

Tuberculosis: prevention, diagnosis, management and service organisation

Information for the public

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About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

This information explains the advice about tuberculosis (TB) that is set out in NICE guideline 33.

This is an update of advice on TB that NICE produced in 2011 and 2012.

Does this information apply to me?

Yes, if you, or a family member or carer, have TB or are at risk of being infected with TB.

Tuberculosis

TB is a bacterial infection. Anyone can catch TB by breathing in the bacteria that cause it. Bacteria are present in tiny droplets coughed out by someone who has TB.

Some people become ill with TB. This is called '**active**' TB. People can become ill within a few weeks, months or years of breathing in the bacteria. In most people, the body's immune system kills the bacteria and the person doesn't get ill.

In other people, the bacteria aren't killed but stay in the body at a low level, so the person doesn't get ill and isn't infectious. This is called '**latent**' TB. If the bacteria start to multiply again months or years later the person could develop active TB. This sometimes happens, for example, if the person's immune system is weakened by another disease such as HIV or treatments such as drugs for cancer.

Active TB mainly affects the lungs, but it can affect other parts of the body, such as the lymph nodes (glands), brain or spinal cord. The most common symptoms of TB include a persistent cough, extreme tiredness, loss of appetite, weight loss, fever and night sweats.

TB is curable, but it is important that both active and latent TB are treated quickly. This is to avoid the bacteria spreading through the body and to other people.

Questions to ask about TB

- Why have I got TB, and where did I get it?
- Can you tell me more about TB?
- Do I have active or latent TB?
- How can I make sure I don't give TB to other people?
- Are there any support organisations in my local area?
- Can you provide any information for my family/carers?
- Is there some other help (like peer support) and information (like a leaflet, DVD or a website) about the treatment that I can have?

Your care team

A range of professionals who specialise in different areas of treatment or support may be involved in your care. These could include specialist doctors and specialist nurses, people providing social care support or working in housing support services, as well as your GP.

Working with you

Your care team should talk with you about TB. They should explain any tests, treatments or support, and their risks and benefits, so that you can decide together what is best for you. You should be encouraged to be involved in your care from the start. If you are an adult, your family or carer can be involved in helping to make decisions, but only if you agree.

If you are a child or young person, your parent or carer may be involved in helping to make decisions depending on your age.

There are questions listed in each section that you can use to help you talk with your care team.

You may also like to read NICE's information for the public on [patient experience in adult NHS services](#). This sets out what adults should be able to expect when they use the NHS. We also have more information on the NICE website about using health and social care services.

Some treatments or care described here may not be suitable for you. If you think that your treatment doesn't match this advice, talk to your care team.

Who is at high risk of developing TB?

People at high risk of TB include people, or the children of people, who:

- have been in close contact with people with TB (see [testing for TB](#))
- have come to work or settle in the UK from a country where TB is common
- have a weak immune system because of, for example, HIV, a kidney transplant or cancer treatment

- might find it difficult to spot the symptoms of TB, go to regular appointments or take medicines.

People in these high-risk groups should be given information about how to recognise the symptoms of TB and how they can get it, and what to do if they suspect they have TB.

Testing for TB

If you are at high risk of TB, you should be given advice and information about the need for testing.

Everyone who has been in close contact (for example, sharing a bedroom, kitchen, bathroom or living room) with someone diagnosed with active TB may need testing to check whether they are infected. This is called 'contact tracing'.

Your local TB team should offer you testing if you are in close contact with someone you know who has TB in their lungs or larynx (part of the throat that contains their vocal cords). Other factors that will affect whether you are offered testing for TB include:

- how much contact you had with the person with TB (for example, if you are a partner, parent, a hospital patient, or a student or work colleague of a person with TB)
- where you work (for example, if you work in the NHS and have contact with patients or clinical samples or if you work in a prison)
- where you live, or where you have lived (for example, people arriving in the UK from a country where TB is widespread, people who are homeless or in hostels, and people in prisons)
- whether you have a weakened immune system
- whether you have been in contact with a particularly infectious person.

Tests for TB

There are a range of tests for TB that you may be offered, depending on your circumstances. These include:

Mantoux test: a small amount of harmless TB protein is injected under the skin (you can't catch the disease from this test). The area is checked to see if your body has reacted to the TB protein 48–72 hours later.

Interferon-gamma release assay: a blood test that is sometimes done after, at the same time as, or instead of, the Mantoux test. If the result is positive, you should have more tests to see whether you have TB.

Sputum smear: you may be asked to cough up a sputum specimen so that it can be examined for TB in the laboratory.

Chest X-ray: you may be given a chest X-ray to see whether you have TB in your lungs.

Depending on your risk and test results, you may be offered further tests or be referred to a TB specialist (see [diagnosing active TB](#)).

If your TB team thinks you are still at risk and you haven't already been vaccinated, you may be offered a vaccination called BCG (see [BCG vaccination](#)).

