

A Family-Centered Approach to the
Treatment and Prevention of Drug-Resistant
Tuberculosis in Children and Adolescents:

COUNSELING TOOLS AND APPROACH

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This material is dedicated to all the brave families who are affected by drug-resistant tuberculosis. They are our inspiration and our guides. May we serve them well.

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OVERVIEW OF THE COUNSELING THEMES, APPROACH, AND TOOLS

Theme 1: What is DR-TB and how does it affect my family?

Issues covered: This theme will aim to introduce the basics of TB and DR-TB to the family in a compassionate and supportive way (including that you can get DR-TB even if you have never had TB before). It will talk about the basics of transmission (focusing on “shared air” in order to avoid blaming or stigmatizing people) and how children become infected with and sick from the TB germ. It will talk about how different strategies might be needed for families in which there is someone else living with DR-TB versus families where the child is the only person with DR-TB. It will also present an overview on how to manage disclosure within the family and how essential it is for families to support one another during the treatment. It will explore the different ways TB can impact families. It will also look at how best to share information with children at different developmental stages when it comes to TB prevention and treatment.

Key questions to address: How did my child become sick with TB? What can I do to prevent my child from becoming sick with TB, especially if someone in our household has it? Who are the people who might give support in the family? Why is this happening to our family? Have you talked to anyone in your family about TB/DR-TB?

Theme 2: Your child will likely get well

Issues covered: This will be a very short theme with a positive message on TB treatment and prevention, that most children go on to have normal healthy lives.

Key questions to address: Can my child go to school/play/get married? Will my child die?

Theme 3: Diagnosis and pathways of care

Issues covered: This theme will first focus on the difference between “sleeping TB” (that is TB infection or what is sometimes called latent TB) and “awake/active TB” (or what is sometimes called TB disease). It will explain how when TB is sleeping it can wake up and make the child sick and treatment will require multiple medications. It will talk about how sometimes in a household or families one person is sick with DR-TB and then someone else might find out a few weeks or months later that they have DR-TB since this is something many people in Khayelitsha can relate to. It will review that sleeping TB can be treated with just one or two medications. It will review how children are diagnosed with TB (including the types of samples that are tested, how we get these samples, and how we look for TB). It will also talk about the role of chest Xray, HIV testing, weight and clinical examination. It will emphasize that there can sometimes be challenges in making the diagnosis and talk about the different care providers/pathways (including specialist referral). It will also stress the importance of communication with families and all the different providers and how trust can be built between families and health care providers.

Key questions to address: How do you know my child has TB? What will happen to my child to see if s/he has TB? Why do different doctors and nurses tell us different things? Why do you need to take an X-ray, draw blood, or get a sputum sample from the nose/throat or stomach?

Theme 4: Treatment specifics and adherence support for different ages

Issues covered: This theme will be complex and will dive into the specifics of treatment of both infection and disease. It will explain the difference between treatment for “sleeping” TB and “active TB” including the numbers and types of medications (with a discussion of how

treatment of TB infection requires fewer tablets and drawing on the experience of the index patient). It will also emphasize that sometimes the color or appearance of the pills can change during treatment even though the medications are the same. It will then talk about different strategies for taking tablets (including dispersibles for the little children, taste masking as we are doing with yogurt for some patients, allowing the children some control, taking doses at night if side effects or going to school, strategies for adolescents). It will also emphasize how to cope with a high pill burden and how to support a “healthy” child in taking the preventive therapy. It will also review practical issues like how the medications are prepared, how the medications should be stored, how children can practice/be coached to swallow tablets. It will also discuss with caregivers that they should always bring the child’s medicine supplies with them to all clinic visits in case providers are giving new or different treatments (to avoid “polypharmacy”). It will also address issues such as how the caregiver can “connect with” the child during treatment.

Key questions to address: Will my child be on the same treatment as I am (index patient is)? If so, should I share my medication with my child? How can I help a child who appears healthy with only “sleeping TB” to take medications? What do I do if my child refuses treatment? What if a dose of treatment is missed? Can I “teach” my child how to swallow tablets better? Where should I keep the medicine?

Tools: Calendars, stickers, wall charts of “journey”, signals a child can put up if they feel good (thumbs up or smiley face) or feel bad (thumbs down or frowning face), alarms/reminder prompts, etc.

Theme 5: The pathway to health, including side effects, monitoring, child development/“growing pains”, and comorbidities

Issues covered: This theme will focus on possible side effects (but in a non-scary and engaging way, focusing on proactivity), how to differentiate side effects from normal child health issues (i.e. teething, growing, menstrual cramps, etc.). It will present possible ideas for managing side effects and when side effects should prompt them to notify the health center or care providers (including CHWs). It will address possible drug-drug interactions or overlapping toxicities with TB treatment/preventive therapy and common childhood remedies. It will also review how the child will be monitored to make sure he or she is doing well on treatment/preventive therapy. It will also talk about how to engage in communication with the child as s/he progresses in the treatment journey and how to engage/help the child engage with different providers. It will also talk about traditional medications and therapies as well. It will also briefly review comorbidities.

Key questions to address: Will the treatment make my child sick? How will I know if the treatment is making my child sick? How can I help my child if s/he feels sick? Should we see traditional providers/take traditional remedies? How can my child and I communicate with each other during treatment? How will I know if my child is getting better? How will I know if I should take my child to the clinic? How can I communicate with the clinical providers if I have worries or there are side effects? How can I offer emotional support to my child/family during this time? How can we manage other sicknesses the child might have (i.e. HIV)

Theme 6: Returning to normal life, including child protection and nutritional support

Issues covered: This theme will focus on all the other aspects of supporting a family/child with TB infection or disease. It will talk about how to know what activities might be “interrupted” as a result of DR-TB and treatment. It will review when it is time for the child

to re-engage with school/creche and with other activities, such as sports, church, etc. It will review strategies for how children can talk to others (including peers, teachers, etc.) about what they are going through. It will emphasize how to support self-esteem and reduce stigma. It will also talk about the importance of nutritional support and where food for children might be accessed. It will review issues of child safety and how caregivers can seek help if they are feeling overwhelmed or need help. It will focus on the need for community care as well.

Key questions to address: Can my child go to school/play/church? What if the other children ask questions or tease him/her? What if the other adults ask questions or are mean to him/her? Should the child take treatment/preventive therapy if he or she has exams/important sporting events, etc.? What if we do not have enough food for the child? Enough clothes? What if nobody in the family is working? What if people in the house are drinking alcohol/using substances? What if someone is hurting the child?

After the six themes, we will also include:

List of Resources (i.e. “Who can help my family get through this period?”)

Tools (Stickers, calendars, “animal tablets”)

Group activities (i.e. things to do with families together or with several children/adolescents who have DR-TB)

Telehealth and community care suggestions (i.e. what can be done via phone calls, home-based care, etc.)

GENERAL COUNSELING APPROACH

Working with children/adolescents and their families as they undertake their DR-TB prevention and treatment journeys can be incredibly fulfilling. It also, however, requires a significant amount of patience and investment on the part of the counseling and health care teams. Each family is unique in terms of the challenges they face and the resources they can call upon while managing DR-TB. Thus, while there are six key “thematic areas” that are covered in these counseling tools, how much information on each topic to cover in a session will depend on what is happening in the family.

This “flexible” counseling approach means that there will not be a standard session(s) or a standard number of sessions held with each family. Rather, the counselor should make sure that the key messages in each thematic area have been conveyed to the family, preferably within a month of the diagnosis of DR-TB being made. The order in which the topics are covered and the level of detail will be determined in partnership with the counselor and the family.

How should the flexible approach be implemented? This can usually start by having the counselor ask the family members/caregivers if they have any questions. Together, a list of the questions can be made and then a plan for responding to each question can be elaborated. If the family members/caregivers do not have any questions, then the counselor can consult the list of possible questions in each thematic area and state “these are some questions other families/children/adolescents ask that we might want to talk about together.”

After the initial session, the counselor should review what has been discussed and then let the family member/caregiver know that there are some other important topics that will be reviewed by sharing the six key themes. A plan can be made with the family/caregivers to talk about each theme area in a way that makes sense.

The counselor should also be sure to engage with the child/adolescent in addition to the family members/caregivers. Tips for establishing rapport and building trust with children/adolescents are reviewed in the body of the counseling themes (see Box 2).

Each thematic area has a background section with information that the counselor should discuss with the family/caregiver(s) and the child/adolescent. Key messages are summarized in the blue boxes. Questions that might be asked or that can be used to prompt discussion are in the pink boxes. Tips, issues to review and counseling pointers are in the green boxes.

In addition to the initial counseling meetings, problem-focused counseling can also be done using this guide and tools. If, for example, a child is struggling with adherence, then reviewing thematic area four can be useful. If a family is facing challenges with food and economic security, then reviewing thematic area six can be useful.

Finally, a structured note sheet for recording the key discussions in each of the thematic areas can be used by counselors to document topics covered and plan for future sessions. An example of such a note sheet is included with the tools at the end of this document.

COUNSELING THEMES

Theme 1: What is DR-TB and how does it Affect my Family?

Families—the groups of people with whom we spend most of our time—form the centers of our everyday lives. Although each family is unique, one thing all families have in common is that they share things. These may include resources, food, housing, feelings, history, memories and the very air they breathe. Tuberculosis (TB) is a sickness that is spread through the air, and thus if one family member becomes sick with TB, all family members who share the same air might also have TB as well. It is important for everyone to be checked for TB so that the family can be as healthy and as strong as possible.

TB is caused by a germ that is breathed into the lungs and it is a very common disease all over the world. It is not caused by any behaviors or supernatural events but simply by the act of breathing, which is something all people do. When the TB germ enters the lung, it can either live there quietly in a “sleeping state” or it can make someone feel very sick, usually with cough, weight loss, fever, and nightsweats—although there may be other symptoms as well. TB can be cured with a combination of different medicines. Sometimes, however, there are medicines, that do not work to kill the TB germ, and this type of germ is called “drug-resistant TB” or “DR-TB”. DR-TB can also be cured but it often requires that more medicines be taken over a longer period of time.

