat when they are together with others. It is safe to eat together with TB-patients – also to share plates, forks and knives with them. TB cannot be transmitted by eating together or sharing utensils (see page 6 on how TB is transmitted).



It is safe to eat together with TB patients.

## Questions from patients about food



### **I have been told to eat food, but I have no appetite. How can I increase my appetite?**

Eating frequent small portions of food that you like can help you 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.

### **Where can I get more advice on what kind of food to eat when I am under TB treatment?**

You can ask your TB coordinator, your doctor, a dietician, or a fellow TB patient for advice.

# 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. 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.



It is best to avoid smoking when you have 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 (for example the Norwegian Quit Line for Smokers: 800 400 85).

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 try to really feel what happens to your body when you smoke, and ask yourself: "I have TB. Do I want to give my lungs time to heal and not give them a harder time by smoking?" One thing is sure: If you stop smoking, your lungs will heal better and faster.

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.



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

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. 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.

If you have completed the TB treatment when the child is born, you can have the child with you after delivery. But if you still have infectious TB, you can not be together with the child. Young children have little resistance to illness, and may therefore be infected by your TB. As soon as it is proven that your TB is not infectious anymore, you can be together with your child.

## Some questions from TB patients about sex and pregnancy



### **Is it true that TB comes from sexual intercourse?**

No, TB is not transmitted through sexual intercourse. TB is transmitted by breathing in TB bacteria from the air (see page 6).

### **I am a TB patient, and my partner is not sick. We enjoy kissing. Can kissing also spread TB, or can we continue?**

Once you have taken effective medicines for 2–3 weeks you cannot infect anybody (see page 8). So it is safe to kiss your partner.

### **I am in treatment for TB, and I am feeling better. My partner wants to have sex, but I have no strength and no desire to have sex. What can I do?**

You should not force yourself to have sex if you don't feel like it. It is important to discuss with your partner how you feel. Since you are feeling better, the desire to have sex will probably come back after a while.

### **When I have sex, I breathe a lot. Does this mean that I stress my lungs?**

Having sex is a kind of physical activity. As with any other kinds of physical activity, it is important that you consider how you feel. But if you don't feel unwell, your lungs will certainly support your having sex.

### **Is there anything in the TB medicine that makes you stop wanting to have sex? Or is it always like that when one is sick?**

The TB medicines are made to kill the TB bacteria, not to kill the desire for sex. But when you feel sick and weak, you may not feel like having sex. The wish to have sex usually comes back when the patient is feeling better. For some, this happens early in the treatment; for others it happens later.





Some patients lose the desire to have sex while they are being treated for TB.

### **I am pregnant and I am also being treated for TB. Will my baby also have TB?**

No, you cannot transmit TB to your child during pregnancy. It is best to avoid getting pregnant while you take TB medicines, but if you already are pregnant, see the advice on page 33.

### **I am a man who has been undergoing TB treatment for two months. Can my wife get pregnant?**

Yes, TB medicines don't affect men's fertility. So, men who are being treated for TB can get women pregnant. But it is best to wait until you are cured to plan a pregnancy. Having children is demanding, so it is best if you are both healthy and in good shape.

## **Social life when you have TB**

Having TB can affect the social life of the patient. Some feel well enough to continue their social life as before – this is good! But for others, it is more difficult. Patients who feel sick and tired over a long period of time can experience that it is difficult to maintain their social life. It can be difficult for them to stay active and keep contact with people they know. Many patients also find it difficult to talk about their disease, and this can make their situation difficult.

This section about TB and social life is mainly intended for patients who experience that the disease has made their social life difficult. First, we describe some common problems that patients have told us about. Thereafter, we present advice and suggest possible solutions to these problems.

## Being afraid

Many TB patients are afraid and hide their disease from others. They usually hide it because they fear that people who learn that they have TB will stay away from them, refuse to eat with them, and the like. Even if the patients actually want to tell friends and others that they have TB, this fear prevents them from being open about their disease.



Some patients are afraid to talk to others about their disease.