BCG vaccination

BCG vaccination should be offered to:

- newborn babies if:
 - they were born in an area where rates of TB are high
 - 1 or more of their parents or grandparents were born in a country where TB is widespread
 - someone in their family has had TB in the past 5 years
- children who are 15 or under who weren't vaccinated as newborn babies and who may be at higher risk of TB

- people who are 35 or under who haven't been vaccinated before and have had a negative Mantoux test result if they:
 - have been in close contact with someone with TB affecting their lungs or larynx
 - have come to live in the UK from areas where TB is widespread
 - work with animals that can get TB (such as chimpanzees or cows)
 - work in prisons, homes for older people, or hostels for refugees, asylum seekers or homeless people
 - plan to live or work for more than 3 months in a country where TB is widespread
- people who haven't been vaccinated before and have had a negative Mantoux test and work regularly with patients or clinical specimens.

If you or your child is offered BCG vaccination, the person offering it to you should give you information about the benefits and risks. This should be in the right language and format for you. You should be able to discuss these with a healthcare professional before deciding what to do.

Diagnosing active TB

If you suspect that you have active TB in your lungs, or have recently been in contact with someone with active TB in their lungs, you can refer yourself to a TB clinic for assessment. The organisations listed in [sources of advice and support](#) should be able to put you in touch with local services.

If you have suspected active TB, you should be assessed by your TB team within 5 working days. If you have confirmed active TB, you should be assessed the next working day.

Tests for TB in the lungs

If you have symptoms of active TB (see [tuberculosis](#)) in your lungs, you should be offered tests by a healthcare professional. These could include a chest X-ray and tests on samples of sputum coughed up from the lungs. If the tests find any TB bacteria in your sputum, you are more likely to pass TB on to other people. This is called smear-positive TB. If no

bacteria are seen, but other tests show you have TB, this is called smear-negative TB.

Tests for TB in other parts of the body

If you might have TB in another part of your body, other than your lungs, a doctor may need to check whether it contains TB bacteria. This may involve removing a small sample of tissue (called a biopsy) or using a needle to remove a few cells or fluid from the affected area. You should also have a chest X-ray to find out whether it is in your lungs as well.

If you have TB that has spread to other parts of your body, a healthcare professional should offer you extra tests to see whether the TB is in your brain or spinal cord. This should include a test called a lumbar puncture (a small amount of the fluid around your spinal cord is removed through a needle). You may need a scan, such as a CT or MRI, as well. If you have TB in the spine and have signs that the nerves in the spinal cord are affected (such as weakness, numbness or tingling), you should be offered a scan to see whether you have TB inside your spinal cord.

While you are waiting for your results

You may need to start treatment before the test results come back.

Questions to ask about finding out whether you have TB

- Why are you offering me these tests?
- Can you tell me more about the tests you've offered me?
- What do these tests involve?
- Where will these be carried out? Will I need to have them in hospital?
- How long will I have to wait until I have these tests?
- How long will it take to get the results of these tests?
- Why is it important for me to start treatment before I get my results?

Treating latent TB

If tests show that you have latent TB (see [tuberculosis](#)) and you are 65 or under, your TB team should offer you antibiotics to prevent this progressing to active TB disease. Treatment usually lasts 3 or 6 months. If you are 35–65, you should only be offered treatment if a doctor thinks there is little risk of liver damage. The TB team should assess you to see if any factors in your life may make it difficult for you to take your treatment. If, for example, you are homeless or you misuse drugs or alcohol, they should put you in touch with support services.

Newborn babies (4 weeks or younger) who are in close contact with someone who has tested positive for TB in their sputum and hasn't had at least 2 weeks of anti-TB treatment should be assessed by a doctor for active TB and treated for latent TB for 6 months. Anyone under 2 years should be assessed for active TB and should be offered treatment immediately. They shouldn't have to wait for test results. Further tests and treatment should be given as needed.

Treating active TB

If you are diagnosed with active TB (see [tuberculosis](#)), a healthcare professional should refer you to a team of experts trained in TB. People with other conditions such as HIV or severe liver disease, and children and young people, should be treated by healthcare professionals specialising in the care of these groups.

The usual treatment for active TB, including TB affecting the lungs, is a combination of different antibiotics for a total of 6 months. If you have TB affecting the brain or spinal cord, your treatment should last for 12 months. Treatment could last longer if you have drug-resistant TB (when standard anti-TB drugs aren't effective enough) or have had breaks in your treatment.

If you have TB of the brain, spinal cord or heart, a healthcare professional should also offer you another type of medicine called a corticosteroid for a few weeks to reduce swelling in the area affected by the TB. You may be offered surgery, if you have increased pressure in your brain or an unstable spine or a compressed spinal cord.

It is important that you finish all your treatment.

