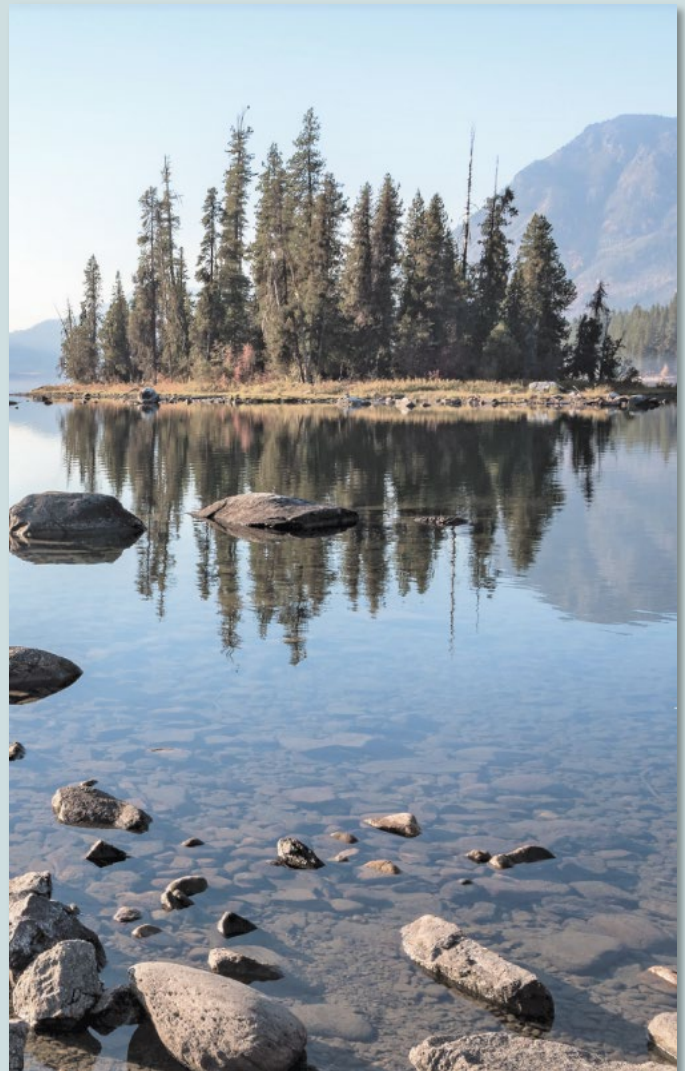


Washington State Tuberculosis Services and Standards Manual

Chapter 13: Communication and Patient Education



DOH 343-222 May 2024



To request this document in another format, call 1-800-525-0127. Deaf or hard of hearing customers, please call 711 (Washington Relay) or email doh.information@doh.wa.gov.

Contact

Washington State Department of Health Tuberculosis Program

Phone: 206-418-5500

Fax: 206-364-1060

tbservices@doh.wa.gov

Acknowledgements

In addition to the multiple resources and references in the **TB Services and Standards Manual** chapters the Washington State TB Program would like to thank the [Curry International TB Center](#) and the [Alaska State TB Program](#); this manual was adapted from these two resources. The TB Program Team was involved in the initial writing and editing of this manual between 2021 and 2023.

Table of Contents

About the Washington State Tuberculosis Services and Standards Manual.....	4
Purpose	4
Audience	4
Eliminating Stigmatizing Language	4
How to Use This Manual.....	5
Icons.....	5
CHAPTER 13: Communication and Patient Education.....	7
Introduction.....	7
Purpose	7
Policy	7
<i>Patient and Family Communication.....</i>	<i>7</i>
<i>Educational Content Areas</i>	<i>8</i>
<i>Health Care Provider Education.....</i>	<i>9</i>
When Educating TB Patients, Families and Health Care Providers	9
General Guidelines.....	9
Assess Language and Comprehension Barriers.....	10
TB Education Topics	11
Medical Diagnosis	11
Isolation.....	12
Side Effects and Adverse Reactions.....	12
Contact Investigation.....	13
Treatment Completion	13
Patient Education Materials & Resources	15
Washington State Department of Health	15
<i>TB Program SharePoint Site.....</i>	<i>15</i>
<i>TB Program Website.....</i>	<i>15</i>
<i>Refugee Health Program Website</i>	<i>15</i>
CDC, Division of TB Elimination	15
Other Sites for TB Patient Educational Materials	16
TB Survivor Stories and Support Networks	16
Other Resources.....	17

About the Washington State Tuberculosis Services and Standards Manual

Purpose

In Washington State, tuberculosis (TB) care and prevention is governed by state law and rule. The purpose of the TB Services and Standards manual is to provide information and guidance to aid local health jurisdictions (LHJs) in fulfilling the requirements detailed in the Revised Code of Washington ([RCW 70.28.005](#)) and the Washington Administrative Code ([WAC 246-170](#)). This manual includes information and links to CDC guidelines and TB Centers of Excellence materials with key steps and information needed to fulfill these required TB care and prevention tasks.

