Living with Complex Drug-Resistant Tuberculosis:

A HOLISTIC COUNSELING GUIDE TO OPTIMIZE CARE

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THE BETTER PROJECT

Building Experience
Treating Tuberculosis with
Expanded Resistance

The BETTER Project is a global partnership of researchers, caregivers, and advocates aiming to develop and deploy evidence- based strategies to provide compassionate and comprehensive care for people with all form of TB, including those whose strains have resistance to newer (bedaquiline, delamanid, and pretomanid) and/or repurposed drugs (linezolid, clofazimine, and the fluoroquinolones). We are a learning network committed to generating and disseminating knowledge and data for immediate action.

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INTRODUCTION

Tuberculosis (TB) is a common infectious disease that makes about 10 million people around the world sick every year. Most people living with TB can be cured, but they must take treatment regimens lasting four to six months and containing three or four drugs. Sometimes, people develop side effects to these drugs ("drug intolerance") or their strain of TB is not killed by the medications ("drug resistance"). These complex forms of TB require different treatment approaches.

While the treatment package for complex forms of TB can cure many people with the disease, they often require more intensive therapy that lasts 12-24 months. This therapy comes with a different panel of drugs that cause side effects, may need to be administered in the hospital or via prolonged intravenous or intramuscular administration, and are highly individualized. There may be limited experience or trial data with some of the medications as well. Complex forms of TB may also reinforce the pervasive social stigma attached to the disease, fueling myths that TB is incurable or "lifelong" due to the extended duration of treatment. For these reasons, people with complex forms of TB need special counseling and support during their treatment journeys.

There are many excellent counseling guides and tools that exist to support people diagnosed with TB. These tools, however, may not address many of the challenges facing people who are undergoing care for complex forms of drug-resistant TB (DR-TB), including the long duration of treatment, monitoring and management of side effects, and the use of medications for which there are limited data. . We thus decided to develop a package that can be used to counsel people on issues that are of great importance when someone has a diagnosis of complex DR-TB. Our goal is not to replicate existing counseling frameworks but rather to build upon them in a way that acknowledges the special circumstances faced by people with complex forms of DR-TB.

This guide is for professionals working at all levels who are involved in the care of people with complex forms of TB. It can also be used by civil society organizations to advocate for and provide necessary support. The guide will cover the following topics:

1. What is complex DR-TB?
2. How to participate in shared decision making between providers and people diagnosed with complex TB
3. What to expect during treatment of complex DR-TB, including possible hospitalization and the use of long-term intravenous access
4. How to monitor and manage side effects of therapy
5. How to consider medications that have not yet been approved for complex DR-TB
6. How to approach end-of-life care

It is meant to be adapted to different national, cultural, and individual circumstances and used alongside other guides that may exist to support people living with DR-TB. It is hoped that the additional material here can help address some unique situations (described in each section) that arise when people are faced with a diagnosis of complex TB. The goal of this counseling guide is to help those working with and living with these forms of TB to provide compassionate, humanistic, and dignified care for people facing the most difficult forms of DR-TB.

A key theme throughout this guide is the formation of active therapeutic partnerships between those living with complex forms of TB and those providing care. Such partnership is crucial in the treatment of all forms of TB, but even more so when it comes to DR-TB that is more complicated to treat. A one-size-fits-all approach will simply not work in this clinical scenario, and shared decision making is a core concept that will be explored. Because there have not been formal trials on how best to treat complex DR-TB, there are not robust data to guide treatment decisions and recommendations. In addition, the treatment may be associated with life-disrupting events and the risk of side effects, it is essential that all parties share their goals, hopes, and fears about treatment with one another. Active listening will be key at all stages of care so that therapeutic decisions can be reached through collaboration and with respect.

HOW TO USE THIS FIELD GUIDE

This guide is intended to support providers, people living with TB, and programs as they understand and address the range of issues that might arise when someone is diagnosed with complex DR-TB. It is by no means an exhaustive review of all the challenges facing people with these types of DR-TB. It is not meant to replace existing counseling materials that have already been developed for TB and DR-TB. Rather, it is meant to supplement those tools and provide information on topics that are important to review when it comes to complex DR-TB and which may not be covered in other counseling guides. It is also meant to be adapted to the unique cultural, epidemiologic, and individual circumstances of people diagnosed with complex DR-TB in a wide range of settings.

Each section will focus on three topic areas during a holistic counseling process: 1) sharing the facts with the person receiving care in each topic area; 2) listening to the needs and understanding; and 3) developing a shared plan for the way forward. For each of the main themes in the guide, specific suggestions for support in each of these areas will be reviewed. It should be mentioned, however, that these steps should not be followed in a linear fashion. Rather, there should be periods of fact sharing followed by listening throughout the counseling process. It should also be noted that some people with DR-TB may want a large amount of factual information about their disease and possible treatments while others may desire less. Therefore, checking in about how people are receiving and processing information is important in the counseling process. Finally, there may be important topics which are not addressed in this guide, as it was meant to be a starting point not an exhaustive review. People with complex DR-TB, providers and programs should feel free to add to and adapt these themes and topic areas in ways that best serve their needs.

This guide is also not meant to be used as a one-time counseling tool which is covered in a linear fashion. Rather, the main themes will likely need to be visited and revisited multiple times throughout the treatment journey of an individual living with complex DR-TB. If the person with complex DR-TB agrees, then individuals from their support networks can also participate in counseling sessions and may, in fact, need additional counseling and support of their own. While this should be **encouraged, the privacy** of the individual—that is their right to only share information about their diagnosis with the people they choose—with complex DR-TB must be **respected** at all times Although the treatment of complex DR-TB is a team effort, the key person in all decision making should be the individual living with DR-TB. This includes who their diagnosis is shared with and who is invited to participate in counseling. Not all the themes and issues raised here will apply in every situation, but we have tried to represent the array of issues people with complex DR-TB might face.

Although a “one-size-fits-all” model of counseling is never the best approach to take, we have included some “checklists” in an Annex for providers and support people who might like to utilize checklists as job aides for remembering essential counseling elements. There is also an Annex offering some tips about how to counsel people about testing/treatment that is not available in their setting.

1. WHAT IS COMPLEX DR-TB?

Introduction

TB is caused by a small germ known as *Mycobacterium tuberculosis.* This germ can be killed by many medications, but it can also change its structure and function so those medications no longer work to kill it. Most people with TB can now be treated with combinations of drugs that can kill most or all of the TB germ in 6 months. Sometimes, however, the TB germ changes enough that longer, more complicated treatment regimens are needed. Sometimes, people develop allergies or side effects to some of the medications as well, making it difficult to keep using the drugs. And sometimes, people have the TB germ in parts of their bodies that are challenging to treat (such as their bones or in their brain or spinal fluid). All these types of TB are complex and mean that the person receiving care will require a different approach to treatment.

