Talking to your patients about latent TB infection (adult patients)

**Purpose:** This document offers information for providers who are talking to patients about latent TB infection (LTBI).

- The first part is a guide for counseling your patients about tuberculosis, LTBI, testing and treatment.
- The second part lists common patient questions and suggestions for how to respond.

**Instructions:** Each section addresses an important question or topic. Use the patient’s answers or information to decide if the particular topic is relevant. You might need to use all or only a few of the sections.

**PART 1: Talking points**

**What do you already know? What concerns do you have?**

- Tell me what you know about TB and any questions you have.
- This will help me focus our time and make sure your questions about TB infection, testing, and treatment are answered.

(Based on the patient’s response, **SKIP AHEAD to the topics needed**)

**What is tuberculosis (TB)?**

- Tuberculosis, or “TB,” is a **disease** caused by bacteria. It spreads from person to person through the air and **usually affects the lungs but can affect any part of the body**.
- When a person who is sick with TB coughs, they **send TB germs into the air**. If others breathe in the TB germs, they can become infected with TB and **some may get sick**.
- You may have heard of TB before, but you might not know **how common it is**. Over 2 million people in California are infected and over 2,000 become ill with TB disease each year.

**What is the difference between latent TB infection (LTBI) and active TB?**

- TB germs can **hide in the body for years**. This is called “latent TB infection” or LTBI.
- People with latent (or “hidden”) TB infection **do not feel sick**, and they cannot **transmit TB** to others.
- Unfortunately, some latent infections will eventually cause disease. After being “latent” or “hidden” in the body for many years, **latent TB infection can suddenly become active**.
- Active tuberculosis disease has **serious symptoms**, and can include **fevers, night sweats**, extreme tiredness, unintended weight loss, and a **prolonged cough with or without blood**. In some cases, people with active tuberculosis **become severely ill and die**.
- People with **active TB disease** are infectious, and **can transmit the germs to family or friends**.
**How does latent TB infection (LTBI) progress to active TB?**

- Most TB disease occurs in people who **had latent infection for a long time**, and **never knew** they were infected.

- **Certain conditions that put stress on the body or weaken the immune system increase the risk for TB infection to progress to active TB.** These conditions include diabetes, kidney disease, immune compromise from illness or medications, and smoking.

**How do you know if you have LTBI? Who should be tested?**

- Fortunately, there is a **simple blood test** to help us determine if you are infected.

- If you have one or more of the **risk factors** below, you should get tested.
  1. **Were you born in** Africa, Asia, Central or South America, Eastern Europe or other countries with elevated rates of TB? **Or have you traveled to or lived in those areas** for longer than a month?
  2. **Are you being treated for HIV, cancer, or another condition that affects your immune system?** Are you taking any medications that impact your immune system (TNF-alpha inhibitors such as infliximab or etanercept, methotrexate, or steroids)?
  3. **Have you ever been in close contact with someone who was sick with TB disease?** Even if you knew someone long ago with TB, you are still at risk for infection because the TB germs can hide in your body for many years.

- If any of these risk factors apply to you, the best idea is to get tested. If we diagnose LTBI, we can treat it and prevent you from developing TB disease. This **protects you and your loved ones**.

- If you know anyone else who may have been exposed to TB or have a risk for TB infection, please encourage them to get tested. It could save their life or yours.

**Who should be treated for LTBI? How do I know treatment is right for me?**

- Most people with a **risk factor for TB infection** and a **positive TB test** should be treated.

- If your blood test (or skin test) comes back positive for TB infection, we will ask you again about symptoms, do a thorough exam and a chest x-ray to make sure that you do not have active TB disease. If you don’t have symptoms, a normal exam, and a clear chest x-ray then you have LTBI, and we need to consider treatment.

- If the test is positive and you are at high risk for developing active TB, we can protect you by treating your infection now! While treatment of LTBI is relatively straightforward, treatment of active TB disease is more challenging and involves more medications. Therefore, we strongly recommend getting treated now for LTBI.