When someone in a family is sick with DR-TB, it affects everyone in the household. Some of this is because families share the same air and thus everyone needs to be checked to see if they also have DR-TB. Families can also be affected if the people with DR-TB are unable to work or do the things they usually do each day because they feel too sick. Families, however, are usually the most important source of support for people when they are going through a difficult time. Thus, when someone finds out they have DR-TB, they desperately need their families to help support them during this difficult time. It may be hard for the person who has been told they have DR-TB to talk with their family about it, as the person might be afraid their family will be angry or blame them for being sick or for making other in the family sick. When someone is diagnosed with DR-TB, the health care workers and counselors should help the person make a plan for sharing their DR-TB diagnosis with others in the family (see Box 1).

Children and adolescents in a family need special attention when someone is diagnosed with DR-TB. They may have worries or be sad that someone is sick and thus require emotional support. They share the same air as the person who was diagnosed with DR-TB and thus they may also have the DR-TB germ in their lungs. When children/adolescents have the DR-TB germ in their lungs, they may be at a higher risk of becoming sick with DR-TB. For this reason, it is important to have a health care provider assess them. It is also important to talk with them and answer questions they may have about DR-TB. Children and adolescents often understand far more than adults think they do, and it is important to talk with them in a caring way aimed at a level they can understand. Some tips and suggestions for talking with children and adolescents are in Box 2. Sometimes, it is a child or adolescent who is the first person in the family diagnosed with DR-TB. Different strategies may be needed when this happens compared with when an adult is the first person in the family to be diagnosed with DR-TB (see Box 3)

When a family is facing DR-TB, they will need help and support as they embark on their journey together. Emphasizing the important role they can play in helping one another is essential in helping them return to health.

BOX 1: TIPS FOR MANAGING DISCLOSURE OF DR-TB TO FAMILY MEMBERS



- Ask the person who has been diagnosed with DR-TB if there is a person or persons in the family who is supportive to them and suggest they talk with this person first;
- Practice what they will tell this person: emphasize that DR-TB is a curable disease, that it is caused by a germ, and that because it is spread in the air, everyone who breathes the same air should be check for DR-TB;
- Offer to be with the person when they share their diagnosis—either at the clinic or in the household;
- Ask the person about any worries or fears he or she has and help him or her make a plan to address those fears;
- Ensure that the person will not face physical harm when telling others about his or her DR-TB diagnosis;
- Plan for how the support person identified can help with disclosure to the rest of the family;
- Remind the person that DR-TB is curable if he or she is able to take his or her medicine correctly and that he or she and the family will return to health;
- Listen to any worries or fears the person may have about how DR-TB might affect his or her family;
- Remember that family members may have concerns and worries about how best to help the sick person and it is important to listen to these concerns and explore the types of support that are available;
- Check in after the disclosure has taken place to see how the person is doing and when the family members are able to be assessed.



- Start by building trust with the child/adolescent before talking about DR-TB. For very young children, this could be done by playing with a toy or coloring/drawing together. For school-aged children, this could be done by showing them a picture and asking them to explain what is going on in the picture (See attached images). For adolescents, this could be done by asking them about what activities or music they like or what their friends like to do. These interactions will help build a rapport and relationship with the child, which is essential to do;
- Consider speaking with the child/adolescent in a one-on-one setting at the beginning. This will allow for a relationship to begin to develop and show the child/adolescent that s/he matters as an individual. Later, bring the caregiver into the discussion as well.
- Sit by the side of the child/adolescent and not across from him or her, as approaching the child/adolescent in a gentle and friendly fashion can help build trust;
- Bring some crayons or pens and paper for drawing and bring a toy or toys for playing;
- Let the child/adolescent be in control of the conversation, as this will help them be more comfortable in a situation where things feel out of control;
- Ask the child/adolescent what s/he knows about what is happening in the family. Give the child/adolescent time to answer this question. The child may feel more comfortable drawing or play acting what is going on. Give the child/adolescent time and space before jumping in.
- Follow the lead of the child/adolescent in answering questions. Always answer honestly but try not to give excess information that the child/adolescent did not ask for. Children/adolescents may process information differently and take time to grasp what is going on, so patience is essential;
- Reassure the child/adolescent that many people are working hard to help the family member(s) to return to health;
- Remind the child/adolescent that his/her family loves them very much no matter what might be going on;
- Ask the child/adolescent if he or she has any questions or other things he or she wants to talk about, allowing him or her to be free to bring up issues of importance;
- Do not be judgmental or scold the child/adolescent but rather try to explore issues with them;
- Make a plan to speak with the child/adolescent again and ask him/her what topics s/he would like to discuss at the next session;
- As much as possible, give the child/adolescent choices throughout the sessions and discussions, since often their choices and control are taken away from them during a period of illness in themselves or their family members;
- Do not be overly directive to the child/adolescent except when absolutely necessary, as “telling them what to do” is not usually as effective as allowing them to be active decision makers;
- Adolescents may be grappling with difficult feelings and emotions, so allowing them to express these is important, as is understanding these emotions may override some of their logic;
- Share these tips with the child’s/adolescent’s caregivers so that they too can understand how best to talk with their child/adolescent about what is happening;
- Understand that not all the information can be shared in one visit with the child/adolescent and that the goal is building a caring relationship in which questions that come up can be answer and fears or worries can be allayed. Encourage this same kind of relationship between the child/adolescent and his or her caregiver as well.



BOX 3: WHEN A CHILD IS DIAGNOSED WITH DR-TB FIRST

- Remind the family that DR-TB is spread through the air, and that anyone who shares air might be at risk for DR-TB;
- Explain to the family that children/adolescents can often be the first person in a family who gets sick because they are less able to fight off the DR-TB germ than adults;
- Discuss that it may not ever be possible to know where someone has breathed in the DR-TB germ, but that the most important thing is to provide support to that person going forward so he or she can get well again;
- Ask the family when they will be able to be checked for DR-TB;
- Reassure them that most children/adolescents with DR-TB do very well with treatment and go on to lead normal, healthy lives.



QUESTIONS THE FAMILY OR CHILD/ADOLESCENT MIGHT ASK:

- How did I/my child become sick with DR-TB?
- What can I do to prevent my child from becoming sick with TB, especially if someone in our household has it?
- Why is this happening to our family?
- What is the best way to talk to people in our family about TB/DR-TB?



KEY MESSAGES:

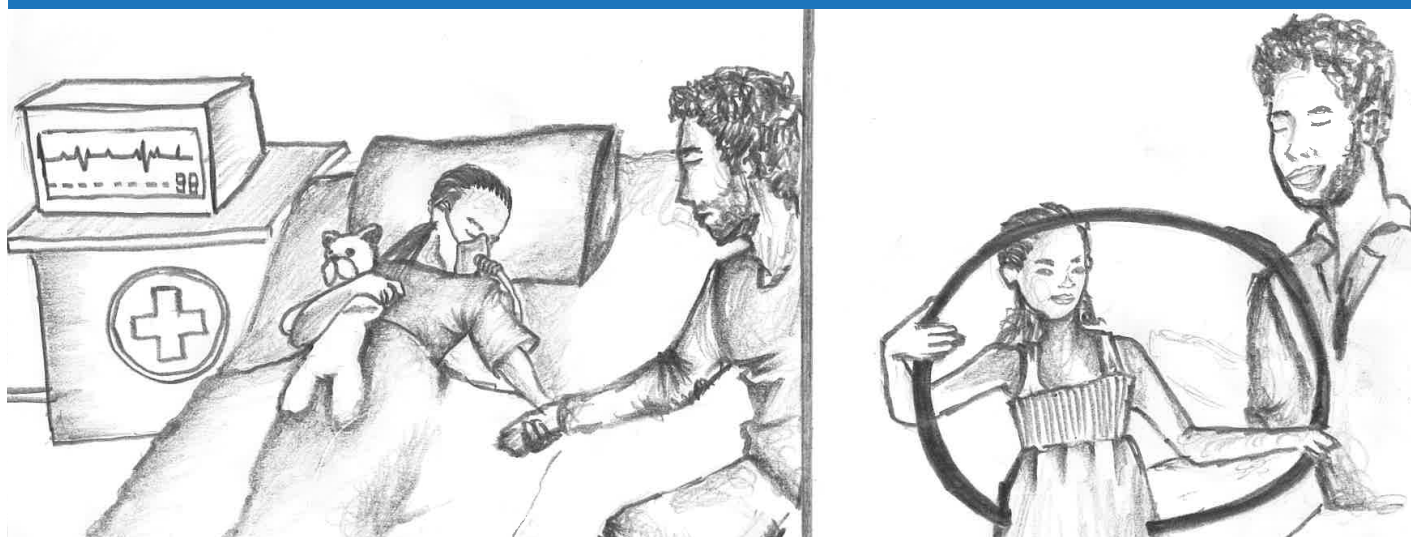
- Families share many things—including the air they breathe—and if one person has TB, it affects everyone;
- Because families share the same air, it is important that when one person is diagnosed with TB that everyone gets checked to see if they have TB too;
- TB and Drug-Resistant TB are caused by germs and can happen to anyone who breathes, not because the person or the family did anything wrong or was cursed/wicked;
- People with DR-TB need the support, love and understanding of their families



Theme 2: You Child will Likely Get Well

Families in which someone is living with DR-TB face multiple stresses, and one of the biggest ones is their worries about their children. They may be worried that because they share the same air, their children/adolescents may also have the DR-TB germ living in their lungs. They may worry that if a child/adolescent is also sick with DR-TB that s/he will not get better. They may also worry that even if that child/adolescent does get better, that s/he will not be able to have a normal healthy life, both because of fears that the DR-TB has damaged their body or because of the stigma surrounding DR-TB. It is not only the adults in the family that may have these worries, but the children/adolescents themselves, and it is important to talk with them all in a frank and open fashion and to answer any questions they may have.

For children and adolescents who are not yet sick with DR-TB but who have been exposed to it in their households, it is important to offer them preventive therapy. The family and child/adolescent can be reassured that if they complete this treatment, the chance of becoming sick with DR-TB is very low. For children and adolescents who are sick with DR-TB, it is important to reassure them and their families that almost all children/adolescents who take their treatment become well again. Box 4 contains tips for talking with children/adolescents and their caregivers about concerns and hopes for the future.



