WHAT IS TUBERCULOSIS?

Patient information

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KNCV TUBERCULOSIS FOUNDATION

To eliminate TB

INTRODUCTION

Your physician has told you that you need to start treatment for tuberculosis (TBC). This brochure provides answers to frequently asked questions relating to tuberculosis and its treatment.

You do not need to read this brochure from beginning to end. You can refer to the relevant section whenever you need specific information. Use the contents page for guidance.

Tuberculosis - facts

- Tuberculosis occurs throughout the world.
- Worldwide one and a half million people die each year as a result of the effects of tuberculosis.
- Tuberculosis is a serious disease but can be cured successfully with appropriate medication.
- Tuberculosis is caused by a bacterium.
- Anyone can catch tuberculosis.
- Pulmonary tuberculosis is the most common form of tuberculosis.
- Tuberculosis can also affect other organs.
- Tuberculosis can be contagious or non contagious.
- It is important to complete the full course of medication.

1 TUBERCULOSIS – GENERAL

1.1 What is tuberculosis?

Tuberculosis (TBC) is an infectious disease. Infectious diseases are caused by bacteria entering the body. TBC is caused by the tuberculosis bacterium. You probably don't know how you got infected with TBC. It may have happened a long time ago or very recently. The bacteria are now active in your system. You are suffering from tuberculosis.
Anyone, irrespective of age, race or gender, can catch tuberculosis.

The disease can manifest itself anywhere in the body. Pulmonary tuberculosis is the most common form of tuberculosis.

Infection:
The tuberculosis germ has entered your body.
Infectious:
Tuberculosis bacteria are spread through coughing.

1.2 Is tuberculosis always contagious?

No, extra-pulmonary tuberculosis is not contagious. Pulmonary tuberculosis can be contagious.

1.3 How do you become infected?

Tuberculosis is almost always spread through the air. When a patient suffering from contagious pulmonary tuberculosis coughs, tubercle bacilli may be projected into the air.
If someone else inhales these bacteria, he/she may become infected. These bacteria may travel to the lungs or to other parts of the body. Usually the body will ensure that these bacteria cannot cause any damage. The body encapsulates the bacteria to prevent them from activating. In that case the bacteria remain dormant (i.e. passive) and the individual in question is a 'carrier' of the disease. Carriers are neither sick nor contagious. However, a carrier may become ill later in life when the bacteria decide to 'activate'. This will trigger tuberculosis (again). It can take many years before you become ill and most people never develop the illness after they have been infected.

- *The contagious form is sometimes referred to as 'open tuberculosis'.*
- *The non contagious form is sometimes referred to as 'closed tuberculosis'.*

Tuberculosis is not caught:
- *by using other people's plates, cutlery, clothes, books, sheets, etc.*
- *by shaking hands*
- *through sexual contact*
- *as a result of blood contact*

Tuberculosis is caught: from someone with contagious tuberculosis coughing, sneezing or spitting

1.4 How can tuberculosis be prevented?

People suffering from contagious pulmonary tuberculosis must be traced and treated as soon as possible. Correct cough hygiene is of the utmost importance, i.e. cover your mouth when coughing/sneezing, use a tissue and avert your head.

1.5 What are the symptoms of tuberculosis?

The most common complaints include:

- fatigue
- loss of appetite
- weight loss
- fever
- night sweats

A person with pulmonary tuberculosis often suffers prolonged coughing bouts accompanied by (sometimes bloody) phlegm.

1.6 How is tuberculosis diagnosed?

evaluation of tuberculin skin test

Tuberculosis can be diagnosed as follows:

- Via a skin test, a so called tuberculin skin test (Mantoux test). This test will reveal an infection with tubercle bacteria. The results are evaluated 2 to 3 days after the test. Further investigation will be required in the event of a reaction.
- By producing an X-ray of the lungs, which will highlight any abnormalities. If this is the case the patient may have tuberculosis.
- Through microscopic analysis of, for example, phlegm, urine or tissue. This method will often detect the presence of tubercle bacteria very quickly.
- By producing phlegm, urine or tissue cultures. TBC bacteria multiply slowly.
  That is why the results of this analysis may take some time, up to a maximum of three months.

2 PULMONARY

2.1 What is pulmonary tuberculosis?

With pulmonary tuberculosis the lungs are infected as a result of a tubercle bacterium having lodged in the lungs after inhalation. This has caused an infection. Sometimes cavities are created in the lung tissue. There are two types of pulmonary tuberculosis: you may have the contagious or non contagious form.

If the site of infection is large many bacteria have multiplied. These bacteria can easily be coughed up, in which case you are infectious to your environment. If the site of infection is small, you will not cough up bacteria so easily and you will be less infectious to others.