Sharing the Facts

- TB is caused by a germ named *Mycobacterium tuberculosis*. This germ can be killed, but it requires a combination of multiple medications. The TB germ can change and make it so these medications no longer work. When this happen, the TB germ is said to be "resistant" to that medication, and the form of TB is called "drug-resistant TB" or "DR-TB".
- When a TB germ has resistance to several types of these medications, especially those that are more commonly used, this is referred to as "complex DR-TB".
- When there is DR-TB, different medications need to be used. Some of these medications are not as effective or as strong at killing TB, and so they may need to be given for longer periods of time. These medications are sometimes called "second-line medications."
- The "second-line" medications may also cause more side effects or medical problems that are caused not by TB but the medications themselves.
- There is strong evidence to support the treatment of TB and some types of DR-TB. However, when it comes to complex DR-TB, there is no standard way to treat it. Most people with complex DR-TB will require their own individual approach. Treatment is possible and many people have good outcomes, but there is less clarity about what makes the best or strongest treatment since there have not been formal studies on these types of TB.
- Drug resistance is something that has to be detected in the laboratory. The doctors/nurses may have some clues that there could be drug resistance (for example, if someone has been treated for TB in the past), but the only way to know there is drug resistance is to look at the TB germ using laboratory equipment.
- Looking for drug resistance in the TB germ can happen in two different ways.
  - The first way is to grown the TB germ in the lab (a technique known as culture) and then to add TB drugs to the culture and see if the TB germ continues to grow. If it is able to grow even when the drugs are there, this indicates there is resistance. This is a good way to test for resistance, but it can take a long time (sometimes several weeks or months).
  - The second way to test for drug resistance is to look at the genetic material of the TB germ. The genetic material is the "blueprint" that tells the TB germ how to function, and there may be changes in the material that show there is likely to be resistance. Another way to think about this is that the genetic material of the TB germ is a recipe for cooking a certain dish. A change to the recipe is called a

"mutation" and this may change the look or taste of the completed dish. Looking for these changes/mutations is one way to know if there is resistance. This is called "genotypic testing." It can often happen more quickly than culture. One downside of this kind of testing is that not all the changes/mutations that are found are certain to cause drug resistance.

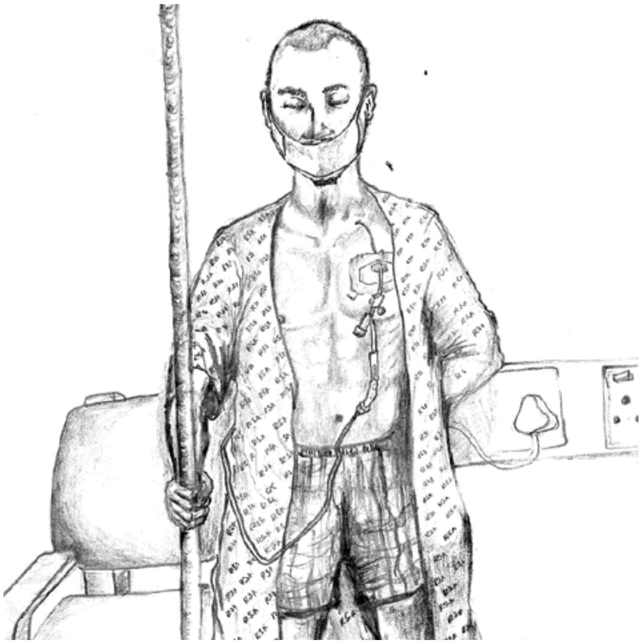
- Often, both types of testing are used in combination to come up with a full picture of drug resistance. However, not all countries or programs have access to both types of testing.
- Sometimes, the results of the two types of testing give different answers. When this happens, these results are known as "discrepant results" or "discordant results." Discrepant/discordant results can happen for a number of reasons and it is important to discuss these in an open fashion with the lab doing the testing and the care provdiers.
- The most common drugs that are tested for resistance are rifampicin, isoniazid, the fluoroquinolones (levofloxacin or moxifloxacin), and bedaquiline. Other drugs that can be tested for resistance include clofazimine, delamanid, linezolid, pretomanid, pyrazinamide, ethionamide, and amikacin. As new drugs are discovered, tests for assessing for resistance to these medications will also become available.
- There are also new methods for drug resistance testing being developed that are also being explored and may become available over time.
- Not all settings will have access to the full complement of testing for drug resistance. Although it is the right of every person with TB to know which medications will work best to kill their specific TB germ, the world is behind in ensuring this kind of access. It is important to review what testing is available locally, how additional tests could be accessed, and how advocacy could be done to improve access to testing.
- When there is resistance to only rifampicin, this is called "rifampicin-resistant TB" or RR-TB. When there is resistance to both isoniazid and rifampicin, this is called "multi-drug resistant TB" or "MDR-TB". When there is resistance to rifampicin and a fluoroquinolone, this is called "pre-extensively drug-resistant TB" or "pre-XDR TB". When there is resistance to rifampicin, a fluoroquinolone, and either bedaquiline or linezolid, this is called extensively drug-resistant TB or "XDR-TB". All these terms can be confusing, but the programs and treating providers use them to help determine the treatment regimens.
- For people whose TB germs have resistance to rifampicin or to both isoniazid and rifampicn, the 6 or 9-month treatment regimens commonly used contain bedaquiline, linezolid, a fluoroquinolone, and either pretomanid or delamanid. If the TB germ has resistance to one or more of these drugs in the 6- or 9-month regimens used or to a drug called clofazimine, then this may also be known as complex DR-TB. With complex DR-TB, an individualized treatment strategy will need to be developed.
- Although the focus of the definition of complex DR-TB includes drug resistance, there may be people who have allergies or intolerances to drugs that mean those drugs cannot be used. If a drug cannot be used because of an allergy or intolerance, the implications are the same as if a drug cannot be used because of resistance. As such, this can also be considered a form of complex DR-TB.
- TB commonly affects the lungs, but the TB germ can cause sickness in any part of the body. When the TB germ gets into the bones or joints or into the brain/nerves/spinal fluid, this also requires more intensified treatment and can be considered complex DR-TB.

