

14. Appendix: NHS LEAFLETS

1. TUBERCULOSIS

i) Tuberculosis (TB) Your Questions Answered (two pages)

ii) Tuberculosis (TB) Treatment (two pages)

(intervening title page)

iii) About Your Treatment for LATENT TB (seven pages)

Note: we hope to add more leaflets on other illnesses



Can TB be prevented?

There is a vaccine for TB known as BCG. However, it does not work in all cases and it is most effective in young children against more severe forms of TB. In the UK, BCG is offered to babies who are more likely to be exposed to TB bacteria and some adults whose jobs put them at increased risk.

BCG is not a routine travel vaccine. If you would like the BCG for travel purposes, you will probably have to pay to have it done privately.

How common is TB?

TB is much less common in the UK than it was early last century, but the number of TB cases has been rising since about 1990. TB is very common in some developing countries where many people cannot easily access the drugs they need to get better.

Can anyone get TB?

Yes, anyone can get TB. The list of ex-patients includes a UK cabinet minister, world famous singers and an archbishop, amongst many others. However, TB is much more likely to affect people who live in poor housing conditions or do not have nutritious diets, as well as people who are affected by other illnesses that weaken their immune systems, such as HIV.

Whilst anyone can get TB, it is still rare to be exposed to TB bacteria in the UK. Two of the most effective preventions against TB are:

- ⊙ Early diagnosis, to stop the onward transmission to others
- ⊙ A strong and healthy immune system

For more information about TB and to read about real people's experience of the illness, please visit *The Truth About TB* at www.thetruthabouttb.org



TB Alert
Community Base
113 Queens Road
Brighton, BN1 3XG
Tel: 01273 234029
www.tbalert.org

If you have an enquiry about TB, or would like to find out more about the TB Action Group (TBAG) – a patient support and advocacy network – please call 01273 234770.

TB Alert is the UK's national tuberculosis charity. Our projects are in the UK, India and Africa, and we also work with international partners to tackle TB as a global issue. Our activities focus on three main areas:

- ⊙ Raising public and professional awareness about TB, and providing support to patients during their treatment
- ⊙ Bringing together statutory health services, voluntary organisations and people affected by TB to plan and deliver better TB services
- ⊙ Developing policy and advocating for the resources to improve the care of patients and the prevention and control of TB

This work supports our organisational mission of increasing access to effective treatment for all people affected by TB.

Any information in this leaflet regarding the diagnosis and treatment of tuberculosis is intended to give general information on the subject only. It is not intended as a substitute for the knowledge, expertise, skill and judgement of physicians, pharmacists or other healthcare professionals in patient care. None of the information contained in this leaflet is intended to be used for decisions on diagnosis or treatment. Questions and concerns regarding diagnosis and treatment should be directed to a healthcare professional.

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Tuberculosis (TB): Your Questions Answered



INFORMATION FOR PATIENTS



Tuberculosis (TB) is an illness that people often do not know a lot about. This leaflet is designed to answer some of your frequently asked questions about TB.

What is tuberculosis?

Tuberculosis (TB) is an illness caused by bacteria. TB most commonly affects the lungs, but you can get TB in almost any part of your body. TB is curable with a course of antibiotics, usually lasting six months. TB in the lungs or throat is the only type of TB that can be infectious, which means it can be passed on to other people. Most people will not be infectious within two weeks of starting to take the correct medicine.

How is TB caught?

When someone with TB in the lungs or throat coughs or sneezes, TB bacteria can get into the air where they can be breathed in by other people. You are most likely to get TB yourself if you have spent a lot of time with a person with infectious TB, for example living in the same household. It is unlikely that you could catch TB sitting next to a person with TB on a bus or train, since close contact for a number of hours is usually necessary to be at risk of infection. TB is **not** spread by spitting or through sharing objects such as cups, plates and cutlery.

What are the symptoms of TB?

