

WHAT YOU NEED TO KNOW ABOUT TUBERCULOSIS

Oregon
Health
Authority
PUBLIC HEALTH DIVISION
Tuberculosis Program

WHAT YOU NEED TO KNOW ABOUT TUBERCULOSIS: A FLIPBOOK FOR TB PATIENTS

“What You need to Know about Tuberculosis” helps TB patients understand their disease and its treatment. Across the United States, TB is increasingly found among people from countries where it remains a common cause of sickness and death. To speak to these cultures and language needs, this flipbook is available upon request in more than a dozen different languages spanning multiple cultures.

THANK YOU

The Multnomah County Health Department’s Communicable Services Disease Program originally created and designed this flipbook. We would like to thank the entire Communicable Disease Services Tuberculosis Case Management team, whose experience in the field inspired the project and guided content development; the Communications and Marketing team at the Multnomah County Health Department Business Services Division, who provided design and printing resources as well as consultation on the project; Jaimee Mayfield from the Communications team for her photography, and all the staff who served as models. Partners outside the Department were also essential. We thank our community partners at Ecumenical Ministries of Oregon’s Sponsors Organized to Assist Refugees (SOAR), who donated their time to help us test the flipbook; and illustrator Brooke Thompson for her beautiful illustrations. Additional thanks go to Melissa McKinney from Communicable Disease Services for her overall guidance of the project, and to Alejandro Juarez of the Communications & Marketing team for his vision of what was possible.

TB FLIPBOOK PROJECT TEAM

Melissa McKinney

Community Liaison
Communicable Disease/TB Programs

Meredith Jones

Community Health Nurse
Communicable Disease/TB Programs

Alejandro Juarez

Communications Strategist
Communications and Marketing
Business Services Division

MULTNOMAH COUNTY HEALTH DEPARTMENT PUBLIC HEALTH DIVISION

Communicable Disease Services

Tuberculosis Program

Immunization Program

Community Epidemiology Services

Environmental Health Services

Equity, Planning, and Strategy

HIV_STD/Adolescent Sexual Health Equity

Maternal, Child and Family Health

Multco Public Health Advisory Board

Operations and Development

WHY WE ARE HERE

SAY THE FOLLOWING:

- Do you know why we are here today?
- We are here today because you may have TB disease and we want to help you get better.
- I am your case manager. I will tell you more about what that means in a few minutes.
- I would like to go over the results of your tests.



CASE MANAGER:

Go over the client's results from the tests that have already been done. Testing that still needs to be done will be discussed later.

- Skin test
- Blood test
- Chest x-ray
- Sputum





BASIC INFORMATION ABOUT TB



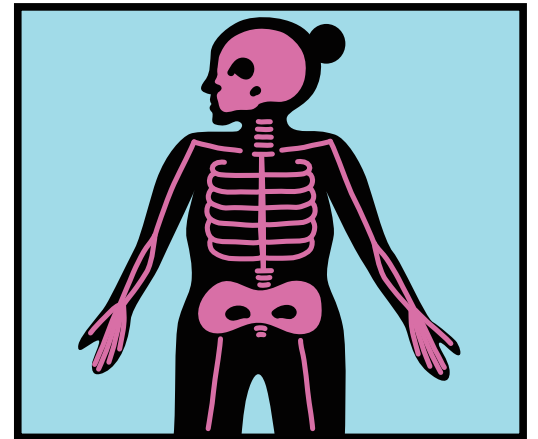
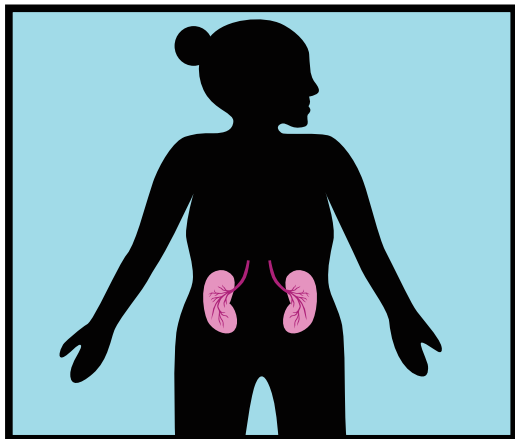
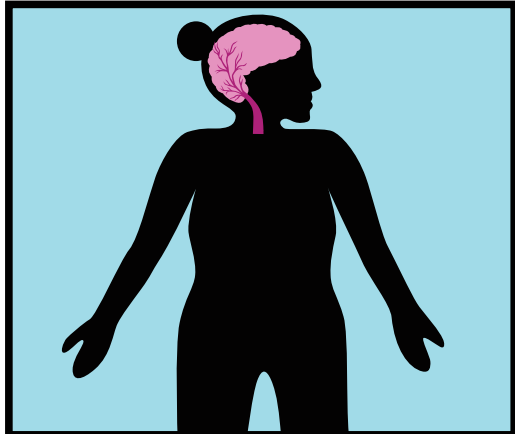
CASE MANAGER:

*Ask client, "What do you already know about tuberculosis disease?"
Modify discussion based on client response.*

SAY THE FOLLOWING:

- It is also called TB disease. TB stands for tuberculosis.
- TB disease is caused by the tuberculosis germ.
- TB germs are bacteria that make you sick.
- The disease happens mostly in the lungs, but the germ can travel to other parts of the body and cause disease there too.



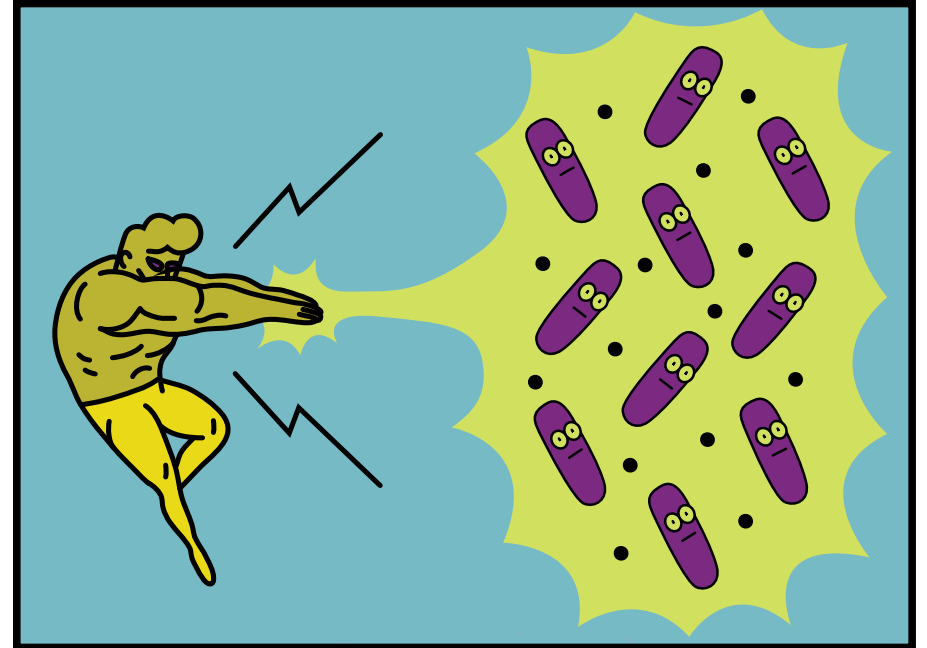


HOW YOU GOT THE TB GERMS

SAY THE FOLLOWING:

- TB is transmitted through the air.
- You got the TB germs by breathing them in from someone else, maybe a long time ago.
- When the TB germs entered your body, your body tried to fight them by building a wall around the germs.
- When the body builds a wall around the germs, we say the TB germs are “asleep” because they cannot hurt your body.
- When TB germs are “sleeping,” it is called latent or inactive TB infection or LTBI.