People who have contact with TB patients are also often afraid. Usually, the reason why they are afraid is that they don't have enough knowledge about the disease. People who don't have enough knowledge have their own ideas or make their own explanations. For instance, many people are afraid of getting infected by TB because they don't know that TB patients who take their medicines every day cannot transmit their disease to others.

Some people show anger towards TB patients and refuse to talk to them. And some TB patients are isolated by friends and relatives or left by their partners. They may be judged as "sinners", seen as "cursed", or as victims of some kind of misfortune. To experience this feels terrible to someone who is sick and is fighting a serious disease. It feels unfair.

It is helpful to know that when people are angry with TB patients, or they blame or avoid them, they are mostly really just afraid. To admit or show that they are afraid is very difficult for most people. Therefore, they may "cover up" their fear and show anger instead.

When people have knowledge about TB and know that patients cannot infect others when they are taking effective TB medicines, they will be able to give persons with TB better care and support.



## Feeling lonely and depressed

Many TB patients say they feel lonely and have periods when they feel depressed. One patient said: “When I realized the seriousness of the disease, I got depressed. I stopped talking to people, even by telephone. I sat by myself”.



Some patients have periods when they feel lonely and depressed.

It is understandable that patients can feel lonely. Some experience that the disease makes it difficult to be socially active, and they don't dare to talk to others about their situation. Some patients feel depressed because they don't have the energy to do things that they used to do and like, and they find it difficult to be optimistic and make plans for the future.

The majority of TB patients 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 feel alone in Norway, especially in the beginning of their stay here.



For many patients, the feeling of loneliness and depression passes or decreases when they start to feel better and/or when they have stayed in Norway for some time and have got used to living here. For others, it takes longer. In the next section, we present advice from patients and health workers on how to better deal with life during the period of illness.

## **What can you do to keep up or improve your social life and emotional well-being while you are 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 and health workers have told us, it seems like sharing experiences with others, as well as staying a little active, are things that have a positive effect on most patients.

### **Sharing your experience / talking about your TB**

Many patients don't talk to others about their disease. They often fear that others will be angry, afraid, or judge them negatively if they learn that they have TB. It is natural to try to protect oneself from such negative reactions. Still, our experience is that patients who manage to be open about their disease benefit a lot from this openness. One patient said:

Talking about my TB is comforting. It helps me. I am not the only one who has TB, and I won't be the last. Why should I hide it then? The reason why many people do hide is that they don't have enough knowledge. When I tell people about what I am going through, I get relief. I cannot see any reason for being negative about TB. I did not get it because of any kind of fault that I committed; it is only unfortunate that I have it.

*Man, 28 years*

Openness gives you the opportunity to get support from other people. If nobody knows you are sick, nobody will know that you need support. And openness can reduce fear: When people are well informed about TB, they will feel safe and no longer be afraid of your TB. In this way, openness can counteract fear and loneliness.



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

If you find it difficult to be open about your TB but have decided to talk about it anyway, it may be wise to plan when to do it. If you feel weak and tired, it may be better to wait. Doing things that one dreads takes much energy; therefore, it may be better to wait until you feel a little stronger. When you feel up to it, start with somebody you trust or feel close to. For many patients it is sufficient to tell people they are close to, like close friends and relatives, about their disease.

You can also talk to a health worker that you trust for support and advice. It is also possible to get support from voluntary organisations, if you, for example, want to talk anonymously with somebody. Through LHL you can get in contact with other patients or former patients who have similar experiences to yours. This is called peer work. Many patients find it very supportive to talk to someone who has had a similar experience.

It is also possible to contact organisations to get a contact person. Some organisations you may find helpful include the following: the Red Cross, the Norwegian Refugee Council (Flyktningehjelpen), the Volunteer Centre (“Frivillighetssentralen”, a volunteer organisation with many different activities), or the communal administration. (See the section called “Practical information” at the end of this booklet.) You can also ask your TB coordinator what other support services are available where you live.

If you feel that you need professional help to handle loneliness and depression, you can talk to your TB coordinator or your doctor.