People who are ill with TB may have some of the following symptoms:

- ⊗ A cough that lasts for more than three weeks
- ⊗ Fever (high temperature)
- ⊗ Heavy night sweats
- ⊗ Unexplained weight loss
- ⊗ Fatigue (extreme tiredness)
- ⊗ No appetite

TB will only cause a cough if it is affecting your lungs. If TB is in another part of the body it can also cause pain and swelling. All of these symptoms may also be signs of

problems other than TB, so if you are worried you should talk to a doctor or nurse at your local surgery or clinic.

How is TB diagnosed?

If the doctor thinks you may be ill with TB in the lungs or throat they will ask you to give a sputum (phlegm) sample, which they will test for TB bacteria. If the doctor thinks you may have TB in another part of your body, they may do the same test using a sample of cells, fluid or tissue. You may also be offered a skin test, blood test or x-ray.

If I have TB, will I have to stay in hospital?

Most people with TB do not have to stay in hospital, although you may be admitted briefly to confirm the diagnosis or if you are resistant to any of the drugs most commonly used to treat TB.

What is the risk to my loved ones?

If you are diagnosed with TB that could be passed on to other people, you will be asked by the TB Nurse to make a list of people you spend most time with. The hospital will then invite these people to the clinic for screening for TB. They will be assessed for symptoms of TB and may be offered a skin test, blood test or x-ray.

What is the treatment for TB?

Your TB doctor or nurse will usually start you on four different drugs. They are:

- ⊗ Rifampicin
- ⊗ Pyrazinamide
- ⊗ Isoniazid
- ⊗ Ethambutol

You may be given all of these drugs together in one tablet called Voractiv. You may be given Isoniazid, Rifampicin and Pyrazinamide together in one tablet called Rifater.

After two months, the treatment can usually be reduced to two drugs, Isoniazid and Rifampicin. These drugs may be given to you in one tablet called Rifinah.

Can TB drugs cause side effects?

TB drugs can cause side effects, although not everyone gets them. Common side effects include:

- ⊗ Feeling sick or dizzy
- ⊗ Pins and needles
- ⊗ Skin rashes
- ⊗ Flu-like symptoms



In very few cases people may experience jaundice, which is the yellowing of the skin or eyes. **If this happens, stop taking your medication and seek medical attention straight away.**

Rifampicin may turn urine and other bodily fluids, such as tears, orangey red. It can also interact with other medicines. In particular, it *reduces the effectiveness of hormonal contraceptives* (oral pill, implants or other).

Ethambutol may rarely cause visual disturbances (blurred and red/green colour disturbance). Your doctor or nurse will arrange for you to have an eye test prior to starting Ethambutol. **If you develop visual disturbances whilst taking Ethambutol, please stop taking it and inform your doctor or nurse immediately.**

Remember:

- It is important to tell your doctor that you are on TB treatment when being prescribed other medicines
- Women should use additional means of contraception when they are taking TB drugs
- Let your TB Nurse or doctor know if you are experiencing side effects

Where can I go for support?

If you are affected by TB, there is help available so you don't feel alone.

Your TB Nurse is there to support you through your TB treatment. Make sure you attend all your appointments and let the healthcare professionals know if you are having any trouble taking your tablets.

You may find it beneficial to speak to someone else who has also had TB and is now better. TB Alert, the UK's national tuberculosis charity, can put you in touch with a member of the TB Action Group (TBAG) who will be happy to chat with you and help you through your treatment.

- Try setting an alarm to remind you to take your tablets
- Ask a family member or friend to be your "treatment buddy" and remind you to take your tablets
- Tell your doctor or nurse if you miss a dose of your TB drugs – they will not be angry and they will try to help you

You should also keep all your clinic appointments. Your doctor or nurse needs to see how you are doing.

Directly Observed Treatment

Making sure you take all your TB drugs can be difficult. It can be especially difficult if your TB is resistant to some of the drugs most commonly used to treat TB, or if you are under other pressures. The good news is that there is help; it's called Directly Observed Treatment, DOT for short.

DOT is a way of helping people during their treatment. Instead of being sent home with your tablets, you might visit your local hospital or pharmacy to take them, or a nurse may come to your home. This means you have someone to chat to, and they can make sure you are able to take all of your TB drugs until you are better.