Directly observed therapy

If you are likely to find it difficult to take your medicine regularly, your TB team may ask if you want to join a programme called 'directly observed therapy'. This involves meeting with a specific healthcare worker each time you take a dose of your anti-TB medicine. Where and when you meet are decided between you and your healthcare worker. But the aim is to make it as easy as possible for you. This kind of treatment is usually given daily, but at least 3 times a week.

All people in prison who are having treatment for TB should have directly observed therapy – and this should continue after they are released.

If you have side effects

If you have severe side effects from your treatment, usually the drugs will be stopped temporarily until the side effects go away. Doctors will check how well your liver is working and your drugs will then be slowly restarted 1 at a time. But, if you have severe TB, you may need to stay on some of the drugs and be monitored at the same time.

When the treatment finishes

Once you have finished your treatment, you shouldn't usually have any more appointments to see a TB specialist. But, the specialist should tell you about symptoms that could mean the TB has come back, and how to contact them quickly if you get these symptoms.

Questions to ask about treatment

- Why you have decided to offer me this type of treatment?
- What will it involve?
- How will it help me? What effect will it have on my symptoms and everyday life?
- How long will it take to have an effect?
- When should I stop taking my treatment? Can I stop taking the treatment when my symptoms go away? Why is it important for me to finish all of the treatment?

- What are the side effects associated with this treatment?
- Can I have treatment for TB if I am already taking other medicines, for example for HIV or after a transplant?
- Are there any other treatments I could have apart from the one you have offered me?
- What can I do to help me remember to keep taking my medicines?
- Can you tell me more about directly observed therapy, what it will involve and how it can help me?
- Do I have drug-resistant TB?
- Who can I contact if I have any questions?

Finishing all your treatment

If you miss doses or stop taking your medicine before the end of the course, the TB is likely to come back and may have become resistant to the medicines (drug-resistant TB). So, it is essential that you take all your medicines correctly. Even if you feel well again before the end of the course, you should keep taking them because you could still be infectious and even pass on drug-resistant TB to your family and friends.

Your TB team should give you the name and contact details of the person you should contact if you have any difficulties with taking the medicines, and who can give you information and any help you need. This should happen within 5 days of your diagnosis. Your TB team may also do other things to help you take your treatment, such as send you reminder letters or texts.

Treatment in hospital

You shouldn't need to stay in hospital for tests or treatment unless you are seriously ill, or there are other clear reasons (for example, if you are homeless) that could make caring for you outside hospital difficult.

If you are in hospital and have TB bacteria in your sputum (known as 'smear-positive'), you should be cared for in a single room until you leave hospital or you are no longer infectious. Most people stop being infectious after they have been on treatment for 2 weeks but, for people with drug-resistant TB, it may be longer. You should wear a mask whenever you leave your room to help stop TB spreading to other patients.

Visiting a child in hospital

If you visit a child with suspected active TB in hospital, you should be checked for symptoms of infectious TB, just in case the child caught TB from you. You will need to keep away from other patients until you have been cleared of having active TB.

Multidrug-resistant TB

If you are diagnosed with TB you will be asked questions and may have tests to see whether you have multidrug-resistant TB. Multidrug-resistant TB is much more difficult to treat because the antibiotics normally used to treat TB aren't effective. If you have multidrug-resistant TB you will need special treatment for longer, which should be monitored carefully. It is important that you finish all your treatment.

If you are in hospital and your team thinks you have multidrug-resistant TB, you should usually be cared for in a special single room (called a negative-pressure room) until you are no longer infectious, or until you don't have this type of TB.

Visitors and staff should wear masks when they visit you. The hospital management should help you with the effects of being isolated for a long time, for example, by giving you free access to the internet, a telephone and a television.

You may be discharged early, if you are able to take your treatment correctly, and have your treatment monitored.

If you have had multidrug-resistant TB, you may need regular checks for 12 months or longer after your treatment finishes to make sure the TB hasn't come back.

Questions to ask about multidrug-resistant TB

- Can you tell me why you have decided to offer me this particular type of treatment?
- What will it involve?
- How will it help me?
- How long will it take to have an effect?
- Are there any risks associated with this treatment?
- How long will I need to take it?
- How long will I need to stay in hospital? How long will I need to stay in isolation?

Sources of advice and support

- British Lung Foundation, 0300 003 0555
www.lunguk.org
- TB Alert, 0127 323 4029
www.tbalert.org / www.thetruthabouttb.org

You can also go to [NHS Choices](#) for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

Other NICE guidance

See other NICE guidance for details of our guidance on these conditions:

- [Hepatitis B \(chronic\): diagnosis and management of chronic hepatitis B in children, young people and adults](#) (2013) NICE guideline CG165
- [Hepatitis B and C: ways to promote and offer testing to people at increased risk of infection](#) (2012) NICE guideline PH43

- [Increasing the uptake of HIV testing among men who have sex with men](#) (2011) NICE guideline PH34
- [Increasing the uptake of HIV testing among black Africans in England](#) (2011) NICE guideline PH33

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