"SLEEPING" TB GERMS

SAY THE FOLLOWING:

- "Sleeping" germs do not make you feel sick.
- While your germs were "sleeping," you could not give these germs to other people.
- People with "sleeping" TB germs can take pills to kill the germs before the germs "wake up" so they are less likely to make them sick.





WHY YOU GOT SICK

SAY THE FOLLOWING:

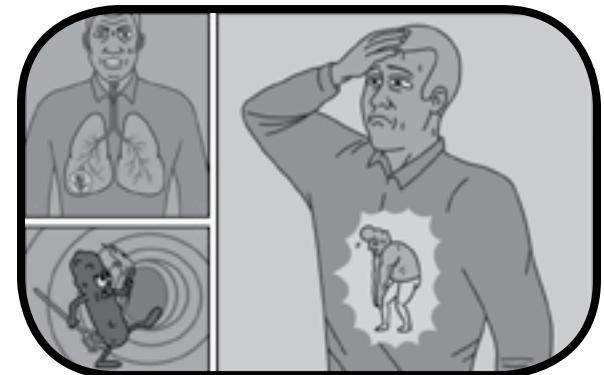
- You got sick from TB when your body could no longer fight the germs. The germs “woke up” and started to grow and hurt your body.
- This is called “active TB disease.”
- Active TB disease makes you feel sick.

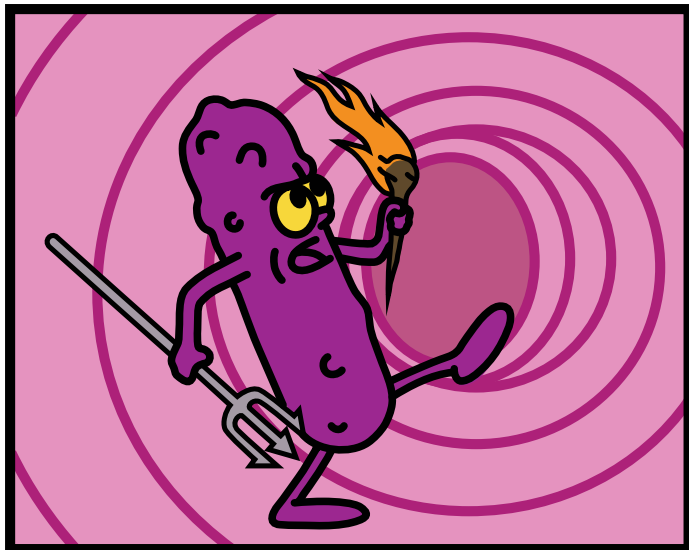


CASE MANAGER:

If an underlying health problem or immune problem is the probable cause for active TB disease, discuss it.

Otherwise, clarify that we don't know the exact reason why their germs woke up.



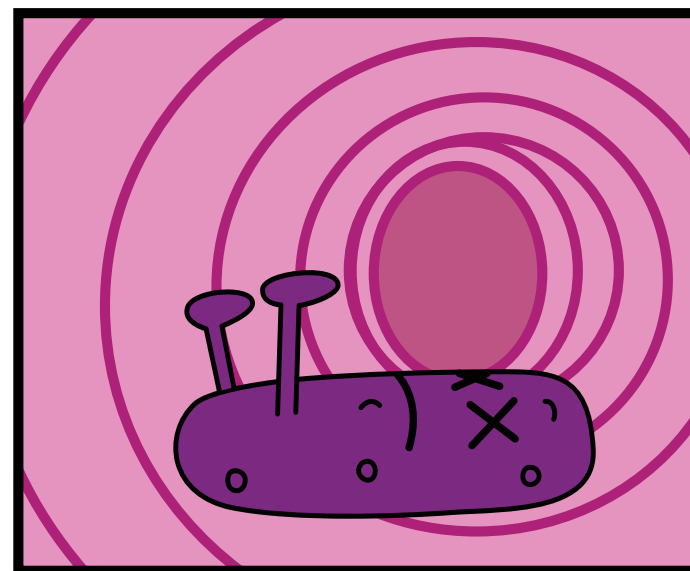
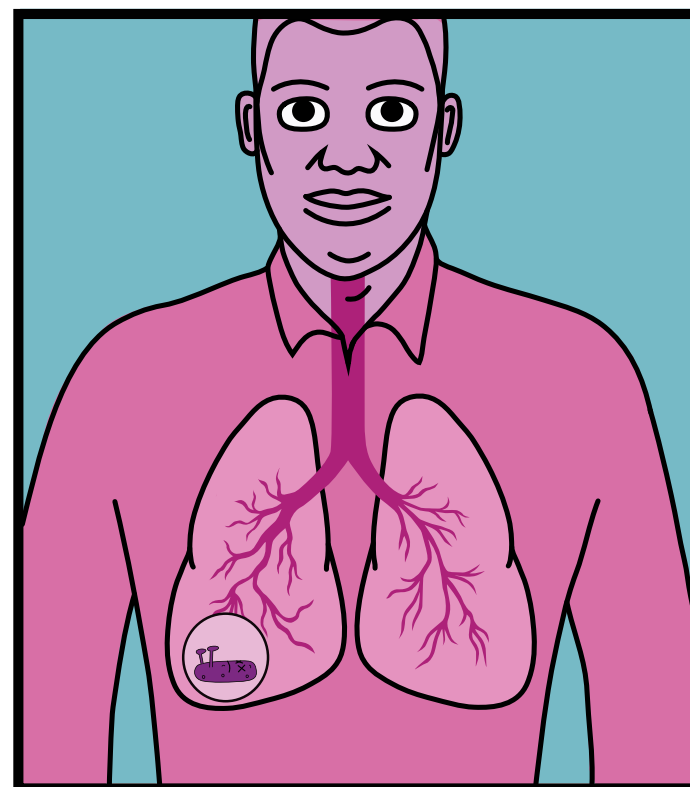


YOU CAN BE CURED

SAY THE FOLLOWING:

- You need to take pills to cure your TB disease.
- You also need to take these pills so you don't spread the germs to other people.
- We will talk more about your TB pills in a few minutes.





YOUR SYMPTOMS TODAY

SAY THE FOLLOWING:

- I want to know how you've been feeling. We need to talk about all the symptoms you are having from your TB disease.
- I have a form I need to fill out to do this.
- May I ask you some questions about how you are feeling and about your health in general?
- FORM: Go through initial TB evaluation with client.



CASE MANAGER:

Tell the client to call you if any new symptoms come up.