BOX 4: TALKING WITH CAREGIVERS AND CHILDREN/ADOLESCENTS ABOUT THEIR FUTURE HOPES AND FEARS



- Find a quiet spot to talk with the child/adolescent using the tips suggested in Box 2;
- Specifically ask the child/adolescent what his/her hopes are for the future. With younger children, consider asking “what do you want to be/do when you grown up?”
- Listen to what the child/adolescent has to say or encourage him/her to express this through play or drawing;
- Ask the child/adolescent if s/he has any worries or fears about the future;
- Listen to what the child/adolescent has to say or encourage him/her to express this through play or drawing;
- Include the caregivers in these discussions as well by sharing what the child has shared/drawn;
- Ask the caregiver what his/her hopes are for the child’s/adolescent’s future (if there is more than one child/adolescent on preventive therapy, ask this for each child/adolescent);
- Ask the caregiver if s/he has any worries or fears about the child/adolescent’s future;
- Provide reassurance wherever possible.

QUESTIONS THE FAMILY OR CHILD/ADOLESCENT MIGHT ASK:

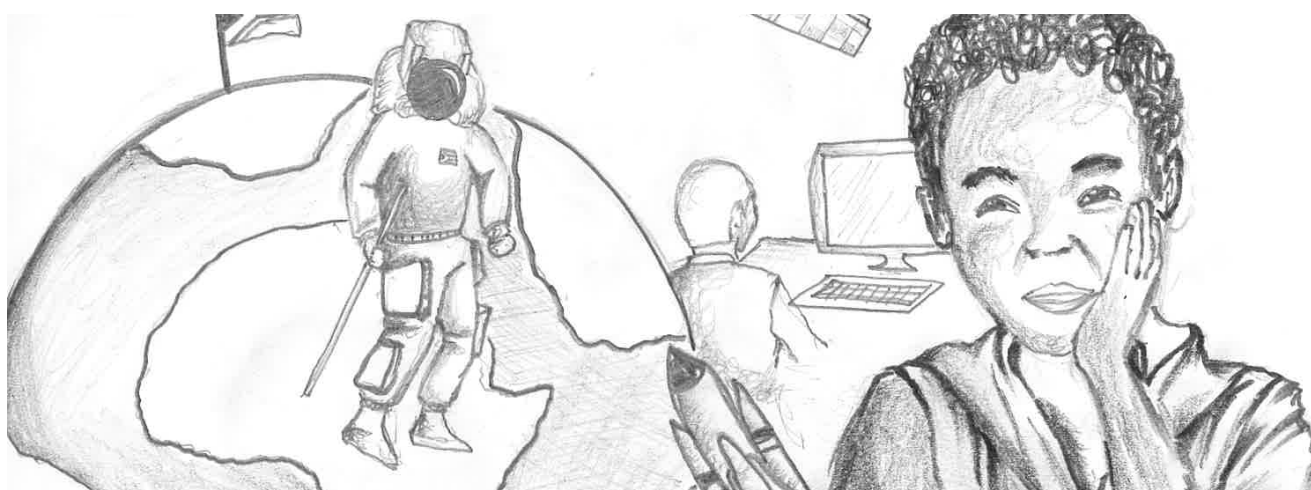


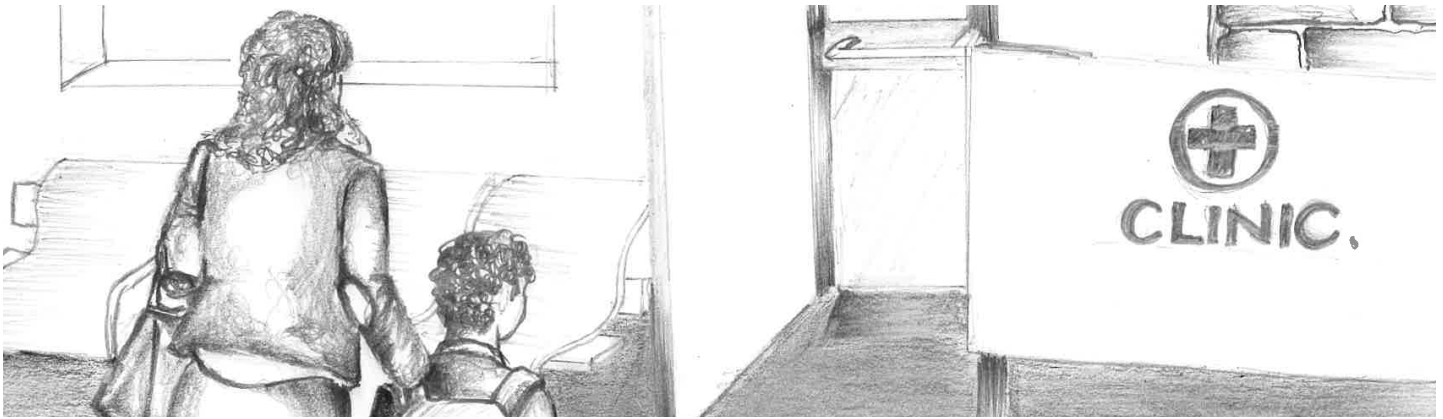
- Can my child go to school/play/get married?
- Will my child die?
- Will my child have permanent or ongoing problems from the DR-TB

KEY MESSAGES



- Even though DR-TB is stressful, most children/adolescents who have DR-TB go on to lead long, normal, healthy and productive lives.





Theme 3: Diagnosis and Pathways of Care

If there is a child/adolescent who has shared the same air as a family member who is diagnosed with DR-TB, it is likely s/he has the DR-TB germ living in his/her lungs. When the germs enter into the lungs, there are two different things that can happen. If only a few germs enter the lungs, the body is able to keep the germs under control and the germs then “go to sleep”. They are still there, usually in only a small part of the lungs, but they do not cause any problems or make anyone feel sick. These sleeping germs can “wake up” later and cause problems, and this is why sometimes in families there are many people who become sick with DR-TB either at the same time or even several months or years later. These sleeping DR-TB germs, however, can be killed or gotten rid of with a course of medication. This is called “preventive therapy” or treatment of infection and only requires one (or sometimes two) medicine(s) since the germs are sleeping and there are only a few.

If a larger number of germs enter the lungs, it is harder for the body to control them. These germs then stay awake, can travel to other parts of the lungs or the body, and they can make people feel sick. This is called “active” DR-TB because the DR-TB germ is growing in number and doing things in the body, which can lead people to have symptoms, including coughing, fever, losing weight, failing to grow normally, feeling tired/sleepy, or sweating in the night. Because there are a larger number of DR-TB germs in the body, treatment for this “active” DR-TB requires that several medications be given to stop the germs. Children and adolescents may be at higher risk of developing active DR-TB if someone in their household has been diagnosed with DR-TB and they are sharing the same air (see Figure 1). Sometimes young children or children without a normal immune system can become sick from many TB germs, and these germs can spread through their blood and go anywhere in the entire body.

Both sleeping and active DR-TB are problems that can be readily treated in children/adolescents, and this is one reason why health care workers want to know about any family/household members when someone has been newly diagnosed with DR-TB. They will want to talk to the children/adolescents and determine if they have sleeping DR-TB or active DR-TB. If they decide the child has sleeping DR-TB, then they can give the child a medication for a few months (usually six months) to stop the DR-TB from waking up and making the child/adolescent sick. If the child or adolescent has active DR-TB, then s/he will be treated with several medications to for several months (usually 9 to 18 months) to make him or her healthy again. This will be discussed in the next session in more detail.

How will the health care providers know if the child/adolescent has sleeping DR-TB or active DR-TB? There is no one test that can determine this 100%. Usually, the child/adolescent will be seen by a nurse or a doctor who will ask questions about the child/adolescent. Some

of the questions will try and determine how much of the DR-TB germ the child/adolescent might have in the lungs. Some questions might ask about any symptoms the child/adolescent is having. While cough and fever might be more common in older children and adolescents, younger children with active DR-TB might not cough at all, but rather they may be more tired or irritable or not as interested in their usual activities. Some other symptoms that the doctors or nurses will ask about include fevers, sweating in the night, and either weight loss or failure to gain weight. If the child/adolescent is losing weight, caregivers might notice that his/her clothes do not fit the same, and while all people may have some sweating at night during hot months, if the child/adolescent sweats so much that the blankets or sheets are wet/need to be changed, this may be something important to tell the doctor or nurse (See Box 5 for a list of possible signs/symptoms of “active” DR-TB).

After asking these questions, the doctor or nurse will usually weigh the child and then examine him or her. The examination is important because while DR-TB usually affects the lungs, in children it can also affect other parts of the body too. For some children, the doctor or nurse may also recommend a chest X-rays since it will help them see if there are any signs of the TB germs in the lungs. It is also recommended that children/adolescents who have breathed in the DR-TB germ have a test for HIV.

If the child/adolescent has symptoms, is losing weight or not gaining weight, or if the chest X-rays shows some signs that there might be DR-TB germs in the lungs, then the doctor or nurse may want to do some other tests. There is no one test that can say for sure if the child/adolescent has “sleeping” DR-TB or “active” DR-TB, which can be very frustrating for families. Usually, the doctors will look at multiple different tests to make a decision about whether or not the child/adolescent needs to be treated for active DR-TB. One common test the doctors or nurses may do is one to look for the DR-TB germ in the phlegm. Older children and adolescents can usually cough their own phlegm out and they may be asked to do this and collect it in a container which is then taken to look for the DR-TB germ. Young children often cannot cough their own phlegm out and many of them actually swallow their phlegm. Because of this the doctor or nurse may try to collect phlegm from their stomach, usually by putting a tube into the stomach through the nose to collect the phlegm. Sometimes they may give the child some salt water to breath in as a mist/steam and then try to collect phlegm after this. Sometimes they may try to collect urine or poop from the child to look for the DR-TB germ there as well. The doctors may take different X-rays or pictures of the child, and they may want to get the opinion of doctors in other places before starting the child on treatment. This can be a difficult journey for the child/adolescent and the family and it is important to talk to the child/adolescent as well as caregivers about what to expect (see Box 6 for a tips on how to talk to children and adolescents about these tests).

One essential element of the journey to find out if the child/adolescent has “sleeping” or “active” DR-TB is communication and trust between the child/adolescent, the caregivers, and the health care providers. Children and adolescents might have questions about why they are having tests, and it is important to talk with them about this. Caregivers and families likely have questions too, and everyone has a right to have all their questions answered. See Box 7 for some tips on how to communicate with health care providers during the journey to determine if the child/adolescent has “sleeping” or “active” DR-TB.

