KNOW YOUR RIGHTS:
TUBERCULOSIS PREVENTION, DIAGNOSIS, AND TREATMENT

YOUR RIGHTS AND TB TREATMENT

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Where should I get TB treatment?

Treatment should be given where it's convenient for you, for example, at a primary care doctor or community health center close to where you live or work, or by having a health care worker come to your house if you are comfortable with that, or by taking it at home with regular check-ins with your health care provider. If TB treatment is not convenient where you live, you may want to encourage your government to update its policies for community-based TB care, in accordance with the Right to Science and the Right to Health.

Why is it not generally necessary to stay in a hospital for TB treatment?

You should not have to stay in the hospital for TB or even drug-resistant TB treatment, unless it is absolutely medically necessary. Hospitalization is not required or even preferred for the majority of cases. Hospitals with poor ventilation can, in fact, spread TB. Hospitalization is more expensive. Sometimes hospitals don't have enough space, meaning patients have to wait to start treatment.

When do I need to stay in the hospital?

You should never have to automatically stay in the hospital for the duration of your treatment. If you are very ill, or if you have side effects that need to be very closely monitored, your doctor may recommend hospitalization. Some hospitals are quite good at caring for people with TB and preventing the spread of TB and can provide a supportive environment for cure, especially for people with complicated TB, so there are times when hospitalization will be the best option. You should not have to stay in a hospital as a condition to get access to newer treatment regimens.

What treatment/drugs should I be able to access?

You should have access to the drug regimen that is effective for your form of TB. Regular drug-susceptible TB requires six months of daily treatment. The WHO recommends daily, fixed dose combinations, which combine different drugs (isoniazid, rifampicin, ethambutol, and pyrazinamide for the first two months, followed by isoniazid and rifampicin for four months) into one tablet and make it easier for you to stick with your treatment. TB meningitis (which is TB of the nervous system, like the brain) and TB of the bones and joints require 12 months of treatment.

If your TB is resistant to isoniazid (but susceptible to rifampicin and fluoroquinolones), you should receive six months of daily treatment with rifampicin, ethambutol, pyrazinamide, and levofloxacin. Because these medicines are not available in a combined tablet, your clinician may give you the standard isoniazid, rifampicin, ethambutol, and pyrazinamide combined tablet, plus levofloxacin. You should have a choice as to whether to take the combined tablet (which is easier to swallow but contains isoniazid, a medicine that likely will not work against your TB and has side effects), or loose individual tablets (which require swallowing more tablets, but you will be avoiding an unnecessary medicine).

If your TB is resistant to rifampicin, you should receive treatment with a combination of four to five medications. The medications should be chosen based on their effectiveness, the side effects they cause, and the type of drug resistance your strain of TB shows. You have a right to have TB treatment based on a drug susceptibility test. Although regimens may vary, the WHO strongly recommends three medications: bedaquiline, linezolid and either levofloxacin or moxifloxacin, because they are been associated with better treatment outcomes and a lower rate of death. You should be given these three medications unless your TB has resistance to them, or you have a medical reason why they cannot be used. The WHO also recommends cycloserine (or a similar drug, terizidone) and clofazimine as these drugs have been associated with better treatment outcomes. The WHO no longer recommends the use of two injectable agents, kanamycin and capreomycin. Though the WHO still recommends injectable agent, amikacin (if there are no other treatment options, if there is documented susceptibility to the drug, and if formal hearing assessments can be done at baseline and monthly while on the medication), the latest guidelines emphasize that all-oral regimens are the preferred standard of care.

The duration of therapy recommended is for 18-20 months. Some countries may offer people with rifampicin-resistant TB shorter treatment regimens (9-12 months) containing all-oral medications under carefully monitored conditions. There are some ongoing studies (clinical trials) to evaluate all-oral shorter treatment regimens using combinations of new and repurposed TB medicines, including bedaquiline, delamanid, linezolid, clofazimine, and pretomanid. You should ask if any of these are being conducted in your area.

There is a standardized shorter treatment regimen that is 9–12 months that does not contain all of these recommended drugs and instead contains older drugs including the painful and toxic injectable amikacin. Though they have not been compared in a study head-to-head, evidence indicates the standardized, shorter, injectable-containing regimen does not work as well as longer regimens that contain the medications bedaquiline, linezolid, and the fluoroquinolones.

As mentioned above, kanamycin and capreomycin are no longer recommended for TB treatment; if you are receiving one of these, tell your health care provider you want to receive bedaquiline instead immediately. If you are on a regimen containing any of the injectable medications (amikacin, streptomycin, or the no-longer recommended kanamycin or capreomycin), you should have your hearing tested prior to starting this medication and every month while you are taking it, and if there are any signs of hearing loss or you are having trouble tolerating the injections, you should ask to be switched to bedaquiline immediately.

You should always know the names of your specific medications, how often to take them, how many pills to take, and the most common side effects to watch out for.

What treatment is recommended for children?