HOW WE KNOW YOUR GERMS ARE “AWAKE”

SAY THE FOLLOWING:

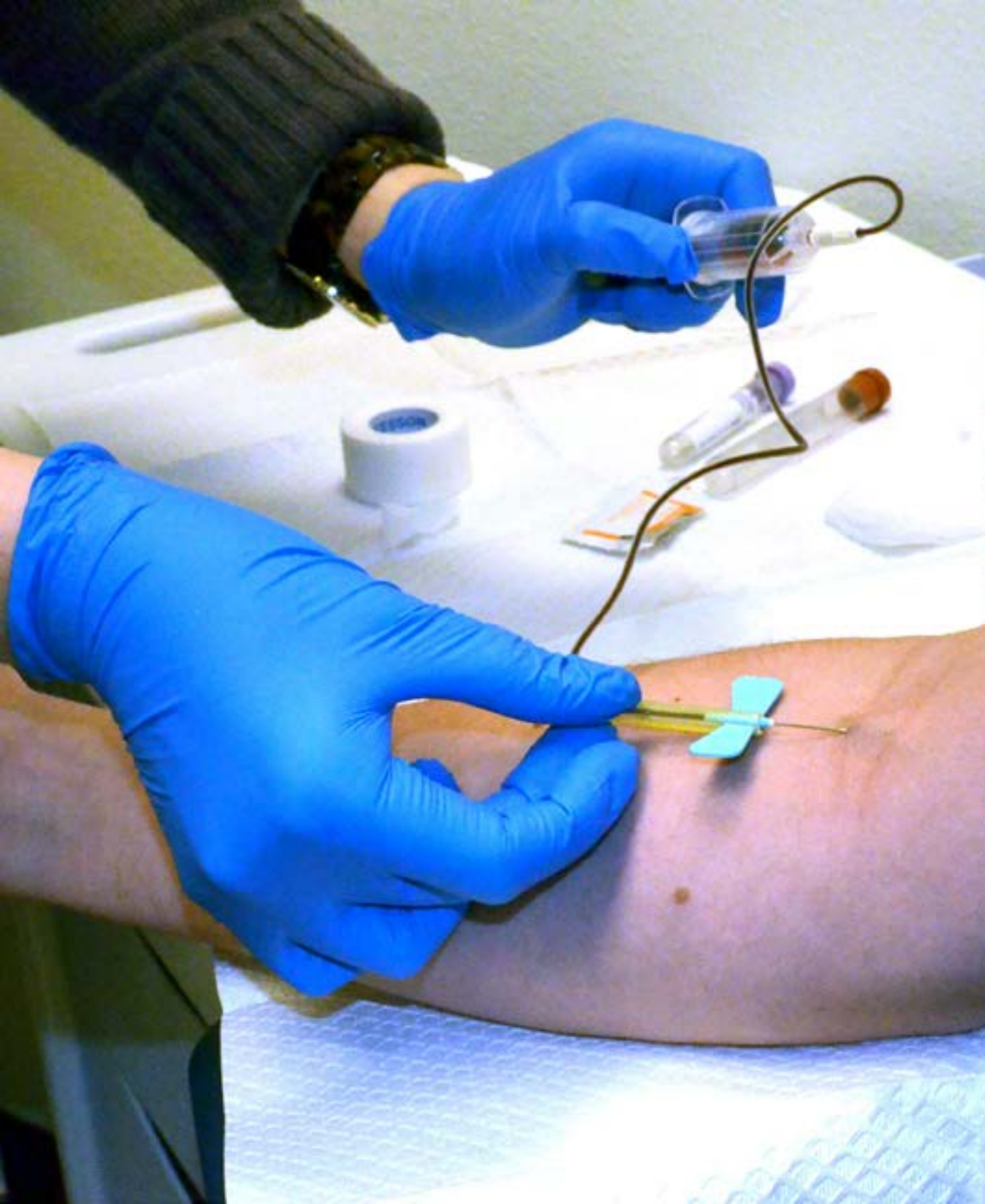
- We did some tests to see if your TB germs are “asleep” or “awake.”
- We will need to do more tests to learn more about your sickness. I am going to tell you about those tests now.



CASE MANAGER:

State again which tests have already been done and which we still need to do (skin, blood, x-ray, sputum).





TB SKIN TEST

SAY THE FOLLOWING:

- The TB skin test tells us if you have had TB germs in your body.
- This test can also be positive if you have had the BCG vaccine. We usually do a blood test instead of the skin test on people who've had the BCG vaccine or may have had the BCG vaccine.
- After your skin test results come back, we may need to do more testing to see if your TB germs are "awake" or "sleeping."



CASE MANAGER:

If this test was not done on client, you may choose to skip this page or review it in the context of why we did not do this common test.





CHEST X-RAYS

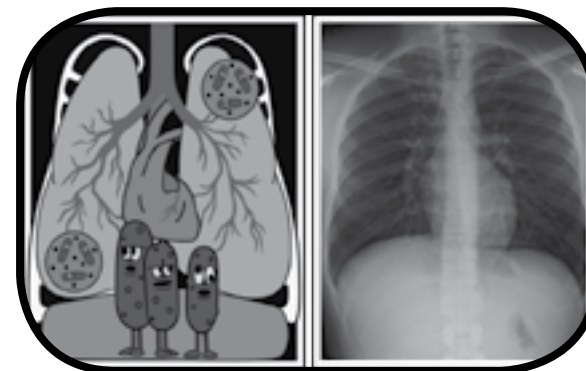
SAY THE FOLLOWING:

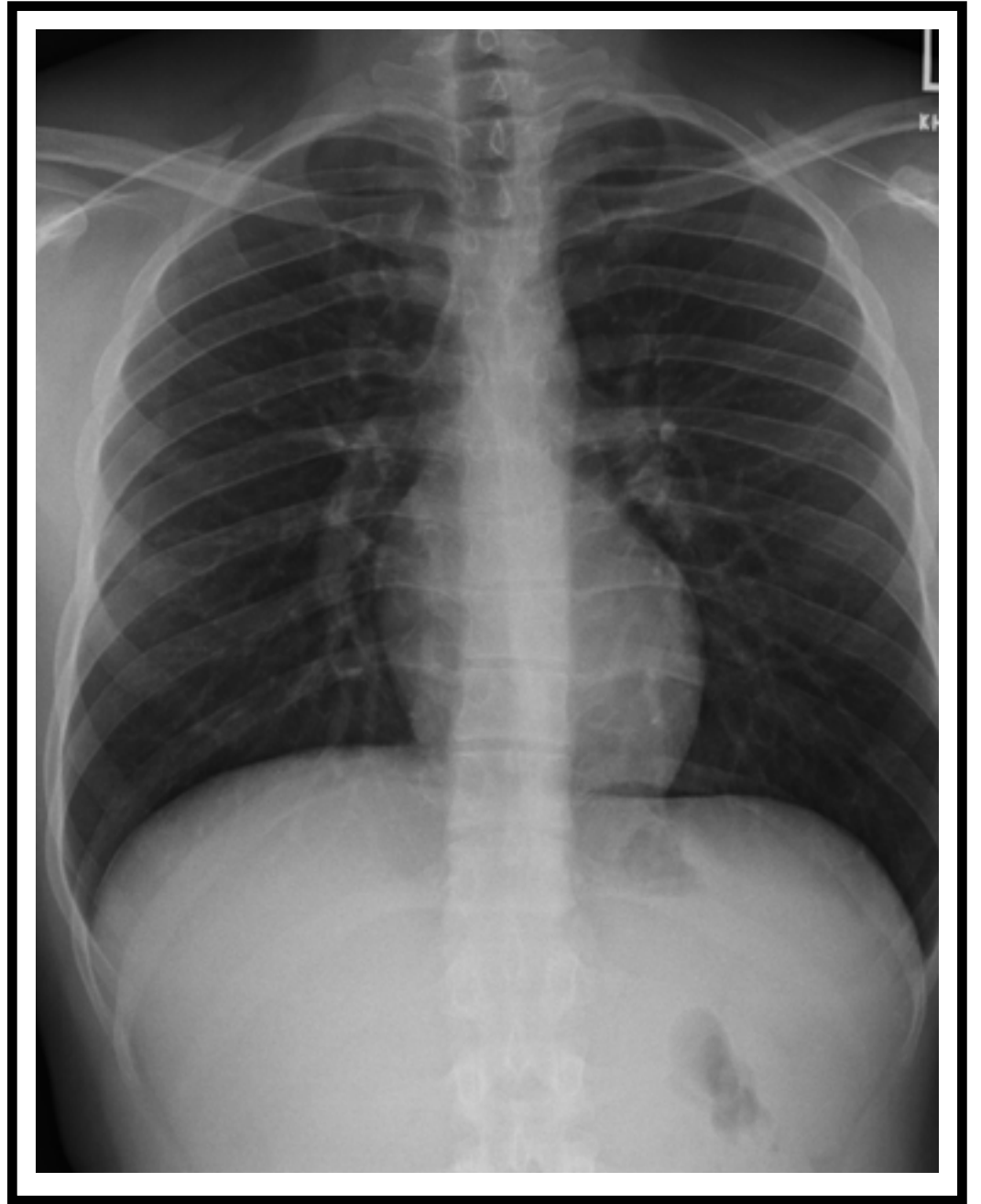
- We did (or will do) a chest x-ray to see if your lungs are healthy or hurt from the TB germs.
- If the TB germs have hurt your lungs, we are usually able to see it on the chest x-ray.
- We do this because we want to make sure your lungs are okay and it helps us understand how sick you are.