Recently, there has been a lot of attention given to a type of germ and disease called “COVID-19”. COVID-19 is also cause by a germ that can be spread through the air or through small drops that pass between people. Some of the signs and symptoms of

COVID-19 are similar to TB. If your child/adolescent is being tested for COVID-19, it is important that s/he also be tested for TB. If your child/adolescent is being tested for TB, it is important to ask about testing for COVID-19. While there is generally a lot of fear about both these diseases, most people with COVID-19 and DR-TB do very well and get better following the treatment and advice of their healthcare providers.

BOX 5: SIGNS/SYMPTOMS OF DR-TB IN A CHILD



- Fever
- Cough
- Weight loss/clothes are too loose or no longer fit right
- Failure to gain weight
- Tiredness
- Irritability
- Loss of interest in playing
- Loss of interest in usual activities
- Sweating in the night/need to change bedding
- Lumps in the neck, under the arms, or in the groin
- Back pain or new curve to the spine
- Children with TB may not cough!

BOX 6: TIPS FOR TALKING TO A CHILD/ADOLESCENT ABOUT WHAT TO EXPECT AT THE CLINIC



- Explain to the child/adolescent that they are very loved and that their health is important to the caregiver/family and that is why they are going to the clinic—to do everything they can to keep the child healthy;
- Ask the child/adolescents if s/he has any questions or worries about the clinic;
- If the child/adolescent has been to the clinic before, it may help to remind him/her about this, especially if it was a good or positive experience;
- Explain to the child/adolescent what will happen at the clinic—that they will be asked some questions and have their weight checks and an examination;
- Ask the child/adolescent again if s/he has any questions or worries about the clinic;
- Explain to the child/adolescent that he or she might also have a picture taken of the lungs called an X-ray and that this will not hurt or cause them any pain;
- If the doctor or nurse does recommend additional tests for the child/adolescent, make sure that the child/adolescent has the chance to ask questions about these tests and why they are being done;
- Do not lie and tell the child/adolescent that a test that might be painful “will not hurt” (for example, drawing blood), since this will cause mistrust. If the child does need to have a painful procedure, explain to him/her that the pain will only be temporary and that s/he will not be alone;
- After the visit to the clinic/tests are done, remember to check in with the child/adolescent to see if s/he has any questions.



BOX 7: TIPS FOR COMMUNICATING WITH HEALTH CARE PROVIDERS

- Remember you have a right to ask questions about what is happening to your child/adolescent, even if the doctor/nurse seems very busy;
- If there is not enough time to answer all of your questions, ask if you can return to ask the questions at another date or time;
- Consider bringing another adult or person with you to help ask questions and to hear/understand what the doctor/nurse is telling you;
- If you are able to, write down (or have someone write down for you) questions you may have for the doctor/nurse before the visit, as it is common to forget things during a busy visit;
- Remember that while doctors/nurses study for many years and know a lot about health, they are also human and sometimes do not have the perfect answers;
- Work with the doctor/nurse to make decisions together about what is best for you and your child/adolescent—caring for children with DR-TB is a partnership;
- Make sure you know how to reach your child's/adolescent's doctor/nurse in case you need to talk with him/her;
- Make sure you know when the next appointment is for the child/adolescent and when you might expect to know the results of the tests;
- Be confident as there is no question that is too big or small to ask.



QUESTIONS THE FAMILY OR CHILD/ADOLESCENT MIGHT ASK:

- How do you know my child has active DR-TB?
- What will happen to my child to see if s/he has “sleeping” DR-TB? “Active” DR-TB?
- Why do different doctors and nurses tell us different things?
- Why do you need to take an X-ray, draw blood, or get a sputum sample from the nose/throat or stomach?
- Why do they need to do an HIV test?



KEY MESSAGES

- “Sleeping” DR-TB happens when there are only a small number of DR-TB germs in the body which means the child or adolescent does not feel sick and the small number of germs can be treated with usually one medicine taken for 6 months;
- If not treated, “sleeping” DR-TB can “wake up”. “Awake” DR-TB happens when there is a larger number of DR-TB germs in the body which can cause symptoms (fever, tiredness, cough, weight loss/failure to gain weight) and which need to be treated with multiple medications for several months;
- Most DR-TB tests were designed for adults, thus diagnosing DR-TB in a child/adolescent may require several different types of tests and several visits to the doctor for examinations, chest X-rays, obtaining samples (such as blood, phlegm urine or stool), and testing for HIV;
- Communication with all the people involved in the health care of the child is key to making sure the child/adolescent has the best health care possible;
- COVID-19 and DR-TB have similar symptoms and if anyone in the family has been tested for COVID-19, he or she should also be tested for DR-TB.





Theme 4: Treatment specifics and adherence support for different ages

Children/adolescents who have DR-TB infection or disease need to take medications for at least six to 18 months. For children with DR-TB infection (i.e. “sleeping TB”), one medication is usually given for six months, and the dose of the medication will depend on the weight of the child. Even though only one medication is given, there may be as many as three or four tablets to take, depending on how much the child weighs. The main medications used to treat DR-TB infection are called levofloxacin (the most common), isoniazid, and delamanid. If the child/adolescent is on the medication called isoniazid, s/he will also be given a vitamin to take with the medication. Because there are only a small number of germs in the lungs of children with “sleeping” DR-TB, only one type of medication is needed to treat the infection.

For children/adolescents with DR-TB, it is necessary to give more than one type of medication. This is because there are a larger number of TB germs in the lungs making the child feel sick. When there are more DR-TB germs in the lungs, more medications are necessary. Some children/adolescents will take four different types of medications while some may have to take as many as seven. The number of drugs needed will depend on type of DR-TB the child/adolescent has. As with DR-TB infection, the dose medications used for treating DR-TB disease will be based on the weight of the child and thus a child may have to take multiple tablets. Treatment of “awake” DR-TB disease lasts between 9 and 18 months, depending on how sick the child/adolescent is. During the treatment, if the child/adolescent is doing well, it may be possible to stop some of the medications or only have to take them on certain days. The child’s doctor/nurse will make the decisions about stopping medications. It is likely the child/adolescent will gain weight during treatment and thus the doses of some medications may need to be increased. The names of the medications along with pictures of what they look like is shown in Figure X. Sometimes, however, the appearance of the tablets may change over time, especially if they are bought from different companies. If you notice a change in any of the tablets your child/adolescent is taking, remember to ask about which medication it is and why it looks different.

Sometimes if there is an adult in the household taking DR-TB treatment, the child/adolescent might receive treatment with different medications. This could be for several reasons. First, some medicines might be safer to give to children/adolescents and thus

included in the child's regimen but not in a regimen for an adult. Second, children/adolescents might receive lower doses of medicines than adults, and thus their tablets might look different. Finally, sometimes younger children might be given special tablets that can be mixed with food/liquid so they are easier for them to swallow. Thus, even if there are multiple people in the family who are on treatment for DR-TB, not all of them will receive the same regimen. Even if family members are on some of the same medications, it is important that they not share or split medicines with one another since each person's therapy has been designed to meet their specific needs. If there is not enough medication or something happens to the medication, then the family should contact the health care providers to obtain an additional supply.

It is important to make sure that you and your child/adolescent understand how to take the medication. Usually, a counselor will review the medications with you. Sometimes the nurse or doctor may ask you to come to the health center for the first few days of taking treatment to make sure everyone understands how it should be taken. It is also possible that they may visit the house. They might provide you with a pill box and help fill it so it is clear which medications should be taken each day. Having a picture chart of the pills may help remember what to take when, as can a wall chart on which doses taken are marked off. Most of the medications only need to be taken once a day, but some need to be taken more than once. If the child/adolescent has trouble taking all the tablets, s/he can split them to take some in the morning and some in the evening, provided they take the same types of tablets together. Some tips for helping remember how to know which medications to take are shown in Box 8.

Helping children/adolescents to take medications can be challenging, with different issues coming up depending on the age of the child/adolescent. For very young children, the tablets may be difficult to swallow, while older children may refuse to take medications in order to exert control. Children/adolescents on treatment for DR-TB infection may not feel sick and thus may not understand why they need to take the medications. Some tips for helping support children/adolescents to take their treatment every day are included in Box 9. Box 10 includes tips for taking medications during special times (i.e. traveling for holidays or funerals) or circumstances (i.e. during examinations or important sporting events)

The preparation of the medications may be complicated as well, and it is important to ensure there are clear instructions from the health care providers about how to get the medications ready to give to the child/adolescent. Sometimes, smaller children will be given tablets that are called "dispersibles" meaning that the medications can dissolve in liquid like water, milk, or juice. Figure X shows an example for how these medications can be prepared and given to children. Some medications only come as tablets and have to be swallowed. See Box 11 for tips on coaching children/adolescents to swallow tablets. Sometimes the taste of the tablets is very bitter, and masking them with yogurt, juice, jam, or another flavor the child/adolescent likes can be very helpful. It is essential that the medications be stored out of reach of all children in the household so they do not find them and accidentally take them. The medicines should be stored in a cool, dry place with labels so that people know the names of the medications.

There may be a time when the child/adolescent needs to go to the hospital or see another specialist, and these additional health care providers may prescribe new or additional medications. It is important to always take the medications the child/adolescent is taking for DR-TB to these other health care visits so that the health care providers do not accidentally prescribe similar medications or medications that could cause problems if they are taken with the DR-TB medicines. Sometimes children with DR-TB infection or disease have other health problems, including asthma, HIV, or diabetes. It is important to make sure all health care providers are aware of all the child/adolescent's health problems and

medicines. Some of the tips for helping children with DR-TB treatment also apply to treatment for other health problems, including HIV.

Finally, it is important for caregivers and children/adolescents to maintain and build other aspects to their relationships. When a child/adolescent has to take medication, especially for months at a time, the medication taking aspect of the relationship can seem to take over. There may be conflicts between family members around the taking of the tablets—especially if they are difficult to swallow or there are side effects. Box 12 has some tips for helping caregivers and children/adolescents connect with one another during the treatment of DR-TB infection and disease.