## 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!

During periods of illness, time can feel like it is moving very slowly and progress can seem like it is taking way too long. Some general advice on how to handle this is to take small steps and put forward small goals that you can achieve (instead of big goals that will be difficult to achieve because of your condition). Mastering tasks – even small tasks – will often make you feel better and more optimistic. One patient, who had problems with his legs and had been using a wheelchair, said this:

To cope with this kind of situation, you have to focus on one thing at a time. First, I had to get out of the wheelchair. The next thing was to get rid of the crutch. You have to have a goal to pursue. As long as you are a human being, you don't stop setting yourself goals. Finally, I want to run like Haile Gebreselassie.

*Man, 25 years*

It may be a good idea to “keep an account” of your activities and small goals that you have achieved. Write things down! This can be encouraging as it will emphasize your progress and help you to focus on something positive.

Some patients feel that they have too little money and that their financial situation puts many limits on their life. Many social activities, like going to the cinema or a cafe, are expensive in Norway. If you don't have much money, you may try to look for social activities in your community that are free of charge. Such activities exist in most communities.

Through peer work, LHL arranges activities and social meetings for patients. This is usually not expensive. You can also contact the communal administration where you live, or organisations like Red Cross or Frivillighetssentralen, and ask what support services they have. See also chapter 4 in this booklet for information on financial rights.



It is good to be social and to keep oneself active.

**And remember:** Your condition will not last forever – you will get better!



# Chapter 4: TB and your financial situation

“It is not enough to get medical treatment for my disease. I need to live well, to have something to eat. When you are sick, it means a lot to have security for these things”.

*Woman, 40 years*

To be financially secure is important, especially when you are sick. It is important that patients don't have to devote all their energy to financial issues, so that they can focus on getting well. In Norway, TB medicines, medical check-ups, and tests that TB patients have to take are free of charge. All persons who are treated for TB in Norway also have the right to get financial support for their basic needs.

In this chapter, we describe rules concerning financial rights which are relevant for TB patients in Norway. You can also ask your TB coordinator to help you get information about your financial rights.

If you are not staying legally in Norway, you still have the right to TB treatment and TB medicines without charge. And remember that health personnel are bound to professional secrecy. This means that they are not allowed to give information about you to anybody (not even to the police or the immigration service). So even if you are not staying legally in Norway, you can feel safe about calling on the Health Service in Norway.

## Rules for coverage of expenses when you have TB

TB treatment in Norway is free of charge. All TB medicines, medical check-ups, and tests are free of charge for patients. Travel that is necessary for treatment is also free, but you usually have to pay for the travel yourself first and get the money back afterwards. It is only if you need bandages for wounds (for instance if you have TB in the lymph glands) or medicines to help with side effects, that you may have to pay a part of the expenses yourself.

## Expenses for medicines

TB medicines are free of charge. Medicines for side effects of TB medicine are not free, but in some cases, you can get back a part of your expenses for such medicines. In Norway, medicines are prescribed on two different kinds of prescriptions – white prescriptions and blue prescriptions. When medicines are prescribed on white prescriptions, patients generally have to pay for the medicines themselves. For medicines prescribed on blue prescriptions, patients only pay a part of the cost of the medicines.

Medicines for side effects are usually prescribed on white prescriptions. This means that you have to pay full price when you buy them at the pharmacy. But if you have large expenses for such medicines, you may have the right to get back a part of what you have paid. For some types of medicines on white prescriptions, patients have the right to get back 90 % of what they have paid if their expenses have surpassed a certain amount within a year. (In 2009 the limit is 1600 kroner per year.) Unfortunately, this arrangement does not apply to anti-allergy or pain-relieving drugs which some TB patients use (if they have itching or pain as side effects of the TB medicine).

In order to get back money for medicines prescribed on white prescriptions, you have to fill in an application form available from the Health Economy Administration (“Helseøkonomi-forvaltningen”) – HELFO – and send it to your local HELFO office. Together with the application form, you have to enclose a receipt from the pharmacy which includes all of the following: your name, the name of the medicine, the price of the medicine, the date when you bought it, the name of the doctor who prescribed it, and a stamp from the pharmacy. The application form can be sent to you by HELFO, or you can download it from [www.nav.no](http://www.nav.no) (later [www.helfo.no](http://www.helfo.no)).