CASE MANAGER:

If this test has not yet been done, review it in the context that it will be done soon.





SPUTUM COLLECTION

SAY THE FOLLOWING:

- We asked you (or will ask you) to cough into a tube.
- The thick fluid you cough up is from your lungs and it is called “sputum.” It is not spit or saliva.
- The fluid tells us if the TB germs are growing in your lungs.
- When we do this the first time, you might have to cough into a tube three mornings in a row and each tube will be tested.
- We will do more of these cough tests for the next few months to see if your TB germs are still growing.
- Some of the results take a couple of months to come back.



CASE MANAGER:

If this test has not yet been done, review it in the context that it will be done soon.





CASE MANAGEMENT

SAY THE FOLLOWING:

- I am your case manager.
- Everyone with active TB disease gets a case manager.
- I will working with you closely over the next several months:
 - I will do more tests to make sure your body is handling the TB pills well.
 - I will do tests to make sure your TB is being cured.
 - I will talk with your TB doctor about your treatment.
- We give you TB pills at no cost to you.
- We deliver the TB pills to you.
- We may have appointments at your house or at the TB clinic.





YOUR TB DOCTOR

SAY THE FOLLOWING:

- If you have your own doctor, we will work with him or her on your treatment plan.
- If you are seeing our TB doctor, we will work with that person.
- You will see me once a month and you will also have regular appointments with your TB doctor.





MONTHLY APPOINTMENTS

SAY THE FOLLOWING:

- I will schedule monthly check-ups with you to make sure you are getting better.
- I will come back to your house to meet with you each month.
- Once you can no longer spread the germs to others, you can also come to the clinic for your appointments.





MORE ABOUT YOUR TB DISEASE



CASE MANAGER:

Give "Active TB Disease" handout ([OHA sheet](#)).

SAY THE FOLLOWING

- TB disease is not common in Oregon.
- It is a curable but very serious sickness.
- TB disease is cured by taking pills for several months.
- You will probably feel better a few weeks after you start taking your pills.
- TB disease usually makes your lungs sick. But it can hurt other parts of your body too.



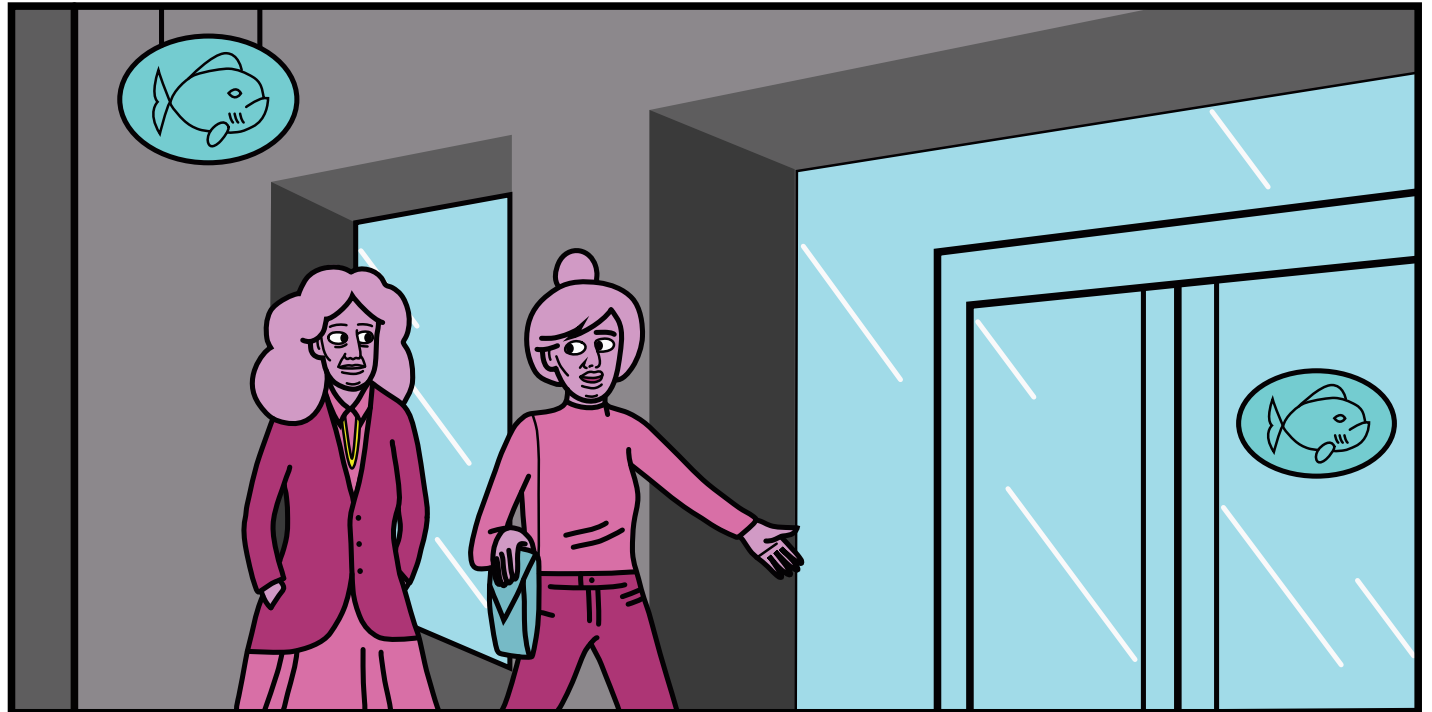
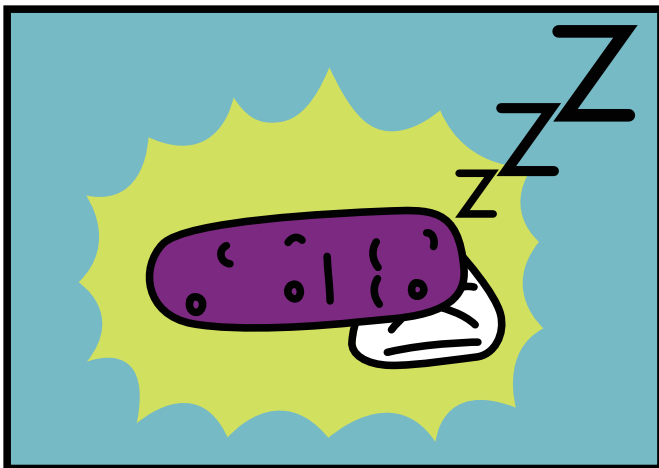


KEEPING OTHERS HEALTHY

SAY THE FOLLOWING:

- Until the pills start working in your body, you can give your TB to other people.
- You can give TB to others when you cough, sneeze, talk or sing.
- You got the disease from someone sick with TB, possibly a long time ago.
- You cannot get TB from shaking hands or from sharing food, dishes or other things.
- It is important to stay away from people while you can still spread the germs.
- We will talk more about what you should do next.