Tubercular pleurisy is a specific type of tuberculosis when fluid is trapped between the pulmonary membranes. People with pleurisy often suffer shortness of breath and pain when breathing. Sometimes a lung puncture is carried out to extract some fluid. This form of tuberculosis is not contagious. With tubercular pleurisy the period between the actual infection taking hold and the disease manifesting itself is fairly short. That's why it is important to find the source of infection and to check whether other people have been infected also.

2.2 What measures are taken in the event of contagious pulmonary tuberculosis?

It is important to observe certain measures. These measures apply for as long as you remain contagious. Once you have taken the medication for a number of weeks you are usually no longer contagious.

- **Manage your cough 'correctly'**

Tuberculosis is mainly transmitted through coughing. Correct 'cough hygiene' generally provides adequate protection to prevent the transmission of TBC bacteria. Correct 'cough hygiene' means covering your mouth with your hand, using a tissue and keeping your head averted while you cough. In some situations the use of a face mask may be necessary.

- **Use of medication**

Also refer to page 5, which explains what medication is available, how long you will have to take it and what its possible side effects may be. Usually the social nurse or another carer will advise on how the medication should be taken. As a rule you will no longer be contagious once you have taken the medication for a number of weeks.

- **Contact with visitors**

On the whole you will be able to continue seeing the people (adults and children) you were in contact with on a daily basis before your illness. You need not keep away from them and vice versa. It is important, however, to limit contacts with other people. You should avoid locations where a lot of people are gathered. Contact with babies and small children should definitely be avoided during this period. Visitors, for example the social nurse, will sometimes wear a face mask for protection.

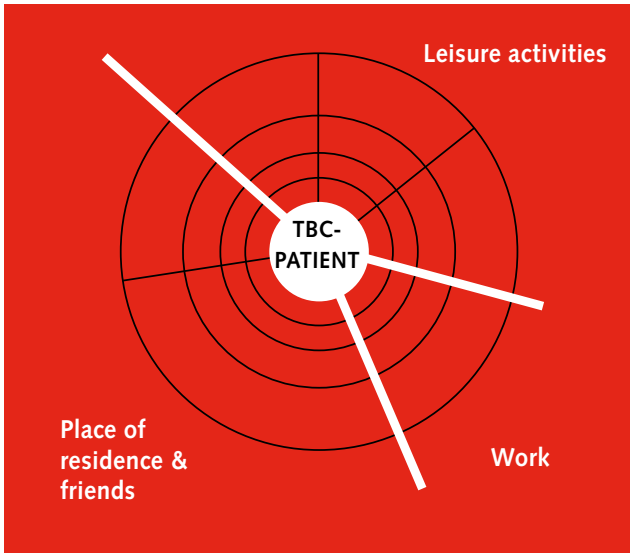
- **Hospital**

In some cases there is a need for hospitalisation. Hospitals have specific rules with respect to the nursing of people with contagious tuberculosis. You must observe these rules.

- **Contact tracing/source analysis**

People you have been in contact with frequently in the recent past will be tested for tuberculosis. This is referred to as 'contact tracing'. The GGD social nurse will provide the necessary information and will ask who you have been in contact with recently (also refer to the 'Contact Tracing' brochure).
The patient's contacts are usually traced on the basis of the 'concentric circle' principle. This implies that those closest to you are examined first. If the results indicate a high rate of infection, examinations will be widened to include people who are less close to you. Sometimes these tests will show who you have been infected by. The objective is to prevent even more people from being infected. This is referred to as 'source analysis'. The GGD will treat all your personal information, and that of other people, in the strictest confidence.

Contact tracing based on 'concentric circle' principle



3 EXTRA-PULMONARY TUBERCULOSIS

What is extra-pulmonary tuberculosis?
With extra-pulmonary tuberculosis TBC bacteria have travelled via the circulation and lymphatic system to other organs, where they have caused inflammation. Tuberculosis can reach other parts of the body, including the lymph glands, joints, kidneys, brain, vertebrae, bones, uterus, ovaries, prostate, intestine, and peritoneum. Tuberculosis is often difficult to detect outside the lungs. These types of tuberculosis are almost never contagious. The following are the three most common types of extra-pulmonary tuberculosis:

- **Tuberculose ganglionnaire**

Tuberculosis of the lymph glands manifests itself in the neck, armpit or groin. The lymph glands will be inflamed and swollen. In some cases they will produce sores. The wound can be covered with gauze if necessary. Sometimes the glands will temporarily enlarge during treatment. This is not a cause for concern.