If the medicines you use against side effects are prescribed on blue prescription, you only pay 36 % of the cost of the medicines when you buy them at the pharmacy, and you never pay more than a certain amount each time (in 2009, 520 kroner for a three-month supply of medicines). The amount that patients have to pay on their own is called patients’ charges (“egenandel”). If the total amount you spend on patients’ charges is more than a certain amount within a year, you will have the excess refunded, and you won’t have to pay any more patients’ charges that year. The yearly amount limit for patients’ charges change from year to year (in 2009, it is 1780 kroner). All patients’ charges must be noted on a patient’s charge card (“Kvitteringskort for egenandeler”) that you can get at your doctor or pharmacy.



If you have had large expenses on medicines against side effects, you may get money back. Keep your receipts.

In order to get money back and/or be exempted from paying further patients' charges, you have to apply to The Norwegian Labour and Welfare Administration – NAV. When you have reached the limit, send your patients' charge card to your local NAV office. You will then get the excess refunded, and you will receive an exemption card ("frikort"), which indicates that you don't have to pay any more patients' charges that year. Bring your exemption card with you to the pharmacy so that the pharmacy will not charge you any more patients' charges for your blue prescription medicines for the rest of the year. When you have got an exemption card, you will also be able to see your doctors without charge – even if the consultations concern conditions other than your TB. Remember to bring your exemption card to your medical appointments.

For blue prescription medicines for children under 12 years and recipients of minimum old-age pension, there are no patients' charges.

## Travel expenses

Some patients have to travel a lot during their treatment. All travel that is necessary for TB treatment is free of charge, but patients usually have to pay for the travel themselves first and get the money back afterwards. The main rule is that you have to travel in the least expensive way: by bus, train, or boat.



If you are well enough, take public transport to the treatment place.

In order to have your travel expenses refunded, you have to apply to the NAV office in your community. You have to enclose an appointment confirmation (appointment card, calling in, or the like) and a paper which confirms that you have showed up for your appointment (you can get this from your TB coordinator or hospital nurse). You must also enclose payment receipts for all of the travel tickets you purchased to get to and from your medical appointment.

If you are too sick to travel by public transport, it is possible to get repayment for travel by other means, for example taxi. In this case, your doctor, TB coordinator, or NAV office can give you a requisition which is valid as travel payment. When you have received the requisition, you will usually have to order your travel through a travel office ("kjørekontor") in your region, but in some regions, patients can order their

travel independently of the travel office. You can search on the web sites [www.pasienttransport.no](http://www.pasienttransport.no) or [www.nav.no](http://www.nav.no) to get information about the rules in your region, or you can ask your TB coordinator for help to order your trip.



Patients who are too sick to travel by public transport can take a taxi.

## Financial allowances

Here, we present financial allowances that can be relevant for persons who have or have had TB:

### Sickness benefit

If you have a job and have sick leave because of your TB, you can get sick pay. Persons who have worked in Norway for at least four weeks have the right to sick pay. It is possible to get sick pay for up to 52 weeks. On page 28 we have described the rules for sick pay in more detail.

### Rehabilitation allowance

If you have been ill or unable to work for a year, you may have the right to rehabilitation allowance. Rehabilitation allowance is an allowance for maintenance (see page 45) during treatment. You can apply for this if you have had sick pay and still are unable to work when the period of sick pay is over (after a year), or if you have been at least 50 % disabled from working for a year. The purpose of rehabilitation allowance is to support people so that they can get (back) into work. It is possible to receive rehabilitation allowance for up to one year. You have to apply to your local NAV office to get rehabilitation allowance.



## Vocational rehabilitation allowance

If your working ability has been permanently reduced because of the disease, or your possibility to choose an occupation has been reduced (if you, for instance, have been forced to interrupt an education program because of your disease), you can apply for vocational rehabilitation allowance. The purpose of vocational rehabilitation allowance is to help people get work or keep the work they have. You have to apply to your local NAV office to get vocational rehabilitation allowance.

