

# TALKING WITH PEOPLE ABOUT YOUR DIAGNOSIS OF DRUG-RESISTANT TUBERCULOSIS

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After a diagnosis of drug-resistant tuberculosis (DR-TB), one important issue to consider is how to tell people you are living with the disease. This is important so that people can provide support to you during your treatment. The process by which you tell others about your diagnosis is called “disclosure.” Disclosure looks different for everyone, and it is up to you who you share your information with. It is important to remember that this is not usually a one-time event, and it can happen over days, weeks, or months after you learn you have DR-TB.

**The following strategies may help you in thinking about what you would like disclosure of your DR-TB diagnosis to look like:**



**Talk with your doctor, nurse, or other trusted health care providers** to see if they have advice for you on how to do this. Ask them if they are willing to help practice this with you or even to be there with you when you disclose your DR-TB diagnosis to others (if you would like).



**Pick someone you trust who you know will be supportive of you as the first person you disclose to.** It is generally easier to do this with a person or people you trust. This person may also help you share information about your diagnosis with others if this is something you need or want support in doing.



**Make sure you understand your diagnosis and treatment so you can explain it to others.** Your clinic or care providers may have information you can share with others about DR-TB. One important thing to understand and be able to explain to others is the difference between “drug-resistant TB” and other kinds of TB. The term “drug-resistant” means that the usual drugs used to treat TB will not work against the type of TB you have. It is important to emphasize that there are still drugs that will work to treat most types of DR-TB, but that they may need to be given for longer periods of time or have different side effects. DR-TB can still be cured in most people diagnosed with the disease.



**Develop a list of people you think you need to communicate the information about your diagnosis to.** Not all people need to know about your diagnosis, and your health information is private. Ideally, it is up to you who you share this news with, what you choose to share, when you choose to share it, and how this is done.



**Know your rights in terms of housing, work, school, and other social settings.** Anyone who breathes can become sick with DR-TB, and there is no need to feel ashamed or guilty for having this disease. Some people, however, may not react to learning your diagnosis in a positive or supportive way. It is good to have a plan to protect yourself in case the people you tell do not have a positive reaction.



**Prepare yourself for what to do if people ask questions about your health, including those who you did not choose to disclose to.** Being sick with DR-TB can lead to changes in your appearance (for example, weight loss) that others notice. Some of the medications used to treat DR-TB can also lead to changes in your appearance (for example, clofazimine can cause changes to your skin). Even being seen going to the hospital or clinic can cause others to wonder what is happening to you. Some people may ask you directly, and it is good to think ahead of how you might respond to them. In general, it is up to you what you want to tell them. One possible strategy is to thank them for being worried about your health and reassure them that you are doing better. Other people may ask your friends or family members instead of asking you, and you may want to think about how to handle this. Remember, nobody has the right to share information about your health except for you.



**Find ways to take care of your mental health as well as your physical health.** Having DR-TB can be a stressful experience for your body and for your mind. It is important to be kind to yourself during this time. Remember that DR-TB is caused by a germ in the air, and you did not do anything wrong that led to you getting sick. Anyone who breathes can get DR-TB. This may be a difficult time, but it is not always going to be this hard. Surround yourself with supportive people and do things that bring you joy.



**Encourage others to go to the clinic and get checked for DR-TB.** Every year, hundreds of thousands of people become sick from DR-TB. Your most important focus is yourself and regaining your health. But because DR-TB is spread through the air, people who you know who shared the same air may also have been exposed. You may be the first person who became sick or to be diagnosed, but others you know may be sick as well. The sooner DR-TB is diagnosed, the easier it is to treat. So if you feel up to it, you may use your diagnosis as a time to encourage other people to get tested too. Your clinic and health care providers usually have a system for doing this (sometimes referred to as “contact tracing”). They may be able to help and support you in planning for people who shared the same air as you to get tested for TB as well. Ultimately, it is the responsibility of the health care system and the others in your networks to get tested for DR-TB. But sometimes it can help to know that you can refer people to the clinic if they ask what they can do after you disclose your diagnosis to them.

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