Listening to the Needs and Understanding

- Establish what is understood about drug resistance or drug intolerance with the person who is receiving care.
- Listen to what the person with complex DR-TB understands about his or her specific drug resistance pattern.
- Discuss any concerns the person with complex DR-TB has about the way the resistance testing was done.
- Specifically review any discrepant results and share why those discrepancies may have occurred.
- Make space for questions.

Developing a Shared Plan for the Way Forward

- Agree on the drugs or medications which probably will not work in treating the complex TB. One tool for helping do this is a picture chart of the medications or using models/pictures of the pills themselves.
- Review the plan for any additional testing to clear up discrepant results.
- Discuss the potential for developing a regimen that could be used to treat the complex TB, being honest about areas of uncertainty. Talking about uncertainty can be challenging, and may be best approached using a "Recognize, Acknowledge, Partner, and Seek Support" framework. In this framework, the uncertainty is named and normalized, how it impacts the person receiving care is explored, and plans are made for managing the uncertainty. Some examples of phrases that might be helpful include:
  - "This is what we know and how we will monitor your care to make sure we are on top of things."
  - "I wish we could say with certainty how these medications might affect you, but we will work together as a team so we can identify any problems early"
  - "I am here with you and we will take this step-by-step"



2. HOW TO PARTICIPATE IN SHARED DECISION MAKING

Introduction

When people with health problems seek care, they are entering into a partnership with the health care providers and system in which these providers work. Unfortunately, there is often a power dynamic that emerges in which the providers take a lead role in telling people seeking care what to do. While some of this is understandable given the training and knowledge of medical providers, it also sets up a situation in which the freedom to choose and humanity of the person seeking care is at risk. This is especially true in TB, where more paternalistic and restrictive measures—such as directly observed therapy---have become a normal part of care provision.

An alternative model of working with people seeking care is through something called "shared decision making." In this model, the people seeking care are viewed as equal partners who possess specialized knowledge about their lives, goals, and priorities. This knowledge is different from that possessed by health care providers, but it is given equal weight in medical planning and decision making. Shared decision making is especially important with diseases like complex DR-TB, where there is no clear best course of therapy, where the treatment is complicated and associated with disruptions to daily life (through prolonged hospitalization) and a high risk of side effects. Therapy is often long, and if people receiving care are well informed, this will contribute to an enhanced therapeutic experience and could improve outcomes.

Shared decision making does not mean that people seeking care are charged with coming up with their treatment plans. Rather, it means that providers actively listen to the needs and wishes of the person seeking care, present medical options to the person seeking care—including frank discussions about side effects—and then together they come up with the best course of treatment. In this way, the health care provider can act as a "coach" helping the person with DR-TB come up with a plan that is consistent with his or her values, preferences, and needs.

One issue that needs to be carefully considered with complex DR-TB is the transmissible nature of the disease. It is important to acknowledge that all too often, fears of contaigion have been used to unfairly label people with TB, leading to horrific discrimination and stigma. Thus, any discussions of DR-TB transmission must be undertaken in a way that does not contribute to shame, isolation, or self-stigma. At the same time, most people living with complex DR-TB are also worried about transmission, and they may have questions to ask about protecting their loved ones and how they can safely engage with those in their networks. When such conversations are approached with dignity and without judgement, people diagnosed with complex DR-TB and their providers will often find they have shared goals and values. It is often helpful to remind people with complex DR-TB that having this disease is not their fault. For example, saying: "Anyone can get complex DR-TB. It is not the disease of the poor, the inferior, or whatever group of people that others say are more likely to get TB." If there are areas where the parties do not see eye-to-eye, then mutually respectful conversations (potentially facilitated by another party) should be had to help them come to an agreement.

For children and for people with limited decision-making capacity, involving the parent/guardian/caregiver in shared decision making is essential.

Sharing the Facts

- Complex DR-TB is a disease for which there is not one clear best course of treatment. There are medications that can work to treat this form of TB, but there is more uncertainty regarding how best to use them in combination. Because of this, it is important to share options with people seeking care and see what treatments might work best in achieving their goals and needs.
- To do this, a process called "shared decision making" should be followed. Shared decision making acknowledges the humanity and unique individual needs of people with complex DR-TB.
- Shared decision making involves active listening on the part of providers. It acknowledges that while all people with complex DR-TB want to be cured, they may have different values and preferences when it comes to the treatment they receive. Knowing these values and preferences will lead to a more satisfying and successful therapeutic relationship.
- Shared medical decision making does not mean that providers become passive. It means that providers share their specialized medical knowledge with people seeking care for complex DR-TB. It means they listen to the concerns, hopes, and daily struggles of people living with DR-TB. It means they consider these things in the ultimate treatment plans.
- Shared decision making should happen at every encounter and not merely at the initial visit or consultation.
- For shared decision making to be effective, people with complex DR-TB need to be given information about their options, about side effects, about how treatment is progressing (i.e. sputum culture results, laboratory testing results, radiography results, etc.), and about alternative therapeutic options. They also need to be included in discussions about how their treatment might impact other areas of their lives (i.e. work schedules, distance to travel from home to treatment center, etc.) and to explore options about how treatment might be adapted to accommodate their other needs and roles.

Listening to the Needs and Understanding

People with complex DR-TB should be asked about:

- Their current health and social status (including immigration and legal status should they need extra protections in these areas), including how their lives have changed since receiving the diagnosis.
- What they understand about their current health condition.
- Their goals and hopes for the current treatment course, both in the short-term and in the longer term.
- Their prior experiences with TB treatment and what was both positive and negative for them about those experiences.
- What kind of social support they have and what they need that they are not receiving.
- Struggles they think they might have with the proposed treatment options.
- How the proposed treatment options might affect their daily lives and the activities they need to take care of daily (i.e. work, school, child care).

- Any alternative treatments—including traditional medicines—that the person might be considering.

They should be offered options for treatment that account for these goals, activities, preferences, and needs. For example, if they cannot be hospitalized to receive an injectable agent because they are the only caregiver for young children, then alternative oral options should be explored, alternative child care options should be explored, etc.

Developing a Shared Plan for the Way Forward

- Agree on the treatment option that is best to help achieve the short-term and long-term goals of the person living with complex DR-TB. This should include a discussion of avoiding any treatments that might lead to more harm than benefit.
- Acknowledge that there may be therapeutic tradeoffs to achieve those goals and review what those tradeoffs might look like.
- Plan to continue reviewing and updating one another at the next visit.
- Be willing to adapt the plan as the needs of the person with complex DR-TB change and according to how the treatment progress.
- Discuss the potential role of traditional medicine/alternative treatments as part of care, noting where such types of healing might be beneficial or could cause harm.