Audience

The most likely readers of this manual are TB providers, primarily those working in Local Health Jurisdictions (LHJs) and Tribal Public Health. As a result, the TB Services and Standards Manual has a special focus on the roles, responsibilities and care given by local public health partners. These TB providers may include, but are not limited to nurses, physicians, Health Officers, Regional Medical Officers, epidemiologists, disease intervention specialists and outreach workers from local and state TB programs, clinics, and hospitals.

Eliminating Stigmatizing Language

Judgmental terms and negative connotations of words such as ‘defaulter’ and ‘suspect’ may be perceived to place blame for the disease and responsibility for adverse treatment outcomes on the patient. To assist in implementing a change in the use of stigmatizing language the Heartland TB Center of Excellence, the International Union Against TB and Lung Disease, the National Society of TB Clinicians, the global TB community and the Treatment Action Group developed the [Stop the Stigma: Eliminating Stigmatizing Language](#) reference tool to aid in identifying suggested replacement language as a reminder of how our words may affect others.

Use This....	Not that....	Use This....	Not that....
Adherence / Non-adherence	Compliance / Non-compliance	Undocumented	Illegal; Illegal alien
Person lost to follow up	Defaulter	Person with TB disease	TB case
TB Prevention and Care	TB Control	Treatment failed	Treatment failure
Person to be evaluated for TB	TB Suspect	Missed doses/ Non-adherent	Delinquent
HIV-Positive	HIV-infected	Contact Analysis; Contact Elicitation; Contact Identification	Investigation; Investigate
Immigrant	Alien	Exposed to TB	TB Contact
Lack of housing; Under-housed; People experiencing homelessness	Homeless/ Homelessness	Tuberculosis	Consumption; White Plague

Adapted from: https://www.heartlandtbc.org/wp-content/uploads/2021/12/FactSheet_Final_5_19_16.pdf

More information can be found at [Case Management Tools/Health Equity](#) in the TB Program SharePoint page which includes additional resources to encourage positive change, sensitize, promote appropriate language, end the stigmatization, and empower people affected by TB.

How to Use This Manual

Icons

Throughout the manual, these icons quickly cue you about important information and other resources:



This warns about high-consequence information you must understand when performing the task.



This signals when you should call to report or to consult on the task.



This highlights special considerations for pediatric patients.



This suggests another relevant area in the manual or another resource that you may want to review.



This alerts you that a form is available for the task.

CHAPTER 13: Communication and Patient Education

Introduction

Purpose

This chapter will focus on providing education to patients and their families about tuberculosis (TB) care and prevention. Included in this chapter are best practices and topics to consider when providing education, available materials and resources, and the importance of patient education to support successful outcomes and promote equitable care.

Adherence to a TB plan of care is difficult! Ensuring the patient successfully completes treatment involves providing them with a broad knowledge of TB. This means talking to patients about the cause of TB, the way it is spread, how TB is diagnosed, and how this relates to their specific care plans. Patients with TB disease must be given ample opportunity to understand the seriousness of the disease and reasons why adherence to treatment is so important. Patients cannot be expected to adhere to treatment if they do not understand the importance of treatment and their role to achieve the best health outcomes and protect their community. Patients who demonstrate an understanding of these concepts are more likely to adhere to treatment and other aspects of their care plan.

People diagnosed with latent TB infection (LTBI) should be given the opportunity to understand their individual risk of progressing to disease, the risks and benefits of treatment, and how treatment can help prevent spread of TB to family, friends, and the community throughout the cascade of care.

Ongoing patient education in conjunction with active listening are essential elements of a patient-centered care plan, including adequate and appropriate medication, quick identification and mitigation of barriers to adherence, and Directly Observed Therapy (DOT) when appropriate, will prevent poor outcomes for patients and public health.