HOW YOU CAN KEEP OTHERS HEALTHY

SAY THE FOLLOWING:

- We want to make sure other people don't get sick.
- We are asking you to stay home, away from people while you can still spread TB germs to people. This is called isolation.
- We will work hard to get you out of isolation as soon as possible.

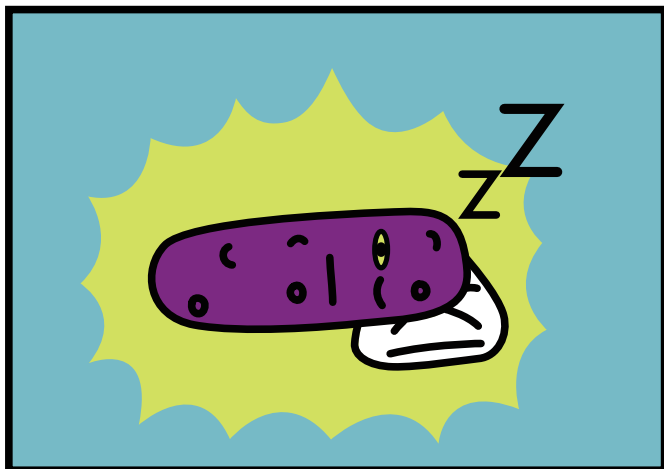
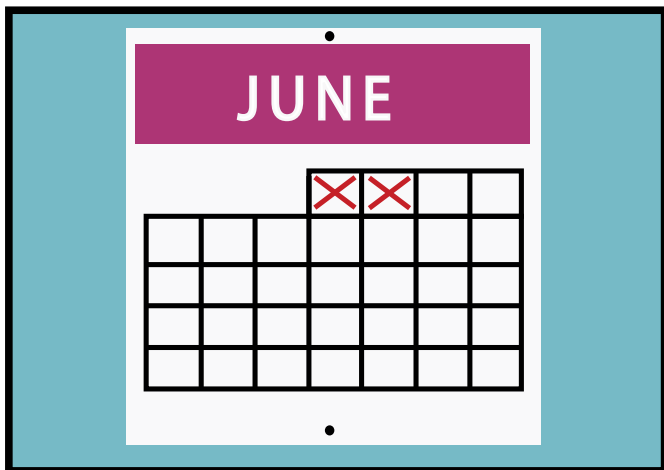


CASE MANAGER:

Talk about client's specific infectiousness situation and how we will handle it:

- *Discuss client living situation; who and where.*
- *Discuss isolation from family and visitors in house.*
- *No visitors. No traveling.*
- *Can the client leave the house? Where can he or she go?*





PILL PLAN

SAY THE FOLLOWING:

- Now I am going to show you the pills that you will be taking.
- You will be taking these pills for at least six to nine months, or possibly as long as 12 to 18 months.
- I need to show you all your pills so you understand how to take them on the weekends by yourself.

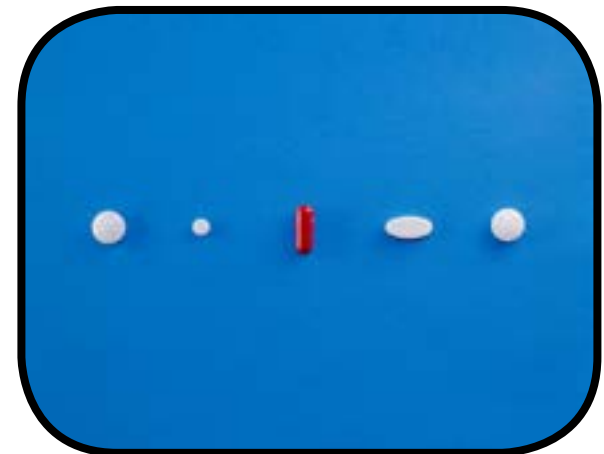


CASE MANAGER:

Go over the pills with the client. For each pill show and tell:

- *The name of the pill.*
- *What the bag looks like for that pill.*
- *What the pill looks like.*
- *What it does (antibiotic, vitamin, etc) .*
- *What time and how many to take of that pill.*

Give client pill sheet showing the pill plan and when to take pills.





SIDE EFFECTS

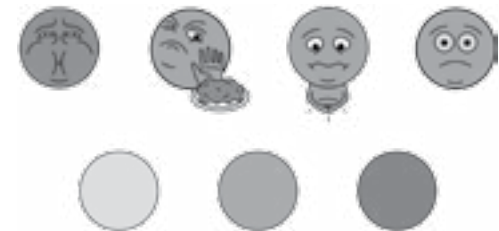
SAY THE FOLLOWING:

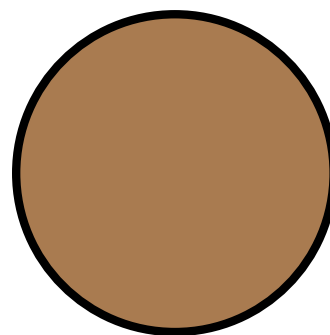
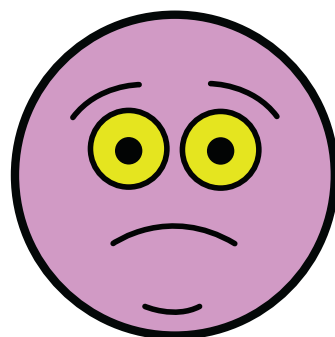
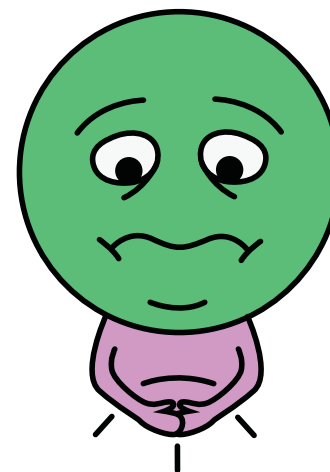
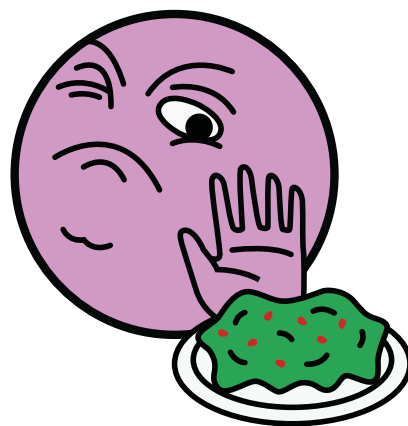
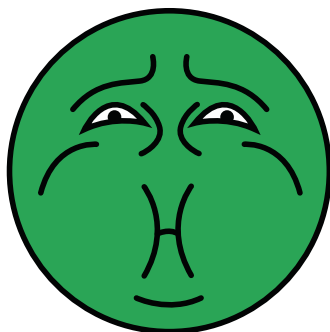
- You might have problems from the TB pills.
- We want to know about any problems you have.
- Call me if you have any of these, or any other symptom that is new.
 - Vomiting, pain in stomach
 - Poor appetite
 - Nausea
 - Yellow eyes or skin



CASE MANAGER:

Also show list of side effects in take-home booklet.





SIDE EFFECTS

SAY THE FOLLOWING:

We want to know if you have any of the following less common side effects.