3. WHAT TO EXPECT DURING TREATMENT

Introduction

Every person's treatment journey is unique, and this is especially true for people with complex forms of DR-TB. Given that people with complex DR-TB will each be receiving individualized regimens—made up of different drugs than most people receive and for longer durations—there is not one pattern or path to expect. There are, however, some aspects of treatment that may be common among people with complex DR-TB, and these need to be discussed in detail, as they have the potential to greatly impact the lives of people receiving treatment.

Sharing the Facts

Many people with complex DR-TB will:

- Need to receive multiple medications. This could be as high as nine or ten different medications, each of which may require swallowing multiple tablets. The high pill burden needs to be discussed with plans made for how this will be managed.
- Require prolonged treatment lasting more than a year and in some cases as long as two years. There will likely be no way to predict exactly how long treatment will last, as it will depend on how the person receiving treatment is responding.
- Receive care in the hospital for some period of time. This will depend on the medications being given and the response to therapy. It is important to discuss this and to consider how this will impact other aspects of the person's life.
- Receive some form of injectable medication. This may need to be given as an injection into the muscle (usually in the buttocks) or as an intravenous medication into the vein. If the medication is given into the buttocks, this can be painful, and the pain can be reduced if the medication is mixed with lignocaine/lidocaine. If the medication is given into the vein, the person with complex DR-TB will usually have a long-term IV line put in called a "port" or a "PICC line" (Peripherally Inserted Central Catheter). This long-term IV line makes it easier to deliver the intravenous medication, but it also carries some risk. These risks include infection, bleeding, and clotting.
- Will face risk of developing side effects, as they are very common with treatment. These will be discussed in detail in the next section.
- Will need to have frequent visits with their health care providers, in addition to daily support of taking medications as prescribed (i.e. "adherence").
- Will need to have plans and support for helping take medications daily. This is especially important as the treatment regimens may be complicated with multiple pills and injections. Struggles taking medication daily are to be expected, and making active plans with the person undergoing treatment for managing these medications along with their other activities will be key, including what to do if doses are missed.
- Will need to have some kind of psycho-social support. Treatment can be a difficult process and there is often a tremendous burden of social stigma associated with complex DR-TB. There are often hidden and unhidden financial burdens as well, even when treatment is free, since people may incur costs at the same time they lose work opportunities. Understanding that anxiety and depression can be common experiences is important. Developing a plan for managing these is a core element of the therapeutic plan.

Not all settings will have access to the full complement of medications for treating people with DR-TB that has complex resistance. Although it is the right of every person with TB to access potentially life-saving medications, the world is behind in ensuring this kind of access. It is important to review what treatments are available locally, how additional medications could be accessed, and how advocacy could be done to improve access to treatments.

Listening to the Needs and Understanding

- Discuss strategies for managing the high daily pill burden. Ask about different techniques people have for swallowing pills and share some ideas for making this easier (e.g. taking with soft foods, dividing up the dosing, etc.).
- Ask about how the person feels about being in the hospital. Ask about what activities the person normally has to take care of at home or in the community. Review different strategies for covering these activities during the hospitalization.
- Ask about psychological and other social support both at home and if the patient needs to be in the hospital, including what kind of support might be needed and accepted by the person receiving treatment and his/her family.
- Consider referral to appropriate patient or survivor resources, including group activities, if appropriate.
- Discuss the possible need for injectable therapy and talk about the different options for long-term intravenous lines. Determine if there is a preference for the type of injectable therapy and ask about any fears the person has about having a long-term intravenous line.
- Review possible barriers to routine clinic visits.

Developing a Shared Plan for the Way Forward

- Make sure that all barriers to care are discussed, including possible mitigating measures.
- Make a plan for location of care, recognizing this may need to change depending on individual experiences and circumstances.
- Make a final plan about how to deliver injectable medications, recognizing this may need to change depending on individual experiences and circumstances.
- Determine how follow-up visits can fit into everyday life.

4. HOW TO MONITOR AND MANAGE SIDE EFFECTS OF THERAPY

Introduction

The goal of treatment for complex DR-TB is to cure the person who has received the diagnosis so he or she can return to living a healthy and productive life. This can be accomplished by using medications that kill the TB germ. With complex DR-TB, there is a need to use multiple medications. Many of these medications can interfere with the body's normal functioning. These are called side effects, and although they are expected, they can be challenging for people undergoing treatment. People can be monitored in a systematic way to detect these side effects as early as possible. Early detection can mean the side effect can be stopped or managed in a way that makes continuing treatment easier. Some side effects, however, may not go away, and it is important that people receiving treatment and providers agree about how to manage the side effects. Sometimes, this will mean a medication needs to be stopped, and the decision to stop a medication should be reached through shared decision-making. With complex DR-TB, there may be limited or no other treatment options if a medication needs to be stopped because of side effects. Thus stopping the medication may mean that treatment is less likely to be effective, and this is something people with complex DR-TB and providers will need to frankly discuss. Although the potential for side effects is common in treatment, each person receiving treatment may experience these in different ways or not at all. People receiving treatment and care providers need to work together in a vigilant, active partnership to monitor for and manage side effects as they occur.

Sharing the Facts

- All medications used to treat TB can have unintended effects on the body. These are called "side effects" and they are to be expected during treatment for complex DR-TB.
- Monitoring for and managing side effects is a key part of treatment for complex DR-TB. Working in active partnership to detect these as early as possible is key.
- Each person is different, and some people will have very few side effects. On the other hand, some people will have many side effects, and this can make continuing treatment a challenge.
- For people with complex DR-TB, knowing which symptoms/feelings might be associated with having complex DR-TB and which symptoms might be side effects of medication can be a challenge. In general, symptoms that were present prior to starting treatment are likely either due to the TB itself or to previous treatments.
- The first few weeks of treatment for complex DR-TB may be the most difficult, as the TB germ is being killed and the body is adjusting to treatment. Usually, people begin to feel better after the first two to three weeks. Any new symptoms that develop are likely due to treatment and may represent side effects. Sometimes, however, new symptoms could also be because of persistent complex DR-TB, in which case the health care provider will discuss this with the person undergoing treatment.
- Some side effects are likely to occur earlier in treatment and some may occur as the body is exposed to drugs over time.
- Knowing about the side effects and talking about them with providers is the best way to ensure that the side effects are recognized and addressed.