BOX 8: TIPS FOR REMEMBERING HOW TO TAKE MEDICATIONS



- Ask the health care providers to give a picture chart of each medicine and the number of tablets of each that should be taken in the morning or at night;
- Ask for a pill box to be provided and for help filling the pill box—remember to bring the pill box to each clinic visit;
- Work with the child or adolescent to make a “wall chart” or tick sheet to mark after each dose of the medicine is swallowed. Stickers can also be used to indicate that a dose was taken;
- Use a calendar with images that are appealing to the child/adolescent and mark off the days when the medicines are taken;
- Set an alarm on a phone or clock to remind the child/adolescent to take the medication—consider using a happy or special ring tone or song as the reminder;
- Ask a trusted family member or friend to help remember to take the medicine;
- Plan the medication taking around something that happens every day—such as brushing teeth or putting on shoes/underwear;
- If a child/adolescent misses a dose of medicine, let their health care providers know. If the medicine is usually taken in the morning, it can be taken at night if the missed dose is noticed before then;
- If the child/adolescent misses multiple doses of medicine, try and figure out why and make a plan for having additional reminders.

BOX 9 TIPS FOR SUPPORTING CHILDREN/ADOLESCENTS TO TAKE TREATMENT EVERY DAY



- Every child/adolescent is different and there is no one-size-fits-all strategy;
- Different strategies may be needed as the child grows and their development progresses;
- Children/adolescents who have to take medications often feel that they have no control, so allowing them some choices can be helpful;
- While there cannot be a choice between taking medication or not taking medication, children/adolescents can be given some choices in the process, such as where they want to take the medications, what time of day they want to take the medications, or the order in which they want to take the medications;
- Positive reinforcement always helps—consider singing a special song for the child/adolescent, having the family clap and cheer for the child/adolescent, or doing a “high five” or some type of other celebratory signal when the child/adolescent takes the treatment.
- For small children, having the child sit on the lap of a loved sibling or family member while taking the medication may help;
- For older children, involving play in the medication administration may help—allow them to “give medicine” to a favorite toy or doll, or consider making a game to play around the taking of the medication;
- For adolescents, allowing them to resume some responsibility for their own medications may help—and they need encouragement too, such as listening to a song they love while taking treatment;
- Mixing the medications with foods or drinks may help with the bitterness or difficult taste;
- Some of the medications may have a smell that the child/adolescent finds upsetting or unpleasant—taking the medicine outside or by an open window might help with this;
- Set short-term goals with the child/adolescent around medication taking—for example, if you take all your tablets this week, we can go play together in the park;
- Consider rewards for meeting short term goals, including sweets, air time, or another small gift the child/adolescent will appreciate;
- Punishing or fighting with children/adolescents—including holding them down or forcing them to swallow by holding their noses or blowing on their faces—may seem like a short-term answer but it usually backfires in the longer-term since children have to take DR-TB medications for several months;
- Ask the child/adolescent if there is anything s/he would like to try that would make it easier to take the medications, and listen to what they have to say—sometimes the best advice comes from the children/adolescents themselves;
- Ask the child/adolescent what his or her motivation for taking treatment is and then remind him/her of this motivation on days when treatment may be difficult. For example, a child may say “I want to take my treatment so I feel strong enough to play football with my friends.” Remind him or her of this goal on days when s/he may not want to take the medicine by saying “Remember how much fun you had playing football with your friends after being sick for so long? If you keep taking your medicines, you will be able to keep playing football and run faster and harder.”

BOX 10: TIPS FOR TAKING MEDICATIONS DURING SPECIAL TIMES OR CIRCUMSTANCES



- If the family is traveling for a holiday or event, remember to let the clinic know and make sure there is enough medicine to last during the time the family or child/adolescent will be away;
- If traveling, normal routines can be upset and thus additional reminders should be considered;
- If someone else will be looking after the child during the travel, then it is important that s/he understand why and how to give the medications;
- Some children/adolescents may not want to take their medications during examinations or sporting events—it is important to stress that medications should be taken each day, but allowing the child/adolescent to take the medication at night or after the exams/events are finished for the day might help.

BOX 11: TIPS FOR HELPING CHILDREN/ADOLESCENTS SWALLOW TABLETS



- Practice “swallowing” with pieces of fruit or candy that are about the size of the tablets the child/adolescent needs to take—or start smaller and build up to the tablet size;
- Give the tablet with yogurt, jam or a peanut spread—something that is thicker or easier to swallow than just a liquid;
- Ask if there are any dissolvable or “dispersible” tablets that can be used to help make it easier for the child to swallow;
- If the child is on dissolvable medications, mix and administer them with a small amount of liquid or food (a spoonful of something is usually enough)—using too much liquid can make it difficult for the child to finish the medicine and may cause nausea or vomiting afterward;
- Place the tablet under the tongue—instead of on top of the tongue—as some children/adolescents find this both less bitter and easier to swallow;
- Have the child practice swallowing with her/his head in different positions—with head tipped back, head tipped forward, head turned left and head turned right—ask him or her to pick which position was easiest to swallow and encourage them to use that position when taking the tablet;
- Try practicing taking the tablet while drinking through a straw—if this helps the child then have a straw available when they take their medications;
- Play a game with the child where you watch a bird swallow some water—note how the bird tips his head back and shakes his throat and imitate doing this with the child;
- Have the child clap his/her hands or wiggle his/her toes while trying to swallow the tablets, and this can help distract them and make the tablets easier to go down;
- If there is an adult or older child/adolescent in the family taking tablets, have him/her show the child how to swallow tablets and practice taking their medications together.

BOX 12: TIPS FOR HELPING CHILDREN/ADOLESCENTS AND CAREGIVERS CONNECT WITH ONE ANOTHER DURING TREATMENT



- Let the child/adolescent express any anger or sadness s/he might have and do not take it personally;
- Explain to the child/adolescent that you are on their “team” and you are both working hard to make sure they are healthy;
- Remind the child/adolescent that even though it may seem like you are making them do things that are hard or difficult for them, you love them and want them to get well;
- Ask the child/adolescent if there is anything you could do differently that might make it easier for them;
- If taking treatment is extremely difficult, consider asking for help from another adult so that your focus can be on supporting the child/adolescent;
- Spend some time with the child/adolescent doing things that have nothing to do with DR-TB or treatment. This can include simple things like singing a song together, going for a walk, or playing a favorite game. This can help build and strengthen normal family ties;
- Do not be afraid to expect things from the child/adolescent as you might for other children in the family—while the child/adolescent on treatment deserve compassion and understanding, having boundaries and expectations are also quite important.

QUESTIONS THE FAMILIES OR CHILD/ADOLESCENT MIGHT ASK

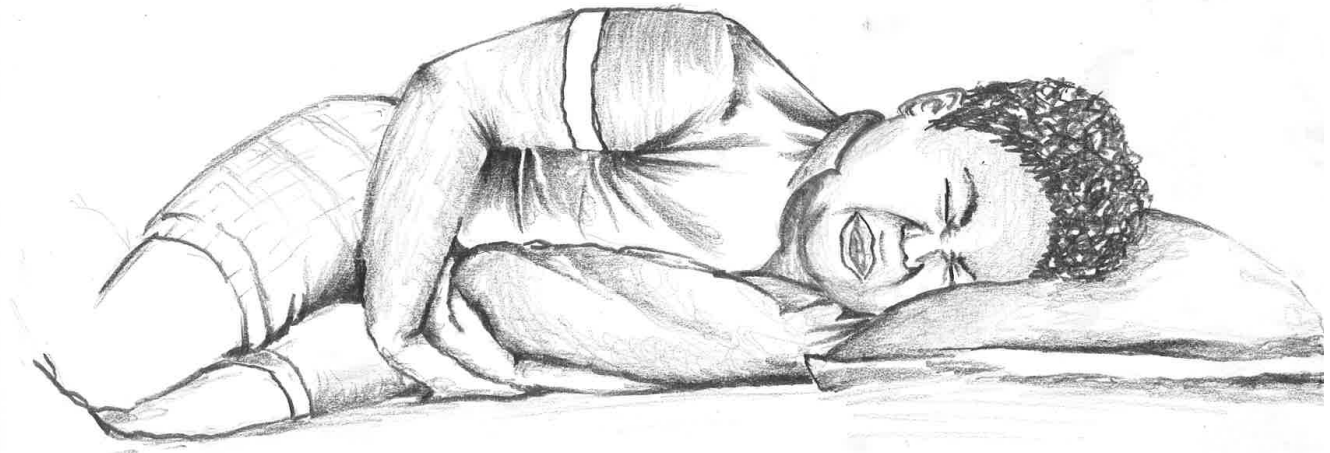


- Will my child be on the same treatment as I am (index patient is)?
- If so, should I share my medication with my child?
- How can I help a child who appears healthy with only “sleeping TB” to take medications?
- What do I do if my child refuses treatment?
- What if a dose of treatment is missed?
- Can I “teach” my child how to swallow tablets better? Where should I keep the medicine?

KEY MESSAGES



- “Sleeping” DR-TB is usually treated with one medicine for six months while “awake” DR-TB is usually treated with several medications for nine to 18 months;
- Children/adolescents with DR-TB may take different treatment regimens from adults, and it is important that each person in the family on treatment have his/her own supply that is not shared;
- Counselors and nurses are available to provide support to each person to remember to take the medicine correctly each day and may provide support such as observed therapy, pill boxes, and wall charts to assist in treatment adherence;
- Different adherence support strategies may be needed at different ages and finding the right method to support the child/adolescent may take patience and practice and need to be adapted over time—positive approaches almost always work better than punishing or forceful strategies;
- Medications should always be stored in a safe, dry place that is out of reach of young children’
- Families should make sure that health care providers are aware of any other health conditions (i.e. asthma, HIV, diabetes) that a child/adolescent has and plan for how the DR-TB medicines can be taken with these other treatments;
- Families should make time to engage in other activities together, since DR-TB and the taking of medications can often be overwhelming.



Theme 5: The pathway to health, including side effects, monitoring, child development/“growing pains”, and comorbidities

When a child/adolescent is on treatment for DR-TB infection or disease, s/he may experience what are called “side effects”. Side effects are things the medicines can cause to happen with the body as a result of treatment, and it is important to know about them for several reasons. First, knowing about them can help families plan for how they will handle it if the side effects develop. Second, sometimes the side effects are a sign that the child/adolescent to she his/her doctor even before the scheduled appointment. Finally, knowing about the side effects can also help families understand what may be related to the treatment versus other things that happen to children/adolescents as they are growing up (such as teething, menstrual cramps, etc.).