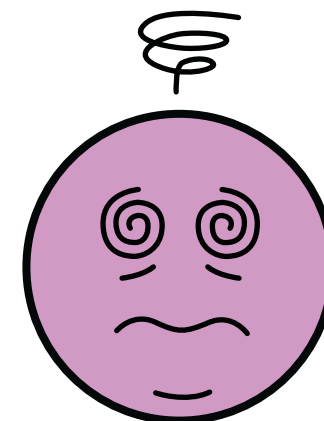
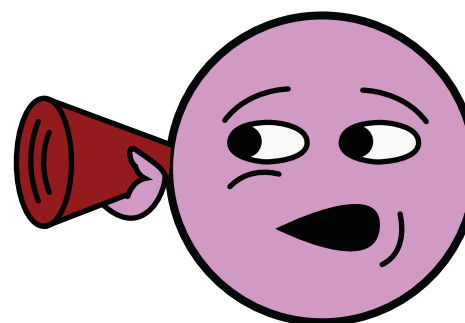
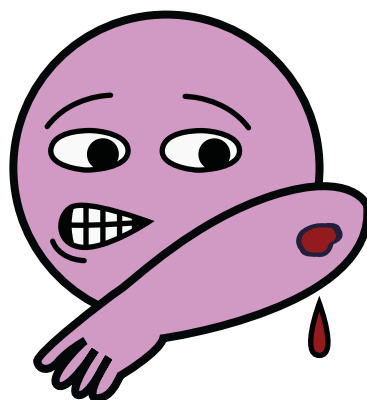
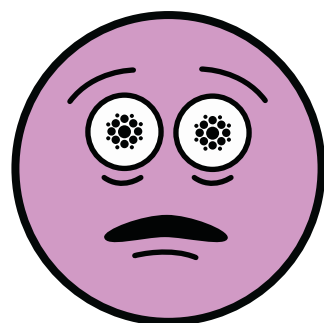
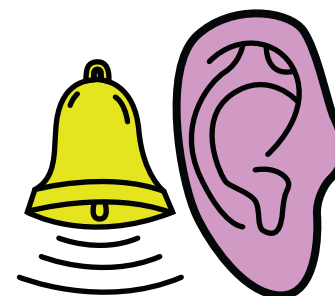
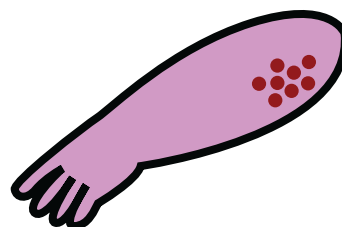
- Tingling fingers or toes
- Skin rash
- Bleeding or bruising easily
- Blurred vision or change in your vision
- Ringing in your ears or trouble hearing
- Dizziness
- Aching joints
- Fever for more than 3 days



CASE MANAGER:

Also show list of side effects in take-home booklet.

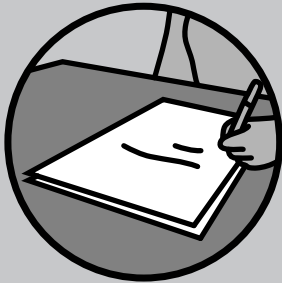




FORM

SAY THE FOLLOWING:

- Now that you know what pills you will be taking, we would like you to sign a form that says you understand what pills you will be taking and their possible side effects.
- May we work on this form together?



SIGN FORM:

"Tuberculosis Medication Consent Form"



Tuberculosis Program

DIRECT OBSERVED THERAPY PROGRAM



John Doe

On Department of Health

If you have tuberculosis with symptoms, you should be treated with medication. It is important to take your medicine every day for the full course of treatment. If you do not take your medicine every day, your tuberculosis may not be completely cured and you may become ill again. It is important to take your medicine every day for the full course of treatment. If you do not take your medicine every day, your tuberculosis may not be completely cured and you may become ill again.

Signature of Patient

Signature of Health Care Provider

Signature of Witness

Signature of Health Care Provider

Signature of Witness

Signature of Health Care Provider

Signature of Witness

Signature of Health Care Provider

Signature of Witness

Signature of Health Care Provider

Signature of Witness

Signature of Health Care Provider

Signature of Witness

Patient

Health Care Provider

Witness

Health Care Provider

Witness

Health Care Provider

Witness

Health Care Provider

Witness

Health Care Provider

Witness

Health Care Provider

Witness

Health Care Provider

Witness

DIRECTLY OBSERVED THERAPY

SAY THE FOLLOWING:

- Now let's talk about the TB pills you will be taking.
- TB germs are strong, so the TB pills take a long time to work.
- We are here to help you through your treatment.
- We know it can be hard to take so many pills each day for many months.
- A health care worker will bring your pills to you each day and help you contact me if you have questions.
- They will ask you how you are feeling and see you take your pills.
- On Fridays they will give you extra TB pills for the weekends.
- They will tell me how you are doing.



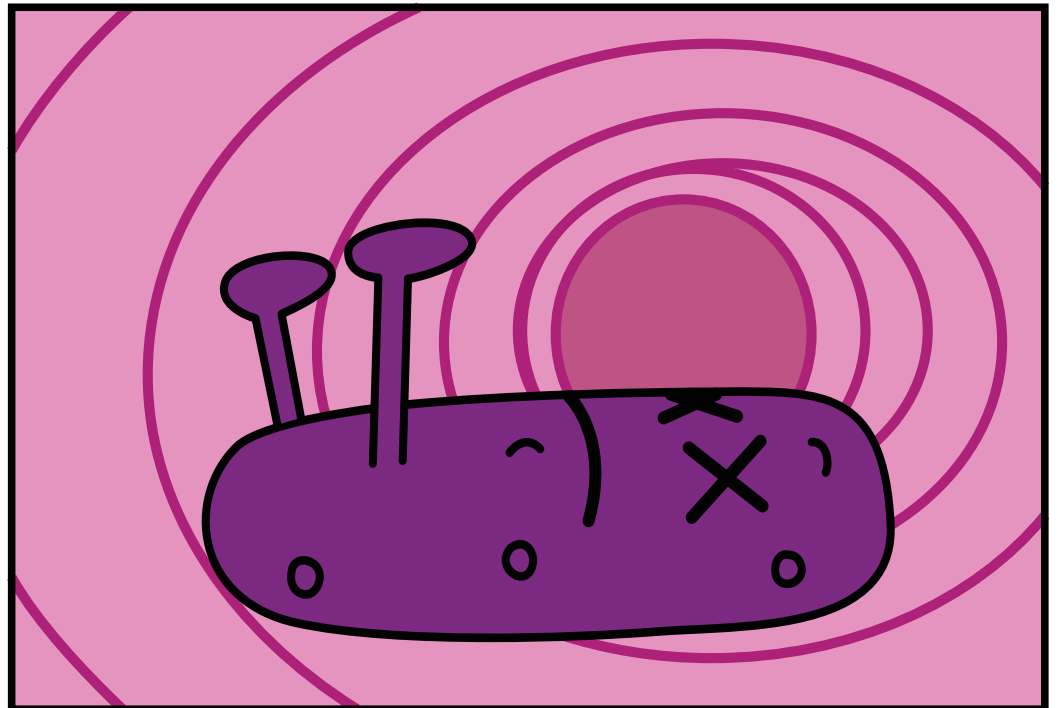
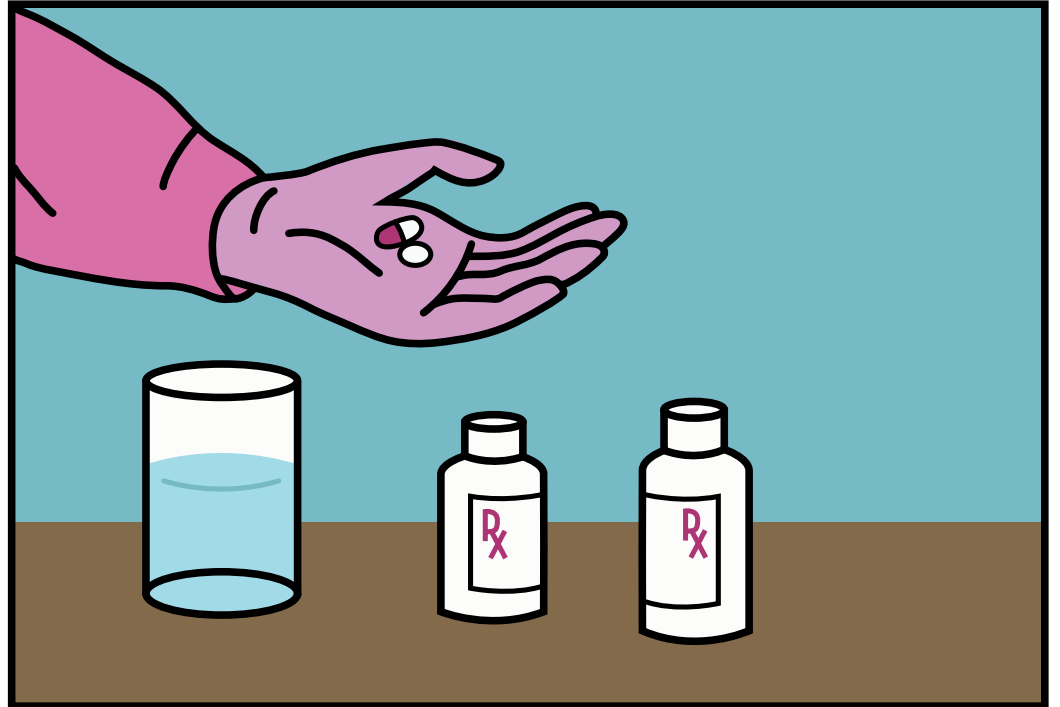