Treatment specially made for children with drug-susceptible TB is now available. The new pills, called fixed dose combinations, are already at the right dose for children, so they do not need any crushing or splitting. They dissolve completely in water, and taste better than the adult tablets.

Most children with rifampicin-resistant TB should receive injectable-free regimens. Bedaquiline is recommended in children age 6 years and older and delamanid is recommended in children ages three years and above. There will be more evidence on younger children available soon. Bedaquiline and delamanid may need to be used in younger children with highly resistant forms of TB and you could ask your doctor to give bedaquiline or delamanid to a child "off-label," or your doctor can request bedaquiline under compassionate use (meaning access to a treatment not yet approved in a country or for a certain population) by writing to JanssenMAc@its.jnj.com. A pediatric formulation of delamanid is also available via compassionate use and information on how to access it can be found here: http://sentinel-project.org/2019/04/10/delamanid-compassionate-use-patient-access-form/. Linezolid is an excellent option for children of all ages, and some providers have had success using PAS in younger children.

The duration of therapy in children depends on the severity of their disease. Children can take an all-oral shorter (i.e. 9-12 month) regimen if the TB is not very extensive. For children with more severe TB, treatment can usually be completed in 15-18 months.

What if I am pregnant or nursing or might become pregnant?

If you have TB and are pregnant or become pregnant, you may have to make some difficult decisions regarding the best way to take care of yourself and your child(ren). There is not much information on safety of most TB drugs in pregnant or nursing (breastfeeding) women. Your health is important and in fact essential for the health of your child(ren). If you are pregnant or nursing, you should discuss with your clinician the risks and benefits of different options and decide what is best for you. You may not want to use certain drugs, or you may want to discontinue nursing or your pregnancy (abortion). If you are not pregnant, but are on TB treatment and may become pregnant, you should ask your provider about birth control options.

Two kinds of drugs used to treat MDR-TB, ethionamide (or a similar drug, prothionamide) and injectable drugs (amikacin, streptomycin, and no longer recommended capreomycin and kanamycin), are thought to be particularly dangerous to the developing baby (fetus). Amikacin and ethionamide/ prothionamide are part of the shorter regimen, but contraindicated for use during pregnancy. As such, pregnant women with MDR- TB are ineligible for the standardized (injectable-containing) shorter regimen. Instead, global standards recommend that pregnant women with MDR-TB be treated with a longer regimen (made for their particular strain of TB with four or more effective second-line medications). Some progressive national programs, including in South Africa, are using the newer drugs bedaquiline or delamanid in these longer individualized regimens for pregnant women. Based on information so far, both of these drugs are thought to be safe in pregnancy. Your doctor can request these drugs for pregnant women under compassionate use by writing to JanssenMAc@its.jnj.com for bedaquiline and medical@otsuka.de for delamanid.

Photo Credit: KUDUwave™ Portable Audiometers

What about side effects?

Your health care provider must inform you about the medicines you take, what the potential side effects are, and how they will be monitored (checked or tested). If they did not give you that information, you should ask for it. Some side effects are expected, like red urine or mild nausea. But some are severe, like liver damage, depression or psychosis, or loss of hearing or vision. These can be stopped if caught early. Your doctor should check that you are getting better, and that includes checking for side effects:

- Injectable drugs (amikacin and streptomycin, as well as no longer recommended capreomycin and kanamycin) can cause hearing loss. Your hearing should be tested (called audiometry) before you start the medicine and monthly afterward, so you know early on if there is damage. If your tests show hearing loss, or if you notice any signs of hearing loss, ask immediately to stop the injectable and switch to delamanid or bedaquiline. If hearing tests are not available, you have the right to ask for another drug such as bedaquiline or delamanid to replace the injectable;

- Cycloserine and other drugs can cause depression and psychosis. If you feel persistently depressed or like you do not want to live, tell your doctor immediately so you can safely switch medicines;

- Linezolid and other medicines can cause tingling, numbness, burning, or pain in the hands or feet. If you feel this, tell your clinician immediately as they may want to lower the dose or pause use of the drug before permanent nerve damage occurs. Your clinician should check for this at every visit. Linezolid can also affect the nerves in your eyes, so you should have your vision checked before starting treatment and each month while you're on treatment, and you should tell your doctor if you notice any changes in your vision while on this medication.

- Linezolid can also affect the way your body makes blood cells. Although TB itself can do this, people on linezolid may have low red blood cell counts ("anemia") or low levels of the blood cells that cause your blood to clot ("platelets") or that fight infection ("white blood cells"). Before starting and while on linezolid, your doctor should check your blood count each month.