- **Finding and treating LTBI early protects you, your loved ones, and others from getting sick.** By working together with my patients and their communities, I hope we can end TB in our lifetime!
## PART 2: Frequently asked questions, with suggested responses

### TB infection and testing

**“I thought TB doesn’t exist in the U.S. anymore. How could I get it?”**

TB does exist in the U.S. Anyone can get TB, but some people are more at risk than others. People have a higher risk of TB if they:
- were born in or traveled to or lived longer than a month in Africa, Asia, Central or South America, or other countries with elevated rates of TB
- have a weakened immune system
- spent a lot of time with a person with infectious TB

**“I thought TB is genetic or inherited so how can it be prevented?”**

There are many myths about TB. Some people think it is hereditary, and others believe it can be caught from cups, utensils or touching someone with TB. In fact, TB can only be caught if you breathe in the germs when a person with TB disease coughs, sings or speaks. The reason TB can cluster in families is because families spend a lot of time together and breathe the same air; it is not hereditary.

**“Why should I be tested for LTBI?”**

Getting tested will show if you have LTBI, and there are treatments available. If you get treated, you can protect yourself and the other members of your family from getting sick and developing TB disease. Similar to getting vaccines to prevent a disease later on, treating TB infection prevents you from getting sick with TB disease.

### BCG vaccine

**“I had the vaccine when I was a child so how can I get TB?”**

The TB vaccine (called BCG) does not work in all cases, nor does it protect you for your whole life. It is most effective in young children against more severe forms of TB.

**“I think my test result must be a false positive because I had a BCG vaccine.”**

There are sometimes false positive results in those with the TB skin test who were BCG-vaccinated, but not with the blood test. We can do a TB blood test to look for infection. If you have a positive TB blood test, you were likely infected with TB, even if you were vaccinated.

### TB treatment

**“Why should I take a medication if I am not sick?”**

The medication kills the TB germs in your body before they have a chance to “wake up” and make you sick. By getting rid of the germs now, you’re protecting yourself and your family from getting active TB, which can make you very ill and do a lot of damage to the body.
**TB treatment (continued)**

**“I have heard treatment takes a long time!”**

TB is a slow-growing bacteria, so treatment of TB infection takes longer than antibiotics you take for a typical pneumonia or minor infection. But it usually less complicated to treat latent TB infection than TB disease, which is why we recommend getting tested and treated for LTBI if you are at risk. There are different treatment regimens for LTBI, some can be completed in only 12 doses, or 3 months. However, if a person doesn’t take all of the medicine, TB germs may multiply and be more difficult to kill. So it is important to treat the infection fully now to prevent TB disease later on.

**“I feel fine now. So why should I take medication?”**

It's important to stop the germs before the germs grow, spread, and make you ill with active TB disease. People with active TB disease can get very sick and spread TB to other people. Unfortunately, nearly 10% of people who develop TB disease in California die. If you get treated, you can protect yourself and the other members of your family from getting sick.

**“Everyone I know has (latent) TB/a positive test result so why does it have to be treated?”**

It is important to stop the germs before they become active because then the germs grow and spread. People with active TB disease can get very sick and can spread TB to other people. Getting treated protects you and the other members of your family from getting sick.

**“I am worried about the harms of medication and side effects.”**

You will be monitored closely throughout your treatment for any side effects. The side effects of the medications, if any, are usually mild, though if needed, your doctor may stop or change your medications. The risk of getting sick with TB is greater than the risk of having a serious side effect.

**“Does taking the medication mean I cannot drink alcohol?”**

Because alcohol is hard on your liver, and TB medications are broken down or metabolized by the liver, taking the two together may cause liver injury. I want to minimize the chances of liver injury, so I recommend that you avoid alcohol while you’re taking medications for TB.

### Other concerns

**“What will happen to me if people find out I have LTBI?”**

Your test results will be confidential. No one can discriminate against you for having LTBI. You also cannot be fired from a job or forced to leave school. People with LTBI cannot be forced to leave the United States.

**“Will I die? Isn’t TB incurable?”**

TB is curable. We have good medications to help eliminate the bacteria from your body. It is much easier to treat TB infection when you have latent vs. active disease, which is why we recommend getting tested and treated for LTBI if you are at risk. However, if you develop active disease, your doctor and health department will find you medicines and support you through treatment.

**“If I have TB, does that also mean I have HIV?”**

Absolutely not. In some parts of the world, people with one disease often have the other, but having TB does not mean you have HIV. As part of your evaluation for TB, we routinely do a blood test to ensure you are HIV negative.