For more information about TB and to read about real people's experience of the illness please visit *The Truth About TB* at www.thetruthabouttb.org

Remember: Your TB Nurse is there to help and advise you throughout your treatment. Please contact your TB Nurse if you feel unwell on your treatment or if there is anything you are unsure of regarding your TB drugs.

Your TB Nurse is:

Your Hospital Doctor is:

Telephone:

Email:



TB Alert, Community Base, 113 Queens Road, Brighton, BN1 3XG
 Tel: 01273 234029 www.tbalert.org
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Tuberculosis (TB) Treatment



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Remember to keep all medicine secure and out of reach of children

Tuberculosis (TB) is a curable illness and the treatment is free to everyone in the UK. This leaflet will help you understand your treatment and stay motivated while you get better.

What is tuberculosis?

Tuberculosis (TB) is an illness caused by bacteria. TB most commonly affects the lungs, but you can get TB in almost any part of your body. TB is curable with a course of antibiotics, usually lasting six months. TB in the lungs or throat is the only type of TB that can be infectious, which means it can be passed on to other people. Most people will not be infectious within two weeks of starting to take the correct medicine.

How is TB caught?

When someone with TB in the lungs or throat coughs or sneezes, TB bacteria can get into the air where they can be breathed in by other people. You are most likely to have caught TB yourself if you have spent a lot of time with a person with infectious TB, for example living in the same household. It is not easy to catch TB sitting next to a person with TB on a bus or train, since close contact for a number of hours is usually necessary to be at risk of infection. TB is **not** spread by spitting or through sharing objects such as cups, plates and cutlery.

How is TB treated?

TB is treated with a combination of specific antibiotics that need to be taken for at least six months. The length of treatment depends on whether the TB bacteria are resistant to any of the drugs used to treat TB and where the TB is in your body.

Finishing the whole course of treatment is the only way to cure TB completely.

What is the standard treatment for TB?

Your TB doctor or nurse will usually start you on four different drugs. They are:

- Rifampicin
- Isoniazid
- Pyrazinamide
- Ethambutol

You may be given all of these drugs together in one tablet called Voractiv. You may be given Isoniazid, Rifampicin and Pyrazinamide together in one tablet called Rifater.

After two months, the treatment can usually be reduced to two drugs, Isoniazid and Rifampicin. These drugs may be given to you in one tablet called Rifinah.

Are TB drugs safe?

TB drugs can sometimes cause side effects, like any other medicine. Information about the different drugs and their side effects can be obtained from TB clinic staff. For example, they may be able to give you another TB Alert leaflet called About Your Tuberculosis (TB) Drugs.

Let your doctor know that you are on TB treatment when being prescribed any other medicines, as they may interact. In particular, TB drugs may *reduce the effectiveness of hormonal contraceptives* (oral pill, implants or other) so women should use additional means of contraception when they are taking TB drugs. Ask your doctor or nurse for advice.

Important: Being on TB drugs puts extra pressure on your liver. Therefore you should try not to drink any alcohol while you are on TB treatment. If you need to drink, it is important to do so in moderation.

Rifampicin, Isoniazid, Pyrazinamide and Ethambutol can be taken safely during pregnancy.

How often should I take my medicine?

TB drugs need to be taken regularly, as directed by your doctor. If you forget to take a dose of your TB drugs, take them as soon as you remember. However, if it is nearly time for your next dose, then miss the one you forgot. **Do not take a double dose.** Always let your doctor or nurse know if you do not remember to take your tablets.

What will happen if I don't finish my treatment?

You should start to feel better once you have been on TB drugs for a while. However, if you do not take all of your tablets for the full length of time prescribed, then the TB will still be in your body.

If you do not finish your treatment:

- You may become more seriously ill
- You may pass on TB to others
- You may develop drug-resistant TB
- Your TB treatment will be prolonged

"I really don't like taking tablets, who does? But I knew I had to, because I didn't want to give TB to my kids or develop drug-resistant TB, which can be really hard to treat. I was so relieved when I finished treatment, as I knew my TB was totally gone."
Natalie, TB patient advocate, TB Action Group

Where can I go for support?

If you are affected by TB, there is help available so you don't feel alone.