- There are two main ways providers will check for side effects. One way is through routine monitoring. This means that at every visit, the person receiving treatment will be asked about symptoms, examined, and undergo blood testing and other forms of testing to see if side effects may be happening. The second way is through symptom directed monitoring. This means that if a person reports certain symptoms, the provider may do a more detailed examination and order specific tests.
- If a side effect is causing serious or lasting damage to the body, then the medication causing that side effect may need to be stopped, either temporarily or permanently. The decision to stop a medication is one that should be made through shared decision making. This is because people with complex DR-TB often have very limited treatment options and stopping even a single medication could mean the treatment will not lead to cure. It is thus important to arrive at a decision about stopping a medication through open discussion and in partnership that also considers the values and needs of the person with complex DR-TB.
- People with complex DR-TB have a right to treatment that is tolerable. They should expect that they will be monitored for side effects and that they will be offered treatment for any side effects that may occur.
- Many different side effects are possible. Some of the most common or serious ones are listed below:
  - People who are receiving the drug amikacin are at risk for permanent hearing loss, and this risk increases the longer the person is on the medication. For this reason, all people receiving amikacin should have their hearing tested prior to starting the medication and every two to four weeks after that.
  - People who are receiving the drug amikacin are at risk for damage to the kidneys. This risk increases the longer the person is on the medication. For this reason, all people receiving amikacin should have their kidney function tested prior to starting the medication and every month after that.
  - People receiving the drug linezolid are at risk for developing problems with the way their body makes blood cells. This can lead to tiredness, shortness of breath, nosebleeds, and easy bruising. For this reason, all people receiving linezolid should have their blood cells tested prior to starting the medication and every two to four weeks after that. If the blood cells are affected, linezolid may be stopped for some time or the dose may be lowered. They may also need to have a blood transfusion.
  - People receiving the drug linezolid are at risk for developing problems with the nerves in their hands and feet or in their eyes. This can lead to burning, numbness, or pain in the hands/feet or difficulty seeing. For this reason, all people receiving linezolid should have their vision and nerves tested prior to starting treatment and monthly after that. If the nerves in the hands/feet or the eyes are affected, linezolid may be stopped for some time or the dose may be lowered.
  - Many people receiving the medication clofazimine will have a change in the color of their skin. This is not permanent and will go away within a few weeks of stopping the medication. It is important to be aware of this as the change in appearance may lead to people asking questions. Planning how to respond to such questions is important.

  - The medication cycloserine/terizidone may be associated with changes in the way people think and feel. It may also cause changes in eating and sleeping patterns and other behaviors. For this reason, all people receiving cycloserine/terizidone should be checked for anxiety and depression prior to starting treatment and every month after that. Discussions about feeling worried, sad, disinterested in life, and other changes in feelings/thinking are very important to have. Sometimes, the impact of receiving the diagnosis of complex DR-TB can cause these symptoms as well. Sharing any changes in feeling/thinking with providers is incredibly important so that steps can be taken to lessen the discomfort caused by these feelings.
  - Several of the medications used to treat complex DR-TB can cause a change in the rhythm of the heart/the way the heart beats. People with complex DR-TB may not notice this or they may report feeling a fluttering/racing heart, lightheaded, dizzy or fainting. Because several medications can cause this, all people with complex DR-TB should have a test to look at the rhythm of their heart (known as an "electrocardiogram" or "ECG/EKG") prior to starting treatment and regularly (every 1-2 months) after that. If a significant change is noted, the person with complex DR-TB may need to be admitted to hospital and have some of their medications stopped.
  - Several of the medications used to treat complex DR-TB can cause nausea, vomiting, or diarrhea. These are hard to live with but often get better over time. Providers should offer medications to help manage these side effects. If they continue past the first few weeks of treatment, then medications may need to be changed. While this can happen with any medication, these side effects may be more common with drugs such as ethionamide and PAS.
  - Several of the medications used to treatment complex DR-TB can cause problems with the liver. Some people may not notice this but some people may have abdominal pain, vomiting, or notice their skin or eyes appear yellow. All people on treatment for complex DR-TB should have their liver function tested prior to starting treatment and every month after that. If there are any problems with the liver, then the person with complex DR-TB may need to be admitted to the hospital. Some of the medications may need to be stopped.
  - Some of the medications used to treat complex DR-TB could lead to problems with the ability to have a baby in the future (for both men and women). Some might also cause harm to women who are pregnant or to their unborn babies. Often, the risks during pregnancy may not be well described since many TB drugs are not assessed during pregnancy. If someone with complex DR-TB becomes pregnant (or if a pregnant women develops complex DR-TB), then a monitoring and management plan to optimize the safety of the woman and the unborn baby will need to be developed. This could include pregnancy termination if it is consistent with the wishes of the woman but should also include plan for supported delivery should the woman chose to continue with the pregnancy.
- Not all settings will have access to the full complement of testing for and management of side effects. Although it is the right of every person with TB have their side effects monitored and managed, the world is behind in ensuring this kind of access. It is important to review what testing and treatment are available locally, how additional tests/treatments could be accessed, and how advocacy could be done to improve access to testing for and management of side effects.

Listening to the Needs and Understanding

- Ask about worries people living with complex DR-TB might have about side effects.
- Discuss a plan for how the person with complex DR-TB will report any worrisome symptoms to health care providers. This should include who to report them to, how to report them, and what steps will be taken to manage them.
- Ask about which side effects are most worrisome to the person receiving care for complex DR-TB. Understand what they might be able to tolerate and what side effects would interfere too much with their lives to risk.
- Plan for discussions about medication discontinuation should an intolerable side effect occur. This should include reviewing the possible alternative medications (if there are any) and how much medication discontinuation might affect the chance of cure.
- Ask about support people who can help with side effect monitoring and management.

Developing a Shared Plan for the Way Forward

- Make sure people with complex DR-TB know what to expect in terms of possible side effects and how they will be monitored and managed. Use visual aids and other types of reminders so that everyone remembers to do routine monitoring.
- Make sure there is a clear plan for how side effects can be reported to health providers and what people can expect when they have side effects.
- Much of complex DR-TB care is about monitoring for and managing side effects, so ensuring there is open dialogue about this is crucial to a positive treatment experience.
- Understanding which medications are most worrisome, which medications could be stopped if side effects happen, and what alternatives exist is a core part of treatment for complex DR-TB.