- Many TB drugs can damage the liver. You should have a liver function test before you start treatment, and regularly thereafter, especially if you have any liver issues or have HIV. If you experience nausea, vomiting, itching, or changes in the color of your skin or eyes, you should request that your health care providers check your liver function. You should avoid drinking alcohol while on your TB medicine if you can. However, drinking alcohol should never be a reason for not allowing you to start treatment (the same is true if you use drugs or are on opioid substitution therapy [OST]);

- Bedaquiline, clofazimine, delamanid, and moxifloxacin (and many other non-TB drugs) can cause changes in the heart's electrical activity (called QT prolongation). This could lead to serious problems with the heart's rhythm. If you are taking one of these drugs, you should have a test called an ECG (electrocardiogram) before starting treatment, and at 2, 12, and 24 weeks after you start. If you are taking more than one of these drugs, you should have an ECG monthly;

- If you have vomiting or diarrhea, or are taking any of the following drugs—amikacin, capreomycin, kanamycin, streptomycin, bedaquiline, clofazimine, delamanid, or moxifloxacin—you should also have your levels of potassium checked. Potassium is a mineral in your body, like a salt. If your levels are too low or too high, it can cause problems with the muscles, with the way your heart beats, or with other systems in your body. You should ask your nurse or doctor to check your potassium levels regularly, which they can do by taking some of your blood. If your potassium levels are low, you should receive a supplement of potassium and of magnesium, another mineral (salt) important to help your body function properly. You do not need testing for magnesium; you should automatically receive a magnesium supplement. Ask your nurse or doctor if you are getting magnesium if you are not sure, and if you are not, tell them you want it.

Can I work or attend school during treatment?

Everyone whose TB is smear negative (not infectious) should be allowed to work or go to school. You should not have to wait until after you complete treatment to go back to work or school. You should not lose your job because you have TB. TB is not infectious after just a couple of weeks of good treatment (though you must still finish the full treatment course to make sure it does not come back). You do not have to tell your coworkers or classmates that you are taking TB medication. Your employer or school must keep your medical situation private. If your colleagues or classmates may also need to get tested for TB, this should be done in way that protects your right to privacy and confidentiality.

What is counseling, and why should I ask for it if I don't get it?

Counseling means that you receive support and a lot of information and explanation together with your treatment, to answer questions and help you finish your treatment (adherence). Treatment for TB can be difficult, with many pills and possible side effects. Good counseling will help you understand TB better, support you, and help you stick with your treatment.

What if I am living with HIV?

Many people have both HIV and TB, and getting treatment for both is important. If you are on antiretroviral therapy (ART), make sure your doctor knows which medicines you are taking. A small number of TB and HIV medicines do not work well together, but this can be solved by adjusting doses or by changing your drug regimen. If you are diagnosed with HIV and TB at the same time, your doctor should first start your TB treatment, and only start your ART after a few weeks. This is important to avoid a dangerous reaction called immune reconstitution syndrome. People with CD4 counts <50 cells/mm3 should start ART after 2 weeks; people with CD4 counts ≥50 cells/mm3 or people with TB meningitis should start ART after 8–12 weeks.

What is Category II treatment?

You should not be on Category II treatment. Category II is basically regular TB treatment plus an injectable medicine, streptomycin. The old recommendation for people who finished TB treatment but still had TB was to take Category II. In 2015, the WHO issued a "good practice statement" against the use of Category II treatment. The new recommendation is to do drug susceptibility testing to decide which drugs work best for your form of TB. If your doctor tries to give you Category II, you should instead ask for drug susceptibility testing and a treatment regimen based on your results.

If I don't want the treatment my doctor tells me, can I be forced to take it?

No, you cannot be forced. International standards are clear that forcing someone to take TB treatment against their will is ethically wrong. You have the right to accept or refuse all treatment, or a particular treatment. Because TB is infectious (can be passed from person to person), if you refuse treatment entirely, you must take steps to protect other people. This may include staying in respiratory isolation, which means keeping your breath from reaching other people. You can do this either through wearing a mask or through physical isolation in a properly ventilated hospital room or at home. On very rare occasions, your government can make you stay in respiratory isolation as a last resort. This is called involuntary isolation. However, you should never have to do so in a prison cell or similar facility

Because children often need the approval of a parent or guardian to consent to treatment, it is up to the parent or guardian to accept or deny treatment on their behalf. When a parent or legal guardian refuses to give consent, but the medical treatment is considered necessary to prevent suffering or death, including from TB, government authorities may take steps to override the parents' decision. This can only happen through the appropriate legal mechanisms according to the laws of your country.

I am taking care of a family member with TB. What do I need to know?

You can take care of both yourself and your loved one with TB at the same time. To care for yourself, think about your physical and also mental/emotional health. You should have access to counseling and information on how to best protect yourself from TB (see Section II of this series, "Your Rights and TB Prevention").

If the person you are caring for is still coughing up sputum or hasn't gained weight after a few weeks of treatment, they should have access to a drug susceptibility test to make sure that their medications are right for their TB. You can help look out for any side effects and make sure they are having the right tests for side effects at the right times, as noted above. You can also help them keep their jobs or stay in school if they are being discriminated against. TB treatment can be difficult, so if you or the person you are caring for want to start or join a TB support group, you have the right to do so. Support groups can help fight stigma by educating others in your community about TB, helping them understand that TB is preventable and treatable. Remember that the person you are caring for has a right to privacy, and it should be their decision whether they want people to know they have TB.