Most children/adolescents who are on treatment for DR-TB infection or disease do very well with therapy and have few or no side effects at all. And some children/adolescents may develop side effects early in the course of treatment as their bodies get used to the strong medicine that is needed to fight the DR-TB. Some side effects are “silent”—meaning that the child/adolescent will not feel or notice any problems, even if they are there. These are the side effects that the doctors or nurses look for at each visit when they examine the child/adolescent, take blood samples, or do other tests such as an electrocardiogram (“ECG”). Box 13 reviews some of the tests that might be done to look for “silent” side effects. Not all children will get all the side effects, but some of the ones to look for are listed below.

- Nausea/vomiting or diarrhea, especially in the early days of taking treatment;
- Loss of energy or tiredness;
- Problems with sleeping or the development of nightmares;
- Changes in the color of the skin;
- Changes in the way the heart is beating;
- Pain or burning in the hands or feet;
- Changes in the vision;
- Changes in the way the child/adolescent is thinking, acting or behaving;
- Rashes

Box 14 reviews some ways to talk to children/adolescents about side effects. Box 15 lists strategies that might be used to help children who are experiencing side effects, including possible danger signs that mean the child needs to see a health care provider right away. It is always important to let the child/adolescent's health care provider know about these side effects. Box 16 reviews some strategies for communicating with health care providers about side effects. Sometimes they might be able to change the DR-TB medications around. Sometimes they can give another type of medication to help with the side effect. Sometimes they might have other ideas about how to help the child/adolescent manage the side effects. Because DR-TB treatment is long, it is important for the child/adolescent, the caregiver, and the health care providers to be part of the same team, working together to help the child/adolescent finish treatment and be as strong and healthy as possible. Sometimes when a child/adolescent has side effects, it may be tempting to want to stop the treatment early. This is an understandable reaction—especially if the side effects are causing the child/adolescent to suffer. Stopping treatment early, however, could mean that the DR-TB germ is not completely killed/eliminated, and there is a chance the germ could make the child sick again in the future.

Children/adolescents are often experiencing normal changes in their bodies—sometimes called “growing pains”—and it can be hard for families as well as the children/adolescents to know if what they are experiencing is a “side effect” or just part of normal child/adolescent growth. When in doubt, it is good to ask the child/adolescent's health care providers for advice. Sometimes families may want to use common medications—such as Panadol—to help the child/adolescent. Sometimes families may want to use herbs or traditional medicines in the same way. These kinds of treatment may help the child/adolescent, but it is always important to make sure these additional therapies do not interact with the child/adolescent's DR-TB treatment. It is also important not to stop the DR-TB treatment, even if traditional providers recommend doing so. Always be careful of health care providers or traditional medicine providers who charge you a lot of money or tell you there is an “easy” solution to the health problems the child/adolescent is facing.

Some children/adolescents on treatment for DR-TB infection or disease also have other health problems, including asthma, HIV or diabetes. Sometimes the medications the child/adolescent is taking for these illness might interact with the DR-TB medications or cause similar side effects. It is important to ask the child/adolescent's health care providers about this and to make sure all the health care providers are communicating with each other about the care of the child/adolescent. This can be done by simply asking the doctor or nurse “have you talked with the doctor who takes care of my child's diabetes about this?”

Finally, many families will want to know how they can tell if the child/adolescent is getting better. The child/adolescent will also want to know this as well. Box 17 reviews some things the family as well as the health care providers can look for to see if the child/adolescent is getting better. Remember, it is always important to ask the health care provider if they think the child is getting better and to see the results of all the tests and examinations done for the child/adolescent.

BOX 13: TESTS COMMONLY DONE TO LOOK FOR “SILENT SIDE EFFECTS”



- A test called an “electrocardiogram” or ECG may be done to look at how the heart is beating. This is done by putting stickers on the chest, arms, and legs and then hooking those stickers up to a machine that shows how the heart is beating;
- A blood sample may be taken to look at how the liver is working;
- A blood sample may be taken to look at how the kidneys are working;
- A blood sample may be taken to make sure there are enough cells to carry oxygen and energy in the blood;
- An eye chart might be shown to the child/adolescent to test the vision;
- The reflexes of the child might be tested by lightly tapping on the arms, legs, and feet.
- Box 14: Tips for talking with children/adolescents about side effects
- Asking the child how s/he feels each day is a good start;
- Sometimes children/adolescent may be overwhelmed by asking a general question, so it may be good instead to ask “Do you have any pain in your tummy?” “Do you hurt anywhere?” “Did you have any funny dreams?” or “Do your hands or feet hurt”?
- Always give the child plenty of time to answer the question;
- Sometimes, observing how the child/adolescent is doing can give more information than asking about it—look to see how the child/adolescent is eating, notice if they are playing less, see if they are limping or rubbing a certain body part;
- Use drawing or pictures if possible or dolls/other toys—ask the child/adolescent to show you “where it hurts;”
- Reassure the child/adolescent that you are there to help with the side effects and that the problems they may be experiencing are temporary and will go away.

BOX 15: STRATEGIES FOR HELPING CHILDREN/ADOLESCENTS WITH COMMON SIDE EFFECTS



- If the child/adolescent has nausea or vomiting, make sure s/he is able to take in some liquids; consider using rehydration salts; avoid strong smells which can make these symptoms worse; try sitting by a window or over in fresh air; eat soft or bland foods such as papaya, banana, apples, or rice; avoid rich foods such as meats, things that are deep fried, or dairy products; try eating small amounts multiple times a day;
- If a child/adolescent vomits after taking treatment, ask the health care provider if s/he should take another dose--usually, if more than 30 minutes have passed between taking the tablet and the vomiting, it is not necessary to take another dose;
- If the child/adolescent has diarrhea, make sure s/he is able to take in some liquids; consider using rehydration salts; avoid fatty foods and dairy foods;
- If the child/adolescent has pain try massaging the area that is painful; place a warm or cool compress on the area, whichever feels better; try rubbing the area with menthol or camphor cream;
- If the child/adolescent has a rash, try washing the area with mild soap; consider rubbing it with aqueous cream;
- If the skin changes color, reassure the child or adolescent that this is temporary; consider covering any troublesome areas with makeup or cover-up (this can be especially helpful with adolescent girls/women);
- If the child/adolescent has a fever, consider using Panadol or rubbing the child/adolescent with a cool cloth;
- If the child has trouble sleeping or develops nightmares, consider identifying a “comfort object” such as a doll/blanket/toy s/he can use to sleep; sing a soothing song; rub his/her back or feet until they are sleeping;
- DANGER SIGNS that mean you should contact a health care provider right away are: the inability to take liquids; rapid or shallow breathing; coughing or vomiting blood; a rash all over the body; inability to walk; sleep from which the child cannot be woken up; bumping into walls or other objects; excessive tripping; skin or eyes turning yellow; violent or threatening behaviors towards themselves or others.

BOX 16: STRATEGIES FOR TALKING WITH HEALTH CARE PROVIDERS ABOUT SIDE EFFECTS



- Consider making a list or diary of any problems the child/adolescent might have—ask someone to help you make a list or diary if you need to;
- Notice how long the problem or symptoms lasted and if there was anything that made the problem better or worse;
- Talk about anything you might have done to help the child/adolescent—sometimes families know best how to help each other;
- Ask the health care provider what they think might be causing the symptom or side effect;
- Ask the health care provider if they have any advice on how to help the child/adolescent with the problem;
- Ask the health care provider if there are any things you should NOT do when the child/adolescent is having the problems;
- Make sure you know how to get in touch with the child/adolescent's health care provider if you have any questions or worries;
- Tell the health care providers if you are using any traditional medicines or herbs to help the child;
- Write down (or ask the health care provider to write down) the names of any new diagnoses, treatments or tests that are recommended as well as why;
- Write down or ask the health care provider to write down the date and place of any follow up appointments;
- Always be honest with the health care providers about things—remember that you are a team;
- Expect to be treated with kindness and respect: asking questions means you are doing your part to take care of the child/adolescent and this is a wonderful thing.

BOX 17: HOW TO KNOW IF THE CHILD/ADOLESCENT IS GETTING BETTER



- Weight gain or no longer losing weight—for this reason your child/adolescent will be weighed at each visit;
- More energy or playfulness;
- No more fevers, cough or other symptoms (although children with DR-TB infection or disease can still catch the common cold or the flu);
- Sputum/phlegm tests to look for the TB germ will not show any germ (although this will not be done for children with “sleeping” TB infection since they always had a small number of germs in the body that cannot usually be found in the sputum/phlegm and some children with “awake” TB disease may not have the germ in their lungs or sputum/phlegm);
- Chest X-rays to make sure the signs of the TB germ are going away.



QUESTION THE FAMILY OR CHILD/ADOLESCENT MIGHT ASK

- Will the treatment make my child sick?
- How will I know if the treatment is making my child sick?
- How can I help my child if s/he feels sick?
- Should we see traditional providers/take traditional remedies?
- How can my child and I communicate with each other during treatment?
- How will I know if my child is getting better?
- How will I know if I should take my child to the clinic?
- How can I communicate with the clinical providers if I have worries or there are side effects?
- How can I offer emotional support to my child/family during this time?
- How can we manage other sicknesses the child might have (i.e. HIV)?



KEY MESSAGES

- Side effects may be common when children/adolescents are taking medication to treat or prevent DR-TB and it is important to let health care providers know if the child/adolescent is having problems and to come up with strategies for dealing with these problems;
- Health care providers will often do specific tests to make sure the medications are not causing problems, and it is important for families to talk with one another openly and ask about any problems that may occur;
- It may be challenging to tell if a physical symptom being experienced by a child/adolescent is caused by the DR-TB, by the medication, or by normal body changes that happen as a child grows—thus it is important to talk with trusted individuals about what is happening, especially health care providers;
- **DANGER SIGNS** that mean you should contact a health care provider right away are: the inability to take liquids; rapid or shallow breathing; coughing or vomiting blood; a rash all over the body; inability to walk; sleep from which the child cannot be woken up; bumping into walls or other objects; excessive tripping; skin or eyes turning yellow; violent or threatening behaviors towards themselves or others.