5. HOW TO CONSIDER MEDICATIONS NOT YET APPROVED FOR THE TREATMENT OF COMPLEX DR-TB

Introduction

Many people diagnosed with complex DR-TB can be cured, but their treatment regimens can be challenging. Many times, the best drugs for treating DR-TB cannot be used since the TB germ is not killed by those drugs or the person being treated has had a side effect to the drug(s) that required the drug(s) to be stopped. There are new drugs being developed for TB, but the definitive studies—that usually involve hundreds or thousands of people—to prove these drugs are effective and safe usually take many years to complete. Recognizing the need to access newer TB drugs as soon as possible for people with complex DR-TB, many countries have pathways in which these medicines can be used before the final studies of these drugs are done. This is called "pre-approval access" or "compassionate use". There is information from early studies showing these drugs can kill the TB germ and that the drugs appear to be safe. This information, however, comes from a smaller number of participants. Successful treatment of complex DR-TB might require the use of some of these newer drugs, and it is important to discuss this when designing treatment regimens.

Sharing the Facts

- To determine if a drug for TB is able to effectively kill TB without causing dangerous side effects, multiple studies of the drug must be done. These studies progress through different phases and often involve hundreds or thousands of participants.
- After the long-term studies have been complete, most TB drugs go through a processed called "registration" or "approval". This means the agency responsible for reviewing drugs in the country has seen the results of the study and feels that there is enough information about the drug to recommend it be used in that country.
- TB drug studies—also known as clinical trials—are a good way to learn about new TB drugs. Sometimes, however, people may not be able to or may not choose to participate in these studies. Individuals have a right to try and access new TB drugs through other mechanisms as well.
- One mechanism or pathway to access newer TB medications is through something called "compassionate use" or "pre-approval access". Many countries have defined pathways through which this can be done, and it is important to understand the laws and rules in the context in which the person living with complex DR-TB is receiving care.
- With compassionate use/pre-approval access, there is some information about the drug, its ability to kill the TB germ, and its safety. However, this information may come from a smaller number of participants (dozens or hundreds), the drug may have been given for a shorter period of time, or the drug may only have been given to people with other types of less complex TB.
- When considering a new TB drug for treatment through compassionate use/pre-approval access, it is important for people living with complex DR-TB and their providers to consider the potential for benefit, which may not have been fully proven. It is also important to consider the potential for risk, including the types of side effects that may occur. If there are questions about this or the pathways for figuring this out in-country are not clear, providers or people receiving care can contact The BETTER Project at CUrequestBETTER@gmail.com.
- Some side effects could occur that are not predictable or not yet known from the early studies of the drugs. While it is important to be aware of this, it is also important to talk about how the person receiving the new medication will be monitored to detect any side effects early in therapy.

- To receive a new drug through compassionate use/pre-approval access, many steps need to be followed. It may take several weeks to access the medication.
- To receive the drug through compassionate use/pre-approval access, the person receiving the drug will usually need to sign a form called a "consent form." These forms contain a great deal of information and may be difficult to understand. It is important to spend time going through the form and explaining it in plain language. Signing the form indicates the person with complex DR-TB understands the potential risks and benefits of receiving the new drug and agrees to receive it.
- The use of new TB drugs is not required for anyone receiving care for complex DR-TB, although this may be suggested by physicians if there are limited other medications available for treatment. When thinking about constructing a treatment regimen, multiple options can be considered, including TB drugs that have been used for years and in thousands of people.
- Providers may suggest using newer TB drugs through compassionate use/pre-approval access if there are very few treatment options or if the existing treatment options cause side effects or intolerance.
- Not all settings allow access to newer TB drugs through compassionate use/pre-approval access. It is important to understand the regulations in the country/setting. If no pathway for compassionate use/pre-approval access exists, it is important to engage with advocacy efforts that could lead to the development of such a pathway.

Listening to the Needs and Understanding

- Give the person receiving treatment for complex DR-TB time to ask questions and to consider their feelings about using newer TB drugs through compassionate use/pre-approval access, including time to review this option with their social support systems.
- Ask about concerns or worries the person receiving treatment might have about using a newer TB drug.
- Discuss the possibility of accessing newer TB medications prior to their approval and consider which drugs could be used, the risks, the potential benefits, and what can be done for treatment if these drugs are not used.
- Review a plan for monitoring for possible side effects.
- Ask the person receiving care what they understand about the use of the newer TB drug in their treatment.
- Answer questions honestly but also in a way that is proactive about how the drug will be used in care. Saying "we do not know" or "we do not have that information" is honest, but may not be helpful. Instead, consider saying "we may not have all the information about this, but I want to tell you how we are going to check/monitor you to make sure this treatment is not causing you problems and is helping you."
- Be ready to have ongoing discussions about the newer TB drugs, as the process of informed consent must be a continuous one.

Developing a Shared Plan for the Way Forward

- If the person receiving treatment for complex DR-TB agrees to receive a new TB drug through compassionate use/pre-approval access, review the process and timeline for when the drug might be available to start treatment.
- Talk about the detailed plans for how the person will be monitored during treatment.
- Ensure that expectations for the newer TB drug are reasonable. Sometimes, people with complex DR-TB may feel desperate and may pin their hopes on the newer TB drugs. This is understandable, but frank discussions about what the newer drug might be able to do are important.

6. HOW TO APPROACH END-OF-LIFE CARE

Introduction

Many people with complex drug-resistant TB can still be cured, and it is important to hold onto hope throughout treatment. There are times, however, when the medicines are no longer helping, and a person may decide to stop treatment. There may also be times when providers determine that treatment is no longer helping and that no further curative therapy should be offered. Stopping treatment aimed at killing TB is a deeply personal choice that should be discussed openly and compassionately with caregivers, friends, and family. If the decision is made to stop therapy, high-quality medical care continues—shifting the focus from curing TB to maximizing comfort, relieving symptoms with medications such as morphine or inhalers, and supporting the person to spend their remaining time in ways that bring meaning and peace.

Sometimes, people refer to this kind of care as "palliative care." Palliative care is focused on relieving symptoms, and it should actually be part of the full spectrum TB care started at the time of diagnosis, since all people have symptoms that need to be addressed. The focus of palliative care is enriching people's lives along the full spectrum of treatment services. Sometimes, however, the term palliative care is used more to talk about the shift in focus from curing TB to providing comfort and support and enriching people's lives as they approach its end, which is especially important.