## Maintenance payments

If none of the arrangements we have described here are relevant to you, and you don't have work or are unable to work, you nevertheless have the right to get financial support. All persons staying legally in Norway have the right to get financial support for their basic needs (namely: food, clothing, heating, and some social activities), if they for some reason are unable to earn money to pay for these things themselves. This kind of support is known as maintenance payments. There are no fixed rules concerning the amount of maintenance payments. Contact the communal administration where you live to get more information.

In order to get maintenance payments, you have to apply to your local NAV office.

## Questions from patients about financial issues



### I have been diagnosed with TB – will it be expensive?

No. TB medicines are free of charge. You also have the right to get a large part of other expenses related to the disease covered (see what we have written in this chapter about medical and travel expenses and the exemption card).

### Why are expenses for medicines against side effects not free of charge the way the TB medicines are?

Medicines against diseases that can cause serious health problems in the population are free of charge. Because it is important that all people get treatment for serious diseases, and in order to avoid the spreading of diseases, the medicines are free. Unfortunately, only the medicines that are needed to cure people are free, and not medicines against side effects. But even if medicines against side effects are not free, you may have the right to get back a large part of your expenses for such medicines – see the last part of the section about expenses for medicines in this chapter.

**I am a TB patient and have two small children. I often find it hard to take care of the children when I am sick. Can I get help with this?**

It is possible to apply for home care services or practical help if you are in great need of help at home during your illness. This type of help is called User-Directed Personal Assistance (“Brukerstyrt personlig assistanse” – BPA). Not many people are granted such help, but if you are very sick and don’t live together with somebody who can help you, it is worth applying. You can talk to your general practitioner or your TB coordinator about this and ask for help applying.

**I have large expenses during my sickness. Among other things, I have to pay for blood tests and medicines for uncomfortable side effects. I only get about 4000 kroner per month for maintenance – how can this be enough?**

As a TB patient you shall not pay for blood tests or other tests that are necessary for the treatment. But sometimes the personnel who work in medical offices are unaware of this, or they may forget it. You can get money back from HELFO if you have a receipt that shows how much you have paid. If you don’t have a receipt, you can go back to the place where you took the tests and ask them to give you one.

You can also get parts of the expenses for medicines against side effects refunded (see the section about expenses for medicines). According to the rules for maintenance payments, all persons staying legally in Norway have the right to get support to assure a “decent life”, which means that they have the right to get support to cover their basic needs. Maybe you can have somebody (for instance somebody who works at NAV) go through your expenses and income and see if you have the right to get more support than you currently receive.

See also page 47 for information about places you can contact to get help.



It is possible to get help from a social worker with questions concerning your finances.



## **Where can I get help and information about my financial rights?**

If you are hospitalized, you can usually talk to a social worker or almoner who can help you with financial questions. You can also visit the web sites [www.nav.no](http://www.nav.no) or [www.helfo.no](http://www.helfo.no) to get information about patients' rights.

If you need help to find out more about your financial rights, or to get help applying for a benefit you think you are entitled to, you can contact the patient ombudsman in your county ([www.shdir.no/pasientombudet](http://www.shdir.no/pasientombudet)), the patient ombudsman at LHL ([al@lhl.no](mailto:al@lhl.no)), or the Centre for Rights at the Norwegian Federation of Organisations of Disabled People (Funksjonshemmedes fellesorganisasjon, FFO). The Centre for Rights at the FFO ([rettighetscenteret@ffo.no](mailto:rettighetscenteret@ffo.no)) works with questions concerning the rights of disabled and chronically ill people. See also the section "Practical information" at the end of this booklet.

# Practical information

Here, we have gathered some internet addresses and phone numbers that may be useful for TB patients in Norway:

## Rights/practical help

### **NAV: The Norwegian Labour and Welfare Organisation**

You can contact NAV to get information about health services and social security services and patients' rights in these areas.

Internet: [www.nav.no](http://www.nav.no)  
Telephone: 810 33 810 (automatic information and service line)

### **The patient ombudsman**

The patient ombudsmen endeavour to promote patients' needs, interests, and rights. If you have experiences that you want to discuss with somebody, you can contact the patient ombudsman in your county of residence. The patient ombudsman can give you information about the rights of patients and relatives and can help you if you have questions or want to complain to the Health Service.