- **Renal tuberculosis**

Renal tuberculosis is caused by bacteria that have spread and lodged in the kidneys. Occasionally renal tuberculosis will have been present for years without causing any discomfort. At a later stage renal tuberculosis may result in complaints similar to those associated with other urinary tract infections, although it will subsequently become clear that your kidney or bladder problems are caused by TBC bacteria. Sometimes the bacteria can be detected in urine.

- **Tuberculosis of the vertebrae or bones**

Tuberculosis of the vertebrae occurs when TBC bacteria become lodged around the vertebrae of the spine and the bone is affected. Often two or three vertebrae will be damaged. The most common complaints include: back ache, impaired movement and a change in back posture. This type of tuberculosis can be diagnosed on the basis of a detailed examination. Surgery and/or a special corset may be required as a result.

4 TREATMENT

4.1 Can tuberculosis be treated successfully?
All forms of tuberculosis can be treated successfully with medication (in the event of insensitivity to the medication the treatment becomes much more complicated).

4.2 Will I have to go into hospital?
Usually there is no need for hospitalisation although in certain cases it may be necessary for you to go into hospital in order

to prepare you for your medication, in which case you will be advised on how to take the medication. You may also have to be hospitalised because you suffer from another illness as well, or your living conditions are not conducive to your recovery. Serious forms of tuberculosis or complications may also necessitate hospitalisation.

4.3 What medication is available?

You will be given different medications simultaneously in order to eliminate the bacteria as quickly and as effectively as possible. During the first stage of the treatment you will be given four (sometimes three) different medications. This initial phase takes approximately two months, during which a large number of bacteria will be killed. A small number of bacteria are more difficult to eliminate. That is why you will receive at least another two different types of medication during the second phase of the treatment. Some patients will receive comprehensive guidance on how to take the medication.

The main medicines (antibiotics) used to fight tuberculosis are:

- Isoniazid
- Rifampicin
- Pyrazinamide
- Ethambutol
- Rifinah (= a combination of Isoniazid and Rifampicin)

Often vitamin B6 (Pyridoxine) is added to the medication. Sometimes one or more other medicines are added if the bacterium is resistant to one or more types of medication.

4.4 What do I need to know with respect to the use of the medication?

- Treatment will take at least 6 months.
  In some cases you will have to take the medication for more than 6 months, depending on the seriousness or extent of the disease. TBC bacteria are difficult to eliminate. It is of the utmost importance, therefore, that you take your medication every day throughout the entire period prescribed by your physician. If you don't observe this rule the bacteria could become resistant to one or more of the medicines. With certain prescriptions the medication needs to be taken 3 times a week.
- The course of medication must not be interrupted. Ensure that you obtain a new prescription on time.
  Check that the dosage is correct. If in doubt contact the GGD nurse.
- You must take your prescribed dose at a fixed time. Decide on a convenient time to do this, for example when you get up or go to bed, or with your evening meal. It is easier to remember this way. A medicine organiser box is an ideal aid in this respect.
- You should not take your medication on an empty stomach. Always eat something before taking your medication.
- Store your medication in its original packaging so that it is clearly identifiable.
- Pregnancy or breastfeeding are not a problem when you are taking the medication.
- Do not change your medication. Always consult your physician first.
- You should not consume alcohol whilst you are taking the medication. Combining the medication with alcohol could cause inflammation of the liver.
- Ensure that you drink enough water.
- You must inform your physician if you are taking other medicines (e.g. the contraceptive pill, medication for the heart, for diabetes, methadone, etc.).
  It may be necessary to adjust the dose of these medications or to stop taking them altogether.

4.5 What are the most common side effects/complaints?

Fortunately most people have no problems taking the medication. You may, however, have problems taking the medication.
In that case you must contact your physician or the nurse who is providing support.

Most common complaints/side effects:

- *Fatigue*
- *Skin rash/itching*
- *Orange/red discoloration of the urine, faeces or perspiration/tears. This colorant may damage soft contact lenses, but is otherwise harmless.*
- *Nausea*
- *Stomach ache (abdomen)*
- *Headache*
- *Aching joints*
- *Troubled vision, disrupted colour perception*
- *Tingling in the hands and feet*
- *Poor concentration*
- *Inflammation of the liver*

Also refer to the information leaflet accompanying your medication.
Consult your physician or nurse if you have other complaints as a result of taking the medication.