Theme 6: Returning to normal life, including child protection and nutritional support

When a child is infected with or sick from DR-TB, it may disrupt their normal lives or activities. This might be because the child or adolescent feels unwell and does not have the energy to attend school, go to church, or play with/interact with their friends. This could also be because the child/adolescent needs to attend clinic visits or even to stay in the hospital. The family is also likely to be impacted by DR-TB and may not be able to do the things they usually do together. These are just some of the ways in which DR-TB can “interrupt” the life that a family is used to.

DR-TB treatment—whether for infection or disease—is meant to help people regain their health and lead the kind of life they hope to live. The sooner children/adolescents are able to return to their “normal” activities, the better. For children/adolescents on treatment of infection (i.e. “preventive therapy”), there is no need for them to be away from school or other activities. They will usually be taking only one medication that has minimal side effects, there is no risk of DR-TB transmission, and most of their follow up visits can be conducted via the telephone or at home to minimize disruptions. For children/adolescents on treatment for DR-TB disease, it may take a little more time to return to normal activities, especially if the child/adolescent is feeling unwell. As soon as the child/adolescent feels well, however, s/he can and should return to normal activities, as long as s/he is able to continue taking treatment. When a child/adolescent is on treatment for DR-TB, the risk of infection is almost zero, provided he or s/he continues to take treatment. It is important to talk with the child/adolescent’s health care provider and plan together for when the child/adolescent can return to normal activities and to make sure the child/adolescent does not miss too much “normal life” to attend appointments or receive medical treatment.

DR-TB, however, is a disease that is often associated with stigma and shame. This often happens because people do not know the facts about DR-TB and they may have misperceptions or beliefs that are simply untrue. Thus, as the child/adolescent or family may be asked questions or treated differently as they try to resume normal life. It is thus important to develop a strategy for talking with others in the community about what is happening in the family. Sometimes friends or teachers will be genuinely concerned and want to know why the child/adolescent was absent and how they can support the child/adolescent or family. Some of the medications may lead to a change in appearance of the child/adolescent and people may ask about why they look different. Some people may be

worried or afraid about the DR-TB, and this could lead to teasing or problematic behavior, and it is important to help children/adolescents come up with plans for addressing this if it should happen. The focus should be on promoting well-being and a sense of self-esteem in the child/adolescent. Some tips for talking with siblings, peers, teachers, and other adults are included in Box 18, including some important facts to share about DR-TB. Some tips for promoting self esteem in children/adolescents are included in Box 19.

Most children/adolescents who become sick with DR-TB do very well in treatment and have no permanent problems or effects. Sometimes, however, DR-TB can lead to permanent health problems. These usually happen if the child/adolescent was sick for a while or if he or she does not have a strong immune system. The kinds of permanent problems a child/adolescent might develop depend on where and how the TB germ is affecting the body. These problems can persist even after the DR-TB treatment is finished. It is important to ask the health care providers if your child/adolescent will have any permanent problems and if so, how these can be taken care of.

For families affected by DR-TB, there may also be other aspects of life in which they need support. For example, if a parent is also sick with DR-TB s/he may not be able to work and the family might struggle financially. There may not be enough food in the house, especially since a child/adolescent on treatment will likely need additional nutrition in order to be able to take their medications and to have the best chance of being cured. In fact, children being treated for DR-TB may have a sudden and notable increase in their appetites, and the family may need additional food resources, even if they have not struggled with food security before. There may be organizations—both governmental and private groups—that can help with these needs. Some possible resources to consider are included in Box 20.

Families may also be under a great deal of stress due to DR-TB. When a child/adolescent has DR-TB, the normal caregiver-child dynamics can be disrupted as caregivers now have to make sure children/adolescents take medications. Treatment can be difficult, and thus the child/adolescent might perceive that the caregiver is “forcing” them to do something difficult. Some tips for managing the changing dynamics in the family are included in Box 21. Tips for managing stress and anxiety are included in Box 22.

All of these issues can lead to depression and anxiety and other behaviors that could harm the child/adolescent, such as substance use or even physical violence. In settings such as this, support should be offered to the entire family, but it is especially important to ensure children/adolescents living in the home are physically safe. It is important to ask for help if there is a child/adolescent who might be in danger. Some signs to pay attention to are included in Box 23 as well as some possible resources to contact for help such situations.



BOX 18: TIPS FOR TALKING WITH OTHERS ABOUT DR-TB



- Knowing the facts can help—DR-TB is spread through the air and anybody who breathes can get DR-TB (and we all breathe). DR-TB is not caused by bad behavior or being dirty, and it can happen to anyone. When someone is taking treatment, there is almost no chance that others can catch TB from them. People with DR-TB did not do anything wrong, and they need the love and support of people around them;
- Make a plan for how to respond if/when people ask questions. Some questions people might ask include “Why were you out of school/church?” “Why do you look different?” “Why do you have to take tablets now?” “Why do you have to go to the clinic so much?” You may want to provide more detailed or honest answer to close and trusted people than to more casual or superficial acquaintances;
- Remind people that you/the child/adolescent are still the same person as before, with the same hopes and interests and dreams;
- If other children/adolescents are teasing or mean about the DR-TB, know who you can turn to for help/support: it may be another child/adolescent or adult who can help diffuse the situation;
- Remember you and your child/adolescent have a right to be back at school or church or other activities that matter;
- Ask your doctor, nurse or counselor if they have any advice for how to talk to others about DR-TB—they might even be willing to talk to people at school or church or in other places;
- Stick with the people who are kind and supportive and surround yourself with them—you all deserve this.

BOX 19: TIPS FOR PROMOTING SELF-ESTEEM



- Remind the child or adolescent that s/he did nothing wrong and it is not his/her fault that have DR-TB infection or disease;
- Reassure the child that s/he will get through this difficult time and that s/he is a strong person;
- Engage in some activities that make the child/adolescent feel good about him/herself. This could include drawing activities or playing a sport or game together. This could include having a special hairstyle or wearing a favorite shirt;
- Encourage the child/adolescent through positive reinforcement, reminding him/her of the good thing s/he does everyday;
- Practice daily gratitude together each and every day—even it is something small, there is always something to be thankful for and it can help to remind the child/adolescent about this;
- Allow the child/adolescent to express concerns and talk about how s/he is feeling—with young children this can be done through drawing or with art. Some children/adolescents might feel they have DR-TB because of something that they have done. Letting them express these feelings and then reassuring them that none of the sickness is their fault can help them feel better;
- Remind the child/adolescent that s/he is not alone in whatever they are going through.



BOX 20: POSSIBLE RESOURCES FOR HELPING WITH NUTRITIONAL AND ECONOMIC SUPPORT

- Food pantries/food banks in the community;
- Community kitchens;
- Churches or other faith-based groups;
- School programs;
- Social grants or programs available from the government
- Neighbors
- Family members



BOX 21: TIPS FOR MANAGING CHANGING FAMILY DYNAMICS DURING TREATMENT FOR DR-TB INFECTION OR DISEASE

- Let the child/adolescent express any anger or sadness s/he might have and do not take it personally;
- Explain to the child/adolescent that you are on their “team” and you are both working hard to make sure they are healthy;
- Remind the child/adolescent that even though it may seem like you are making them do things that are hard or difficult for them, you love them and want them to get well;
- Ask the child/adolescent if there is anything you could do differently that might make it easier for them;
- For events or procedures that are extremely difficult, consider asking for help from another adult so that your focus can be on supporting the child/adolescent;
- Spend some time with the child/adolescent doing things that have nothing to do with DR-TB or treatment. This can include simple things like singing a song together, going for a walk, or playing a favorite game. This can help build and strengthen normal family ties;
- Do not be afraid to expect things from the child/adolescent as you might for other children in the family—while the child/adolescent on treatment deserve compassion and understanding, having boundaries and expectations are also quite important.



BOX 22: TIPS FOR MANAGING STRESS AND ANXIETY

- Talk about the feelings with a trusted person, as stress/worry can grow when it is kept inside;
- Set aside time to do something enjoyable each day—even taking five or ten minutes to relax or do something pleasing can help;
- Ask for support when you need it—DR-TB treatment is a long journey and it is normal to need and ask for support along the way;
- Plan a special day when certain key milestones have been reached: for example, after completing one month of treatment, consider taking a walk to the park or the beach or cooking a special meal;
- Cry if you need to cry: tears can be a relief and are not a sign of weakness;
- Avoid alcohol and drugs: they may seem to help ease or forget things in the short-term but they often lead to more problems in the future;
- Embrace spirituality—either through a church, a religious leader, or meditation—find the comfort when you can;
- Talk with others who have been through a similar journey as they will understand what you are going through and may be able to help;
- Remember this situation is temporary and it will pass;
- Remember there may be good days and bad days during treatment—take time to be grateful for something each day.



BOX 23: POSSIBLE SIGNS OF DEPRESSION, SUBSTANCE ABUSE, OR VIOLENCE AND RESOURCES FOR HELP

- Children/adolescent who are depressed may stop engaging in normal activities. They may have problems with their sleep. They may cry more or seem more irritable/angry. They may eat less or lose weight. They may withdraw from their usual activities;
- Children/adolescents who are using substances may have strange or erratic behavior. They may have changes in their appearance. They may have new groups of friends or seem more secretive about their activities. They may smell like alcohol or cigarettes. They may begin to steal;
- Children/adolescents who are victims of violence may have cuts or bruises on their bodies. If asked about these physical changes, they may give an explanation of how they got injured that does not seem to fit (i.e. a person with a blackened eye may say they walked into a wall or fell down). The child/adolescent may wear inappropriate clothes or hide parts of their bodies—they may show a reluctance to get undressed or change in front of others.
- If any of these problems occur, it is important to alert the doctor or nurse right away. They may alert the social services or social worker in the community. If there is pressing danger, it might be appropriate to involve the local police or other authoritative bodies operating in the community.

QUESTIONS THE FAMILY OR CHILD/ADOLESCENT MIGHT ASK



- When can I go back to school/church/sports?
- What should I tell people about my treatment?
- What do I do if people tease me/bully me or my child?
- Why am I/my child eating so much?
- What can we do if we do not have enough food or money for our family?
- How will I know if my child/adolescent is depressed?
- How can my child/adolescent and I stay connected to and supportive of one another when I have to force him/her to take tablets each day?