WHY WE BRING YOU THE PILLS

SAY THE FOLLOWING:

- We bring the TB pills to you because this is the best way to make sure you get all the medicine you need and to make sure the medicine is working.
- If there is a problem with your pills, it can be fixed right away.
- This is how people with TB all over the world take their pills.
- Watching patients take their TB pills every day is normal. Everyone does this.

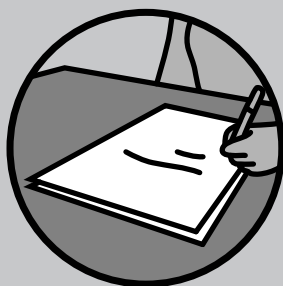




FORMS

SAY THE FOLLOWING:

- We ask everyone with TB disease to look at and sign forms.
- May we work on some of these forms now?

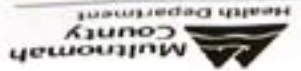


SIGN FORMS:

Explain the “Direct Observed Therapy Agreement” form and ask client to complete.

- *The DOT agreement says that you agree to have us deliver the pills, and you will take them as we ask you to do.*





Tuberculosis Program

DIRECT OBSERVED THERAPY AGREEMENT

DOB: 11/1/99

Signature: John Doe

Location: Multnomah County Health Department

I, the undersigned, hereby agree to the following:
I understand that I am being treated for Tuberculosis and that I must take my medicine every day as directed by my healthcare provider. I understand that if I do not take my medicine as directed, my health may be put at risk and I may become contagious to others. I agree to take my medicine every day as directed and to inform my healthcare provider if I have any side effects or if I am unable to take my medicine as directed. I agree to attend all appointments with my healthcare provider and to follow all instructions given to me. I agree to inform my healthcare provider if I travel out of the country or if I change my address. I agree to inform my healthcare provider if I am pregnant or planning to become pregnant. I agree to inform my healthcare provider if I am taking any other medications. I agree to inform my healthcare provider if I have any other health conditions. I agree to inform my healthcare provider if I have any other concerns. I agree to sign this agreement and to provide my signature to my healthcare provider.

Signature of Patient: _____
Signature of Healthcare Provider: _____
Date: _____

YOU WILL FEEL BETTER SOON

SAY THE FOLLOWING:

- After you have been taking pills for a few weeks, you will start to feel better.





MORE TESTS DURING YOUR TREATMENT

SAY THE FOLLOWING:

- We will tell you when you can no longer spread the germs to other people. We will know this by doing more tests.
- We may ask you to cough in a tube once a month. This will help us know if you can still spread the germs to other people.



CASE MANAGER:

Show client how to do sputum collection using images.

OPTIONAL: *Explain how testing works.*

- When we test your sputum we give it a grade of zero to four. A grade of four means you can easily spread the TB germs to other people. A grade of zero means you are unlikely to spread it to others. When your sputum gets three zero grades in a row then you can come off isolation and return to your normal activities.





MORE TESTS DURING YOUR TREATMENT

SAY THE FOLLOWING:

- We will also do more chest X-rays.
- We usually do this after two months and again at the end of your treatment.
- This helps us understand if your lungs are healing.

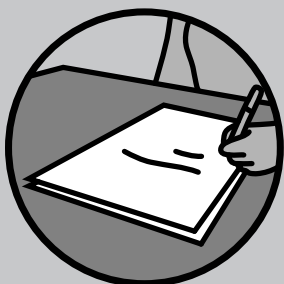




FORMS

SAY THE FOLLOWING:

- We may need to talk about your TB disease with other people so you get the best care.
- You can choose someone from you family for us to talk to about your disease and treatment.
- If you sign this form, you are saying it's okay for us to talk about your TB disease with the person listed on the form. We do one form for each person we need to share information with.
- Can we work on these forms now?



SIGN FORM:
*"Authorization for Release of
Information"*



Tuberculosis Program



DIRECT OBSERVED THERAPY AGREEMENT

Patient: John Doe

Local Health Department Name: _____ DOB: 1/7/37

Treatment of active tuberculosis with prescribed medications will in most cases cure TB. TB medications must be taken for at least 6 months, and sometimes longer. The standard of care for taking TB medications is called Directly Observed Therapy (DOT) and is done by your local health department. DOT requires you take your TB medicine while being watched by a nurse or other staff.

- I, John Doe (Name of Client) _____ understand and agree to the following:
1. I will be at: _____
 2. I will tell my DOT worker of any complaints, questions or problems that I have, between _____ to take my TB medicine.
 3. I understand that if I miss my appointments and do not take my medicine regularly, legal action may be taken.

In return the local health department will:

1. Meet you at the above location during the time arranged. If the appointment needs to be changed, we will notify you.
We will provide you with medications for TB without charge.
We will maintain your confidentiality, respond to your questions and address your concerns

I have read the above information, understand it, and agree to the conditions.

Patient John Doe _____ Designee _____

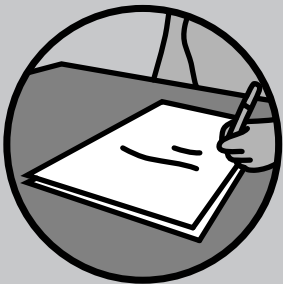
Date 12-22-2016 _____

426 SW Stark St.

FORM

SAY THE FOLLOWING:

- We need to ask you to stay home while you can still spread the TB germs to other people.
- We have a form that asks you to do this. Let's go over the form now.



SIGN FORM:

"Agreement to Help Me Stop the Spread of TB" form.