Your TB Nurse is there to support you through your TB treatment. Make sure you attend all your appointments and let the healthcare professionals know if you are having any trouble taking your tablets.

You may find it beneficial to speak to someone else who has also had TB and is now better. TB Alert, the UK's national tuberculosis charity, can put you in touch with a member of the **TB Action Group (TBAG)** who will be happy to chat with you and help you through your treatment.

How can I remember to take my TB drugs?

It is not always easy!

You will be taking your TB drugs for at least six months, so you should get into a routine. Here are some of our suggestions:

- Take your tablets at the same time every day and keep them in the same place
- Put your tablets in a weekly dispenser
- Mark off each day on a calendar as you take your TB drugs

Information on Latent TB



Public Health
England



About your treatment for **LATENT TB**

What is TB?

Tuberculosis (TB) is an illness caused by bacteria. When someone with TB in their lungs coughs or sneezes, they send TB bacteria into the air. If you breathe in these bacteria, one of three things will happen:

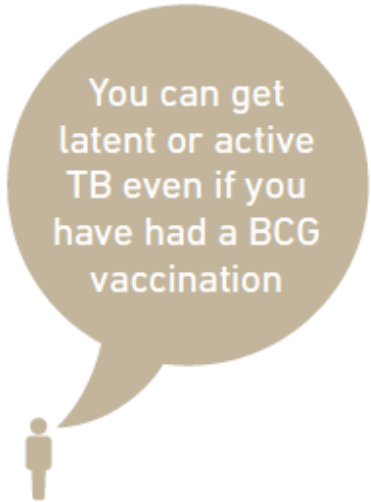
- your body kills off the TB bacteria so they cannot harm you now or in the future
- the TB bacteria make you ill – this is called **active TB**
- the TB bacteria remain asleep in your body – this is called **latent TB**.

About active TB

When people talk about TB, they usually mean 'active TB'. If you have active TB, the bacteria are making you ill and you might be passing TB on to other people. Active TB can be very harmful to your health, but it can be cured with a course of medicine.

About latent TB


If you have latent TB, the TB bacteria in your body are 'asleep'. You are not ill and you cannot pass TB on to others. However, the bacteria might 'wake up' in the future, making you ill with active TB. The good news is that latent TB **can be treated** to prevent this happening.



You can get latent or active TB even if you have had a BCG vaccination

How do I know I have latent TB?

If you have latent TB, you will not have any symptoms. The only way to know if you have latent TB is to have a blood test or skin test. If you have latent TB, a course of medicine can kill the bacteria before they have a chance to wake up and harm you.



Prevention is better than cure

Will I develop active TB?

About 1 in 10 people with latent TB will develop active TB in the future. There is no way to know if you will be one of them. It is possible to become ill with active TB many years after you breathe in TB bacteria. That is why it is a good idea to put your mind at ease by treating the latent TB while you are healthy and before the bacteria wake up.

What treatment do I need for latent TB?

A course of antibiotic medicine will treat latent TB. You may be given *Rifampicin* and *Isoniazid* for three months (which is likely to be together in a tablet called *Rifinah*) or *Isoniazid* by itself for six months.

Your doctor or TB specialist nurse will talk through the treatment with you and answer any questions you may have. Make sure to tell them about any medicine you take, or if you use hormonal contraceptives, as these may not work so well while you are taking TB medicine.

Latent
TB testing
and treatment
is free and
confidential



What do I need to know about latent TB treatment?

Take your medicine regularly and complete the full course. The best chance for this treatment to work is to take all of the medication as prescribed.

- Take your tablets at the same time every day.
- Tick days off the treatment diary in this leaflet as you take your tablets.
- Always keep your tablets in the same place.
- Use a weekly dispenser (a dosette box).
- Set an alarm to remind you to take your tablets.
- Ask a family member or friend to remind you to take your tablets every day.

Take your medicine between meals and avoid alcohol. Try to take your TB medicine at least one hour before you eat food or two hours afterwards. You can eat anything you like, but you should avoid drinking alcohol.