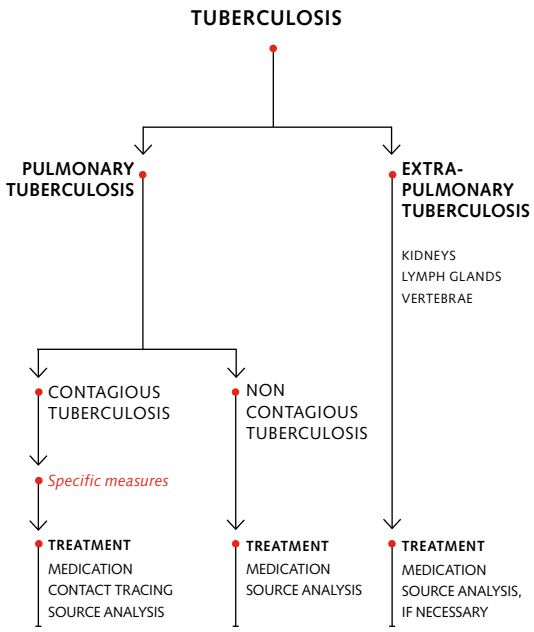
4.6 Once I feel well, do I have to continue taking the medication?

Yes! You must continue taking the medication even if you feel better.
There are still large numbers of TBC bacteria active in your body, even if you are not aware of this. If you stop taking your medication the bacteria can start multiplying once more so that you become sick again. In that case tuberculosis would be difficult to treat/cure.

4.7 What about the treatment of small children?

Tuberculosis is easy to treat in small children. Babies and small children can be given the medication in liquid or powder form, so that it can be mixed into milk or other food.
We will establish the best method for your child together with

you. If your child develops complaints as a result of taking the medication you must contact your physician or nurse.



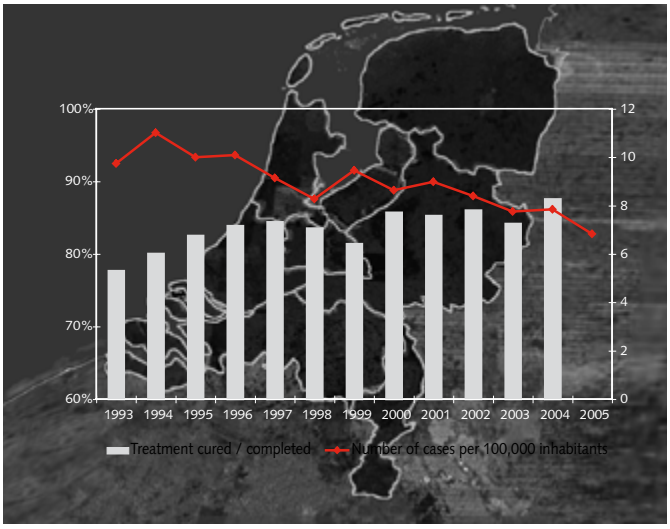
5 PRACTICAL INFORMATION

5.1 Have you got specific questions?
Please contact your physician or nurse in the event of the following:

- You develop complaints as a result of taking the medication
- You have problems with the treatment
- You are in doubt as to whether you have the correct medication
- You have questions relating to tuberculosis

5.2 What does the GGD's TBC control department do?
Your physician must (legal requirement) inform the GGD physician and nurse of the fact that you have tuberculosis. The GGD (TBC control department) treats and supervises people suffering from tuberculosis. The GGD also tries to trace people who have been infected through contact tracing. The GGD also vaccinates children that qualify for BCG (tuberculosis vaccine) vaccination. People travelling to countries with a high rate of TBC may qualify for a TBC examination or BCG vaccination (refer to brochure: Tuberculosis, travel to countries in Eastern Europe, Africa, Asia, Central or South America).

5.3 What does the GGD social nurse do?
For many people being diagnosed with "tuberculosis" is very worrying. It is important, therefore, to receive adequate support. This back-up is provided by the GGD's social nurse, who will visit you at home or in the hospital as soon as possible. He/she will explain what tuberculosis is all about and will advise you in relation to taking the medication. Usually contact will be made daily or by appointment three times a week when the social nurse or another carer will give you your medication. Generally you will have to visit the GGD on a regular basis so that you can be given support with taking the medication ('DOT' = Directly Observed Therapy).



The nurse will also ask you who you have been in frequent contact with in the recent past. When someone is diagnosed with pulmonary tuberculosis contact tracing is almost always necessary. In order to determine who needs and who doesn't need to be examined, the social nurse will compose a list of names with you. Usually this will start with the people closest to you with whom you have the most intensive contact. If infection is detected in this group the analysis may have to be extended to include others. The test will also attempt to determine who could have infected you. This is referred to as source analysis. Even if you (or your child) are not contagious it may be necessary to examine the people close to you to establish whether others have been infected also. The GGD treats your personal information in the strictest confidence.

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To eliminate TB

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