Internet: [www.shdir.no/pasientombudet](http://www.shdir.no/pasientombudet) (Here, you will also find addresses and phone numbers for all the patient ombudsmen in Norway.)

### **The Centre for Rights at the Norwegian Federation of Organisations of Disabled People (FFO)**

The Centre for Rights works with rights of disabled and chronically ill people. Employers at the Centre answer questions from patients and patients' relatives and can provide legal assistance.

E-mail: [rettighetssenteret@ffo.no](mailto:rettighetssenteret@ffo.no)  
Telephone: 22 79 90 60

### **The Patient Ombudsman at LHL**

Here, TB patients can get help and get answers to questions about their rights.

E-mail: [al@LHL.NO](mailto:al@LHL.NO)  
Telephone: 22 79 93 00 (LHL switchboard – ask for the patient ombudsman)

## Health information

### **The Norwegian Institute of Public Health (FHI)**

Here, you can find useful information about TB and the treatment system in Norway:

Internet: [www.fhi.no](http://www.fhi.no)

### **The Norwegian Quit Line for Smokers: 800 400 85**

The Quit Line for Smokers provides information and advice if you want to stop smoking. When you stop smoking, having someone to talk to can be a big help!

Opening hours: Monday - Friday: 9 am - 6 pm  
(Between 23 June - 8 August, Monday - Friday: 9 am - 4 pm)

## Information about social services

### **The Volunteer Centres – Frivillighetssentralene**

The Volunteer Centres (Frivillighetssentralene) are meeting places for people who live in the same neighbourhood. The centres organize social activities and facilitate contact between people. There are volunteer centres all over Norway. To find the centre closest to where you live, go to the web site [www.regjeringen.no](http://www.regjeringen.no) and search for “frivillighetssentraler”.

### **Red Cross Visitor Service**

The Red Cross Visitor Service arranges visits to people who require support and encouragement in their everyday lives. Red Cross visitors can visit you in your home (or in the institution where you live), or you can meet in a cafe or the like. The Red Cross also arranges excursions, Christmas celebrations, and other social activities.

Contact the Red Cross, or ask a friend, relative, or a home nurse to do it for you.

Internet: [www.redcross.no/visitor](http://www.redcross.no/visitor)  
Telephone: 05003

There are also other volunteer organisations that arrange social activities and support services for people who need it. You can contact the communal administration where you live to get information about the services available near you.

## For immigrants and asylum seekers

### **Norwegian Directorate of Immigration (UDI)**

The Directorate of Immigration is responsible for immigration and refugee policies in Norway. On their web site, you can find information about rules for staying and working in Norway, and you will find various application forms: [www.udi.no](http://www.udi.no)

UDI has an information portal for immigrants. The address is [www.nyinorge.no](http://www.nyinorge.no).

### **The Norwegian Organization for Asylum Seekers (NOAS)**

NOAS aims to advance the interests of asylum seekers in Norway. It can provide legal aid or general welfare to persons who seek or have been granted asylum status or protection in Norway.

Internet: [www.noas.org](http://www.noas.org)

Telephone: 22 36 56 60

Do you want to read more about TB and get more advice and stories from patients? Then you can visit the web site [www.tbsurvivalproject.org](http://www.tbsurvivalproject.org), a web site made by and for persons with TB.

Or do you want to become a member of LHL?

Go to the web site [www.lhl.no](http://www.lhl.no).



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In 1943, the Helping Organisation for People with Tuberculosis was founded in Norway by five tuberculosis patients. The patients fought for the right to better treatment and better living circumstances and the right to insurance and work. This organisation was the forerunner of LHL. LHL is now a countrywide interest organisation for people affected by heart and lung diseases. Tuberculosis can be combated, not only with medicines and health services, but also by socio-political measures to better people's living circumstances. Tuberculosis is a serious health problem in many countries, and LHL is still working to improve rights of TB patients both nationally and internationally. LHL's work is motivated by solidarity with vulnerable groups and respect for human rights.



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