KEY MESSAGES



- Children/adolescents on treatment for DR-TB may have to interrupt some of their normal activities when they begin treatment, but they should return to these as soon as they feel well enough and after checking with the health care providers;
- People may ask about what is happening with the child/adolescent, and it is important to think about and practice what the family will tell others who ask;
- DR-TB can cause multiple stresses for families and there are multiple resources in the community that can help with food, clothing, shelter, and other physical needs;
- Anxiety and stress can be common when a family is dealing with DR-TB and it is important to find ways to manage this, including identifying when a child/adolescent might be at risk of physical harm;
- DR-TB might change the way family members interact with one another, and it is important to find activities and shared interests to engage in apart from DR-TB.

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ANNEX 1: STRUCTURED COUNSELING NOTE SHEET

Date: _____

Counselor Name: _____

Family name: _____

Patient name: _____

How many previous sessions have been held with this family? _____

Briefly describe topics discussed in each thematic area:

Thematic area	Topics discussed
1. What is DR-TB and how does it affect my family?	
2. Your child will likely get well	
3. Diagnosis and pathways of care	
4. Treatment and adherence strategies (for the different age groups)	
5. “The pathway to health”: managing side effects/monitoring/child development	
6. Returning to “normal life”	

When will the next counseling session take place?

What are the goals/topics to be covered in the next session?

Was the family referred for any additional support/services? If so, which services?

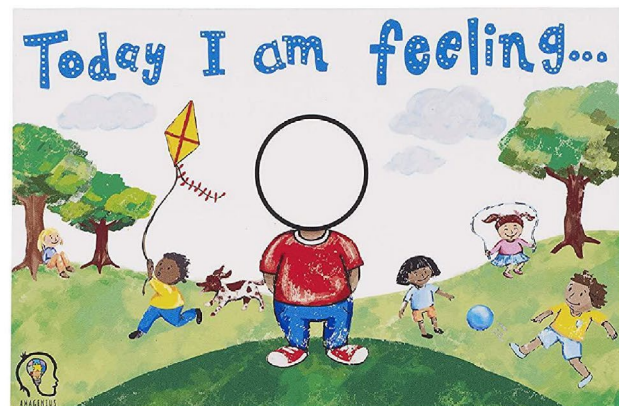
ANNEX 2: COMMUNITY RESOURCES TO SUPPORT FAMILIES WITH DR-TB

There are often other groups of service providers and organizations that can help families living with DR-TB. They may help with food, clothing, transportation, child care, or other needs. It will be important to map the types of services that are available in your community and to provide families with this information.

ANNEX 3: SAMPLES OF “FEELINGS” CHARTS/AIDS

For children and adolescents on treatment for DR-TB infection or disease, a variety of feelings or emotions may come up during their journey. These feelings range from anger and sadness to a sense of accomplishment and relief. It is normal to experience a range of emotions, and it is important for family members to talk with each other about how they are feeling. This is because negative feelings can less and positive feelings can increase when they are shared with others.

It can be a challenge, however, for children/adolescents to use words to describe their feelings at times. They may lack the proper vocabulary to do so, or they may feel too frightened or shy to say their feelings aloud. For this reason, “feelings charts” can be developed and used both for counselors and for families/caregivers when they are working with children who have DR-TB infection and disease.



Below are some examples of “feelings charts/aids” that could be used or adapted in different settings.

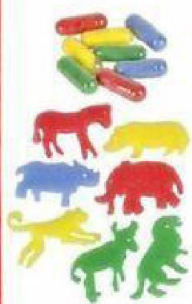
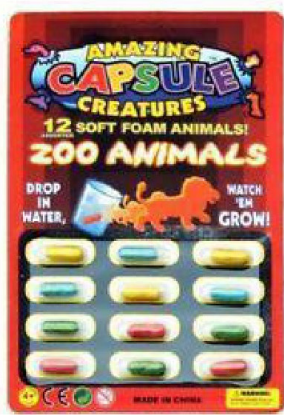
ANNEX 4: ANIMAL TABLET ACTIVITY

Incorporating play into adherence activities is an important part of treating DR-TB infection and disease in children/adolescents. Playing is one way children make sense of the world and process their experiences. It can also allow counselors and family members to be able to explain things to children/adolescents in a way that they can understand. Play can also bring a positive energy to what can be a challenging activity (daily consumption of tablets) and lighten the burden for all involved. Families/caregivers, counselors, and children/adolescents should all be encouraged to be creative in thinking about ways to make medication taking more interesting and fun.

One activity that can be done with younger children involves using “dissolve-able tablets” that are made of gelatin and have sponge animals inside. The gelatin dissolves when placed in warm water, and the sponge animal emerges (see attached photos). This process can be used to explain what medicine does what it is in the child’s body.

To do this activity, a gelatin capsule with a sponge animal inside and a container with warm water are needed. Show the child the capsule and state that it looks similar to the medicine s/he takes for the DR-TB. Place the capsule into the container of warm water and explain that this container is like the stomach, where the pill goes after the child swallows it. See what animal emerges from the gelatin capsule and show the child. If it is a lion, for example, explain that lions are strong and powerful and can help fight DR-TB, just like the medicine (depending on the animal, different attributes can be emphasized).

This animal can then be used to help the child throughout treatment. The caregiver/family member or counselor can remind the child that his/her “animal” is always with him/her. The child can be asked how the animal is feeling or doing each day and what the animal is doing to fight DR-TB.



It is important to make sure the child does not try to eat or swallow the gelatin capsule or sponge animal!!

ANNEX 5: POSSIBLE GROUP ACTIVITIES FOR FAMILIES WITH DR-TB

Families in which one or more individuals is on treatment for DR-TB infection or disease can feel isolated or alone. For this reason, group activities can be an important way to reinforce social bonds, build relationships with others who are going through similar challenges, and network with peers. Formal “group therapy” sessions can be one way to bring people together, as is sometimes done with adults who have DR-TB. Such formal sessions, however, may be more challenging and less impactful with children and adolescents. Engaging in social and “play” activities together, however, can be as effective as formal group therapy and will help open up community dialogues and build robust support networks. Some suggested group activities are included below:

- Host a “caregiver appreciation” event or day to recognize the important (and often difficult) work done by families: handing out certificates or small gifts to the family members caring for children/adolescents with DR-TB recognizes the important journey they are on;
- Obtain an instant camera and come up with a “photo booth” for families/caregivers and children/adolescents to use. Put “props” in the booth that enhance self esteem or open up conversations. Photos are precious to families and using an “instant” camera means they can take the pictures home right away. This is especially important if a child/adolescent needs to be hospitalized or away from the family as part of treatment;
- Obtain some “butcher paper” in long sheets as well as crayons/pencils/markers and have each child or adolescent lie down on the paper. Make a tracing of the outline of their child/adolescent’s body and then have him or her color or draw in what is happening “inside”. Have each child/adolescent explain the drawing when s/he is finished;
- Use the “butcher paper” and crayons/pencils/markers to do another activity (on a different day) where you help the child/adolescent draw a “map” of his or her neighborhood. Have the child/adolescent draw in the places and people in his/her day-to-day life that are meaningful and then have them share their “map” with the group;
- Have a popcorn and movie night/afternoon and screen a movie that has a positive message about TB (i.e. “The Lucky Specials”) or health: discuss what people liked the most about the movie, what they liked the least, and what they felt they could relate to;
- Have a “talent” night/afternoon where children/adolescents are encouraged to sing, dance, make music, write, share poems, etc.;
- Host a “cooking” class where a families and their children/adolescents are given ingredients to make a simple and healthy recipe: consider making this a quarterly activity;
- Engage in outdoor play or sports, such as visiting the beach/mountains, holding a “scavenger hunt”, low-impact play with balls or water balloons, etc.
- Have a quarterly event to celebrate birthdays, “cures” or other milestones to feature important events in the lives of the families/caregivers and children.

ANNEX 6: TELEHEALTH AND COMMUNITY CARE SUGGESTIONS

While many activities for families/caregivers and children/adolescents with DR-TB infection and disease take place in health care facilities, it is also important to identify opportunities for community-based care and for telehealth services. Much can be learned about a family's strengths, struggles, and resources by doing a home visit, and home-based assessments/care should be a routine part of DR-TB counseling. These visits can be combined with medical assessments, adherence support, medication drop-off or targeted problem solving. Families and caregivers should always have a say in whether or not they are visited in their homes, and care should be taken to protect their privacy when home visits occur.

Telehealth rose to prominence during the COVID-19 pandemic and is another tool that should be utilized when counseling families/caregivers and children/adolescents with DR-TB. Counselors can call families to "check in" routinely and this may be both more convenient and cost saving for all parties. Some topics may be covered well over the telephone (such as reviewing test results or talking about where food parcels can be obtained). Other topics may be better done in a face-to-face setting (such as reviewing the names and appearance of medications or talking about substance use) and the counselor will need to work with each individual family to see how best to incorporate "telehealth" into the DR-TB counseling.

Telehealth can also be an important way for families and peers to connect with one another. Some communities use "whatsapp" groups (or other platforms) to share information, and this can be done through a counselor or at the discretion of families themselves. Adolescents may use telecommunications as the primary way they interact with each other and with health providers and they may feel safer doing so.

Some families may not have phones or airtime, and programs treating families with DR-TB might consider providing airtime to them or letting them borrow phones to facilitate counseling and treatment. Airtime can also be an excellent incentive for adherence—especially for adolescents—and a useful "thank you" gift for families.

ANNEX 7: WALLCHART REMINDER FOR TAKING TABLETS

A daily calendar or “wallchart” can be an excellent way to remind families/caregivers and children/adolescents to take their medications. A ritual can be made of marking the wall chart with stickers or a tick mark. Some examples of adherence wall charts are included below that can be updated and adapted for different settings.

Week:

Weekly Meal Planner

Weekly Weight: lbs

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Breakfast							
Lunch							
Dinner							
Snacks							
Water							

Medication Plan

* Date

* The patient's name Name of primary care provider primary care phone

Name and dose of the medicine	This medicine is for	How do I take the medicine?	How much and How often?				REMINDER
			Morning	Noon	Evening	BedTime	When to take it?

* If you feel a problem with your medicine, **DO NOT WAIT!!!** call to care provider rightaway



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