Make a note of any side effects and tell your doctor or nurse about them as they can help you deal with them. As with all medicines, there may be side effects. Some are mild, while others may be more serious. Depending on the treatment you receive, you may experience the following side effects:

Side effects	<i>Rifinah</i> (Rifampin and Isoniazid in combination)	<i>Isoniazid</i>
orange staining to tears (which may stain contact lenses), saliva, urine and other bodily fluids – this is not harmful	Y	
flu-like symptoms	Y	
menstrual disturbances	Y	
reduced effectiveness of hormonal contraceptives (oral, implant, other)	Y	
tingling or numbness	Y	Y
rashes and itchiness	Y	Y
sickness or diarrhoea	Y	Y

Very rarely the medication can affect your eyesight or cause jaundice (yellowing of the skin or eyes). If you notice either of these side effects, stop taking your TB tablets and speak to a doctor or nurse immediately.

Make sure you keep all your clinic appointments and keep in touch with your doctor or nurse. Your doctor and nurse are there to help you. Let them know if you miss a dose or need help to remember to take your treatment. You can fill in the treatment diary in this leaflet and also make notes of the things that you want to mention to your doctor or nurse.

When I finish treatment, will I be free of TB forever?

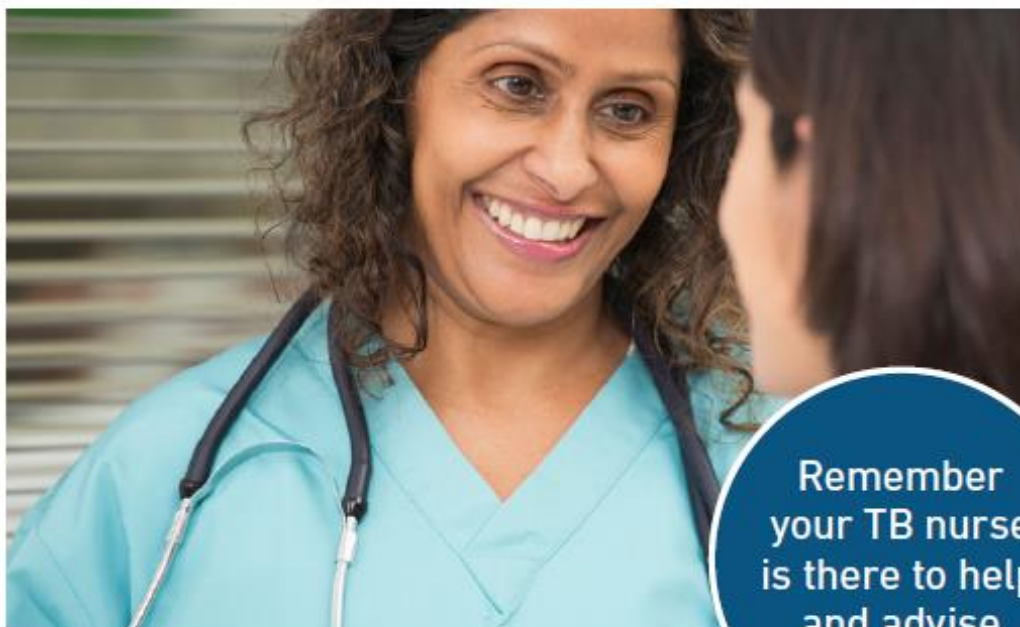
There is always a chance you could breathe in TB bacteria again in the future. The chances of this are low for most people but it is useful to know the most common symptoms of active TB and see your GP if you have any of them:

- a cough which lasts for three weeks or longer
- fever (a high temperature)
- night sweats
- weight loss
- no appetite
- tiredness

Your treatment notes

Make a note here of any questions or comments you may have. You may want to make a note of side effects, your emotions on a particular day, or any tips you find useful to help you complete your treatment:

Where can I get advice and support?



Remember
your TB nurse
is there to help
and advise
you.

Your TB specialist nurse is:

Your hospital doctor is:

Contact number:

Email:

For help in your language

Ask your doctor or nurse for information about local translation and interpreting services.

Other sources of information and advice



TB Alert
The UK's national TB charity
www.tbalert.org
www.thetruthabouttb.org/latent-tb

NHS Choices
www.nhs.uk