RETURNING TO ACTIVITIES

SAY THE FOLLOWING:

- Our TB doctor will tell you when you can return to work, school or other activities
- After you have been on daily pills for a couple months, you may be able to take fewer pills or take pills less often. We will tell you if you can do that.



CASE MANAGER:

Offer a medical excuse letter for work, school, etc.





CONTACT INVESTIGATION

SAY THE FOLLOWING:

- We will test your family and people who you spend a lot of time with to see if they have TB germs.
- If they do have TB germs but are not yet sick, they will be offered pills to cure the “sleeping” TB germs.
- I’m going to ask you a few questions about your family and people close to you so we can decide how to help them.
- How many people live with you?
- Are there any children under 5 years old in the household?
- Is there anyone in the household with an immune system problem?
- What do you do for work?



CASE MANAGER:

If client is a child ask:

- *Where does your child go to school and how does your child get to school?*
- *Is there anyone in the household with a cough, fever or weight loss?*





TAKE PILLS

SAY THE FOLLOWING:

- *Now it's time to take your first dose of pills.*



CASE MANAGER:

*Give client the first medication packet.
Go over pill regimen/instructions again.*





Multi-count County Health Dept.
Washoe Health Center
1000 N. Carson St.
Reno, NV 89501

YOUR TREATMENT SUMMARY

SAY THE FOLLOWING:

- I would like to go over your treatment with you again.
- Your medication person will bring you pills every day.
- I will visit you once a month to see how you are doing.
- We may ask you to cough sputum in the tube once a month.
- Your medication person or I may pick it up.
- We will ask you to get another chest x-ray in two months.
- We will work with your doctor to provide you the care you need.
- You may need blood tests if you have a problem or just to make sure the pills are not causing a problem.
- You can call me if you have a question or problem.



CASE MANAGER:

If client is over 50 or has an immune condition or liver disease, tell him or her we will also draw blood once a month.





LAB TESTS

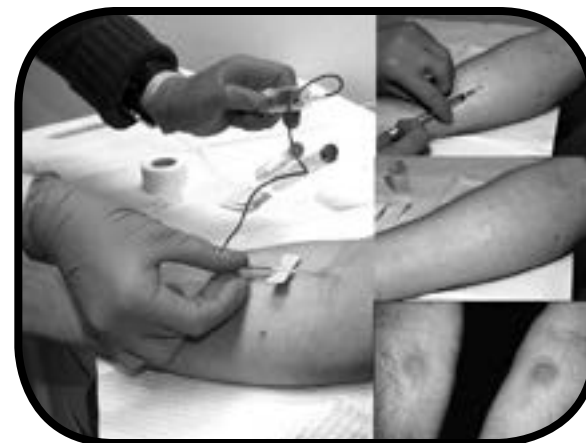
SAY THE FOLLOWING:

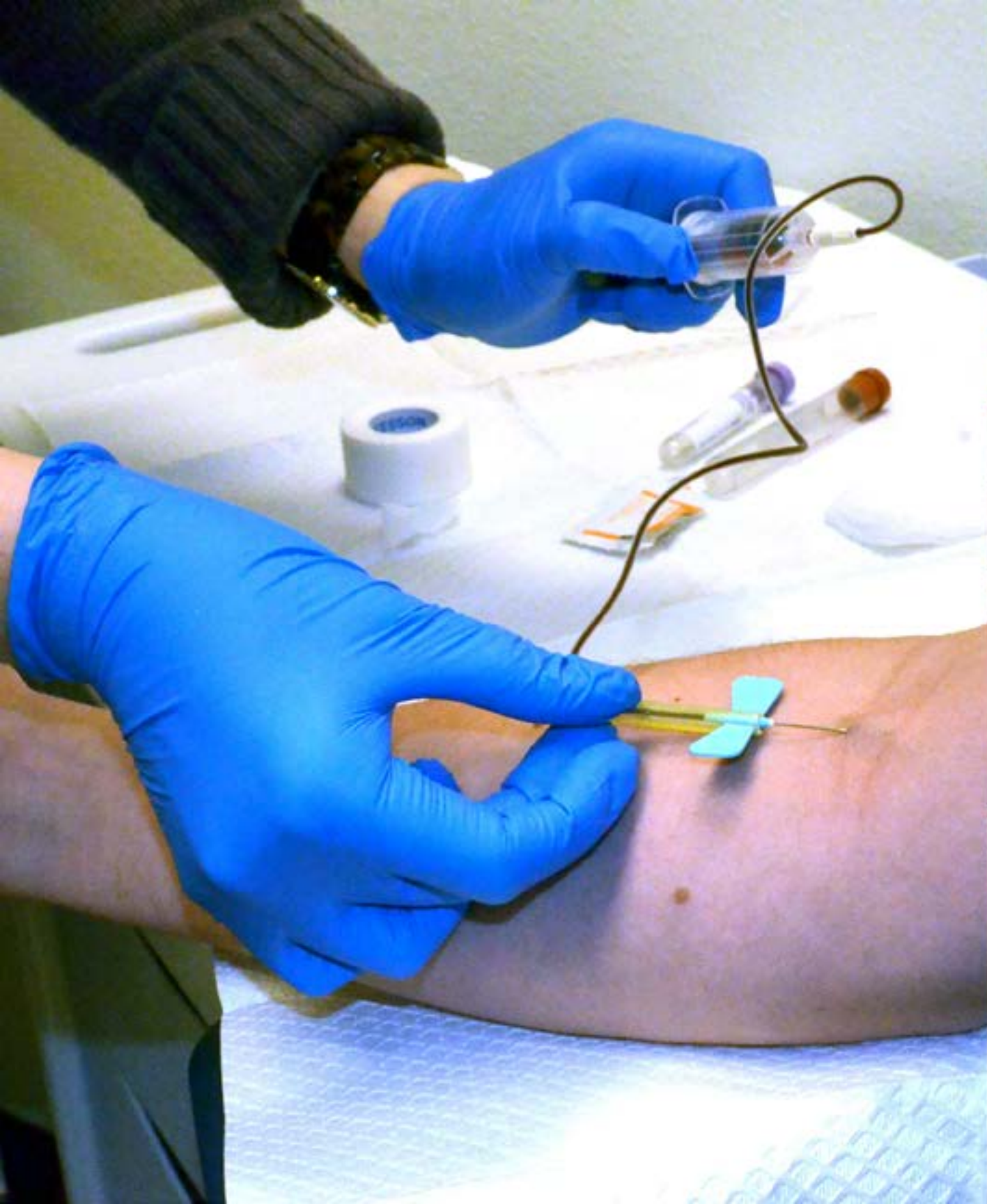
- I am now going to draw some of your blood so we can do some more tests. I may take up to seven tubes of blood.
- QuantiFERON Gold test helps us learn more about the TB germs in your body.
- A complete blood count (CBC) helps us learn if you have a healthy amount of all the different types of cells in your blood. This tells us about your general health.
- A comprehensive metabolic panel (CMP) helps us know if your kidneys and liver are working well so they can handle the TB pills.
- We will do an HIV test to make sure we are treating your TB the right way. HIV can change the way your body responds to the TB pills.



CASE MANAGER:

If the client wants to know, explain what you are testing for while drawing blood.





HOW TO CONTACT US

SAY THE FOLLOWING:

- I want to make sure you know how to contact me while you are on treatment.



CASE MANAGER:

Give take-home booklet and point out contact information.







PUBLIC HEALTH DIVISION

Tuberculosis Program

You can get this document in other languages, large print, braille or a format you prefer. Contact TB Program at 971-673-0169 or email heidi.behm@state.or.us. We accept all relay calls or you can dial 711.