Talking about death can be difficult and "taboo" in many settings. Death is a topic that is feared, and people may be quite uncomfortable speaking about it. Most people who are facing an illness such as complex DR-TB, however, have thought about their mortality. Having discussions about this with them can be a relief, as they then do not have to carry their fears alone or in secret. While it can be upsetting or stressful to talk about end-of-life issues, providing love and dignity during these times can be among the most meaningful acts of healthcare providers

Sharing the Facts

- Sometimes, despite everyone's best efforts, the treatment for complex DR-TB may not work. When this is happening, people receiving care have a right to stop their DR-TB treatment. Their providers may also suggest to them that curative treatment be stopped if there is no evidence of benefit.
- Stopping treatment for complex DR-TB does not mean that care should be stopped. Rather, it means that the focus will be solely on comfort and dignity rather than on TB cure.
- Without treatment, complex DR-TB will eventually lead to death. For some people, this happens within days. For others, it may take months.
- End-of-life and palliative care should focus on a holistic approach which focuses on the physical (symptoms), the psychological (feelings), the social, and the spiritual, emphasizing freedom and choice. in all these domains.
- End-of-life care should also consider the loved ones who will be left behind and include bereavement support.
- End-of-life care for complex DR-TB must also consider infection control issues since the TB germ is spread through the air. The comfort and dignity of the dying person should always be prioritized, and there are multiple ways in which transmission can be reduced without punitive or restrictive measures (including mask wearing, provision of nutritional support for family members, open windows, etc.). When discussing infection control, great care should be taken not to isolate, blame, or stigmatize the person who is dying from TB

Listening to the Needs and Understanding

- Make sure to use plain and easy-to-understand language in all discussions.
- Ask about any physical symptoms the person might be having.
- Ask about any feelings the person might be having as they move through this phase of treatment, including positive feelings they may want to share and negative feelings they might need relief from or assistance managing.
- Ask about what the dying person with complex DR-TB would like to accomplish in the time they have remaining.
- Offer education and discussion about what dying might look like for the person with complex DR-TB.
- Listen to specific social fears/worries the person might have. These fears could include the family they are leaving behind (especially children), housing issues, life goals they may not be able to accomplish, or concerns about pain/loss of dignity.
- Review positive social support and situations. Ask the person with complex DR-TB who is able to provide support for them during this time.
- Discuss any spiritual needs or practices the person has and engage with spiritual leaders if the person wishes this to be done.
- Discuss with the dying person what areas of care they would like to have more choice or control over and make plans to address these areas when possible.
- Ask the dying person who in their family or social support network they would like to involve in their end-of-life care and planning.
- Ask about other support needs for food, housing, income, etc. that the person with complex DR-TB and their family/social networks might have.

Developing a Shared Plan for the Way Forward

- Ensure that the person has equipment and supplies for dignity, including red towel for hemoptysis, swabs or lip balm for dry mouth, buckets for vomiting or waste elimination. and objects that are comforting, including pictures, music, etc.
- Plan for where the person would like to be while receiving end-of-life care.
- Plan for when the next visit and consultation would take place.
- Review timeline for completing important/meaningful tasks (i.e. filling out wills or guardianship paperwork).
- Review medications/interventions that will be used to relieve physical and psychological symptoms and ensure these are available for the person receiving care.
- Discuss plans for care seeking, emergency management, and referral so that the person with complex DR-TB and their family members have clear ideas what they can do should a worrisome situation arise.
- Develop a plan for bereavement support for family and social networks.

CONCLUSION

People living with complex DR-TB face a challenging treatment journey. They will often require counseling and support that is different—and likely to be more intensive—than the counseling needs of people with other forms of TB. This counseling guide is meant to serve as a tool to build on when providing holistic support to people with complex forms of DR-TB. It should build upon other counseling tools that exist not only for TB but also for other health problems, as it is by no means exhaustive. Rather, it is meant to identify some areas in which unique needs could come up that will need to be met.

Everyone's journey with TB is different, and this is true of complex DR-TB. The key to offering support during the journey is acknowledging the beautiful and precious individuality of everyone who faces this challenging disease. They are brave individuals who want what we all do: a chance for a life that is dignified and meaningful. And while it is hoped that the treatments they receive will allow this life to be long, there is also something meaningful that can happen if the individual and his or her right to make decisions about his or her life is respected throughout, including at the end.

The concept of shared decision making has been central in developing this guide, envisioning a partnership between people living with complex DR-TB and those providing care. All too often this partnership approach is lacking in public health and it should be core to all engagements that have to do with well-being. It must be front and center in the care of complex DR-TB, however, given the true uncertainty around the best care path forward and the long journeys many people with this disease make. They should be the leaders, the inspiration, and the core of all our work.

ANNEX A: HOW TO COUNSEL INDIVIDUALS ABOUT TESTS/TREATMENTS NOT AVAILABLE IN THEIR SETTING

In the ideal world, people with complex DR-TB would have access to the full complement of testing and treatment options, both for their TB disease and for possible side effects associated with treatment. A key part of managing complex DR-TB is continued advocacy to realize this standard for people all over the world. While such health equity work is ongoing, however, it is likely that providers and people living with complex DR-TB may find themselves in situations in which tests and treatments that could be helpful are not available. When this happens, it is important to acknowledge this. It is also important to come up with some shared actions that can be taken so that people with complex DR-TB and their providers do not feel helpless. These actions could include speaking with government/hospital officials, petitioning health authorities, undertaking community actions, or working to generate funds in a collective fashion.

Although there is never an easy way to communicate that testing or treatment exists that could be helpful but is unavailable, so guiding principles in talking about this complex topic include:

- Emphasize what will be done to ensure the best possible outcome instead of what cannot be done;
- Acknowledge the frustration and sadness such a situation is likely to evoke;
- Remind the person with complex DR-TB that s/he is not alone and that his/her life matters;
- Avoid over-promising or asking the person with complex DR-TB and/or their family to undertake difficult or expensive activities to try and gain access to testing/treatment;
- Connect the person with complex DR-TB to others in the community working on advocacy.

ANNEX B: JOB AID CHECKLISTS FOR COUNSELING THEMES

What is Complex DR-TB

☐ Establish what is understood about drug resistance or drug intolerance.

☐ Listen to what the person with complex DR-TB understands about his or her specific drug resistance pattern.

☐ Discuss any concerns the person with complex DR-TB has about the way the resistance testing was done.

☐ Specifically review any discrepant results and share why those discrepancies may have occurred.

☐ Make space for questions.

☐ Agree on the drugs or medications which probably will not work in treating the complex TB.

☐ Review the plan for any additional testing to clear up discrepant results.

☐ Discuss the potential for developing a regimen that could be used to treat the complex TB, being honest about areas of uncertainty.

How to Participate in Shared Decision Making

☐ People with complex DR-TB should be asked about their current health and social status, including how their lives have changed since receiving the diagnosis.

☐ People with complex DR-TB should be asked what they understand about their current health condition.

☐ People with complex DR-TB should be asked about their goals and hopes for the current treatment course, both in the short-term and in the longer term.

☐ People with DR-TB should be asked about prior experiences with TB treatment and what was both positive and negative for them about those experiences.

☐ People with complex DR-TB should be asked about what kind of social support they have and what they need that they are not receiving.

☐ People with complex DR-TB should be asked about struggles they think they might have with the proposed treatment options.

☐ People with complex DR-TB should be asked about how the proposed treatment options might affect their daily lives and the activities they need to take care of daily (i.e. work, school, child care).

☐ People with complex DR-TB should be offered options for treatment that account for these goals, activities, preferences, and needs. For example, if they cannot be hospitalized to receive an injectable agent because they are the only caregiver for young children, then alternative oral options should be explored, alternative child care options should be explored, etc.

☐ Agree on the treatment option that is best to help achieve the short-term and long-term goals of the person living with complex DR-TB.

☐ Acknowledge that there may be therapeutic tradeoffs to achieve those goals and review what those trade offs might look like.

☐ Plan to continue reviewing and updating one another at the next visit.

☐ Be willing to adapt the plan as the needs of the person with complex DR-TB change and according to how the treatment progress.

What to Expect During Treatment

- ☐ Discuss strategies for managing the high daily pill burden. Ask about different techniques people have for swallowing pills and share some ideas for making this easier (i.e. taking with soft foods, dividing up the dosing, etc.).
- ☐ Ask about how the person feels about being in the hospital. Ask about what activities the person normally has to take care of at home or in the community. Review different strategies for covering these activities during the hospitalization.
- ☐ Ask about social support both at home and if the patient needs to be in the hospital.
- ☐ Discuss the possible need for injectable therapy and talk about the different options for long-term intravenous lines. Determine if there is a preference for the type of injectable therapy and ask about any fears the person has about having a long-term intravenous line.
- ☐ Review possible barriers to routine clinic visits.
- ☐ Make sure that all barriers to care are discussed, including possible mitigating measures.
- ☐ Make a final plan for location of care.
- ☐ Make a final plan about how to deliver injectable medications.
- ☐ Determine how follow-up visits can fit into everyday life.

How to Monitor and Manage Side Effects of Therapy

- ☐ Ask about worries people living with complex DR-TB might have about side effects.
- ☐ Discuss a plan for how the person with complex DR-TB will report any worrisome symptoms to health care providers. This should include who to report them to, how to report them, and what steps will be taken to manage them.
- ☐ Ask about which side effects are most worrisome to the person receiving care for complex DR-TB. Understand what they might be able to tolerate and what side effects would interfere too much with their lives to risk.
- ☐ Plan for discussions about medication discontinuation should an intolerable side effect occur. This should include reviewing the possible alternative medications (if there are any) and how much medication discontinuation might affect the chance of cure.
- ☐ Ask about support people who can help with side effect monitoring and management.
- ☐ Make sure people with complex DR-TB know what to expect in terms of possible side effects and how they will be monitored and managed. Use visual aids and other types of reminders so that everyone remembers to do routine monitoring.
- ☐ Make sure there is a clear plan for how side effects can be reported to health providers and what people can expect when they have side effects.
- ☐ Much of complex DR-TB care is about monitoring for and managing side effects, so ensuring there is open dialogue about this is crucial to a positive treatment experience.
- ☐ Understanding which medications are most worrisome, which medications could be stopped if side effects happen, and what alternatives exist is a core part of treatment for complex DR-TB.

How to Consider Medications Not Yet Approved for the Treatment of Complex DR-TB

- ☐ Give the person receiving treatment for complex DR-TB time to ask questions and to consider their feelings about using newer TB drugs through compassionate use/pre-approval access, including time to review this option with their social support systems.
- ☐ Ask about concerns or worries the person receiving treatment might have about using a newer TB drug.
- ☐ Discuss the possible options to the newer TB medications.
- ☐ Review a plan for monitoring for possible side effects.
- ☐ Ask the person receiving care what they understand about the use of the newer TB drug in their treatment.
- ☐ Answer questions honestly but also in a way that is proactive about how the drug will be used in care. Saying "we do not know" or "we do not have that information" is honest, but may not be helpful. Instead, consider saying "we may not have all the information about this, but I want to tell you how we are going to check/monitor you to make sure this treatment is not causing you problems and is helping you."
- ☐ Be ready to have ongoing discussions about the newer TB drugs, as the process of informed consent must be a continuous one.
- ☐ If the person receiving treatment for complex DR-TB agrees to receive a new TB drug through compassionate use/pre-approval access, review the process and timeline for when the drug might be available to start treatment.
- ☐ Talk about the detailed plans for how the person will be monitored during treatment.
- ☐ Ensure that expectations for the newer TB drug are reasonable. Sometimes, people with complex DR-TB may feel desperate and may pin their hopes on the newer TB drugs. This is understandable, but frank discussions about what the newer drug might be able to do are important.

How to Approach End-of-Life Care

- ☐ Make sure to use plain and easy-to-understand language in all discussions.
- ☐ Ask about any physical symptoms the person might be having.
- ☐ Ask about any feelings the person might be having as they move through this phase of treatment, including positive feelings they may want to share and negative feelings they might need relief from or assistance managing.
- ☐ Ask about what the person with complex DR-TB would like to accomplish in the time they have remaining.
- ☐ Listen to specific social fears/worries the person might have. These fears could include the family they are leaving behind (especially children), housing issues, life goals they may not be able to accomplish, or concerns about pain/loss of dignity.
- ☐ Review positive social support and situations. Asl the person with complex DR-TB who is able to provide support for the person during this time.
- ☐ Discuss any spiritual needs or practices the person has and engage with spiritual leaders if the person wishes this to be done.
- ☐ Ask the person what areas of care they would like to have more choice or control over.

☐ Ask the person who in their family or social support network they would like to involve in end-of-life care and planning.

☐ Ask about other support needs for food, housing, income, etc. that the person with complex DR-TB and their family/social networks might have.

☐ Ensure that the person has equipment and supplies for dignity, including red towel for hemoptysis, swabs or lip balm for dry mouth, buckets for vomiting or waste elimination. and objects that are comforting, including pictures, music, etc.

☐ Plan for where the person would like to be while receiving end-of-life care.

☐ Plan for when the next visit and consultation would take place.

☐ Review timeline for completing important/meaningful tasks (i.e. filling our wills or guardianship paperwork).

☐ Review medications/interventions that will be used to relieve physical and psychological symptoms and ensure these are available for the person receiving care.

☐ Discuss plans for care seeking, emergency management, and referral so that the person with complex DR-TB and their family members have clear ideas what they can do should a worrisome situation arise.

☐ Develop a plan for bereavement support for family and social networks.