Policy

Domain 3 of the [Tuberculosis Nurse Case Management: Core Competencies](#) from the National TB Nurses Coalition (NTNC) outlines communication and education skills required for TB case management to be effective when interacting with patients, families, and health care providers. Competent TB program staff demonstrate effective verbal and written communication skills, use strategies that build trust and rapport, and work to ensure that interactions are respectful and equitable. The policy of the WA State TB Program is adapted from these Core Competencies stating that LHJ TB nurses and staff should follow this guidance in their interactions with patients, families and health care providers.

Patient and Family Communication

To ensure equitable goal setting, TB program staff should:

- Establish achievable care goals with the patient and the patient's family that recognize their specific challenges and strengths
- Develop and communicate a written plan (preferably in the patient's first language and at their literacy level) with the patient and the patient's family to achieve anticipated goals within a specified time frame

- Engage the patient and the patient’s family in implementing the plan of care
- Provide an accurate, consistent, and clear message that is relevant to the intended audience

To provide emotional support, staff should:

- Apply cultural humility to patient interactions
- Demonstrate respectful and equitable attitudes and behaviors
- Identify emotional barriers and provide equitable access to care
- Provide education, emotional support, encouragement, and resources throughout the course of isolation and treatment

To provide education, staff should:

- Assess the patient’s readiness to learn, level of health literacy, TB knowledge, attitudes, and beliefs
- Identify knowledge gaps and provide information
- Tailor information to meet the needs and health literacy of the target audience
- Develop messages that consider the language proficiency of the target audience
- Disseminate educational materials in multiple formats
- Limit the amount of information in each session
- Provide an overview at the beginning and a summary at the end of each session
- Encourage questions
- Incorporate the use of support systems

Educational Content Areas

The TB program staff should incorporate the following messages into educational offerings:

- Clearly state that TB is curable
- Review how TB transmission occurs
- Define TB infection and TB disease
- Explain isolation processes and limitations on visitors
- Describe disease prevention through the treatment of TB infection
- Clarify the purpose of contact investigation
- Explain the role, responsibility, and legal authority of the health department

The program staff should provide education about contact investigation topics, including:

- Definition of contact
- Infection and disease progression risks
- Test timeframes, whether by IGRA or TST
- Meaning of a positive test
- Evaluation process after a positive test
- Options for TB infection treatment
- Reasons for deferring TB infection treatment
- Importance of and methods for ensuring confidentiality
- Role of public health staff, support services, and resources

Health Care Provider Education

The TB NCM should provide or facilitate **health care provider** education when needed to:

- Assess the knowledge base, identify gaps, and provide information to meet the provider’s needs
- Clarify the role of the private provider and the public health responsibilities for their jurisdiction:
 - Prescription and provision of TB-related medications
 - Medical and clinical care
 - Orders for imaging and monitoring labs
 - Ongoing case monitoring and management
- Provide regular, timely updates on patient’s progress to the provider and the health care team

The WA State TB Program provides consultation and resources for providing patient education and information concerning TB infection and disease, TB transmission, treatment, common TB medication side-effects, and the importance of patient adherence to therapy and monitoring.

When Educating TB Patients, Families and Health Care Providers

General Guidelines

Some general guidelines for the educational process include the following:

When Educating Tuberculosis Patients	
Do	Don't
<ul style="list-style-type: none"> • Create an environment conducive to learning with trust, respect and acceptance. • Find out what patients know and believe about tuberculosis (TB). • Reinforce and provide correct TB information and correct any misconceptions. • Adapt teaching to the patient's level of readiness, past experiences, culture, language and understanding. • If necessary, use an interpreter. • Encourage questions and provide appropriate answers. • Involve patients throughout the learning process by encouraging them to establish their own goals and evaluate their own progress. • Provide opportunities for patients to demonstrate their understanding of information and to practice skills. • Inform patient of findings clearly and concisely. • Discuss treatment plans in terms of specific behaviors. • Utilize appropriate written, audiovisual and computer-based materials. • Review the educational materials with patients. 	<ul style="list-style-type: none"> • Flood patients with information about TB and its effects without allowing them to participate in the discussion. • Hand out pamphlets and brochures to patients without reviewing the materials with them.

Sources: **Patient education**. American Academy of Family Physicians. Am Fam Physician. 2000 Oct 1;62(7):1712-4. Available at: <https://www.aafp.org/pubs/afp/issues/2000/1001/p1712.html> and **Five strategies for providing effective patient education**. HEALTH. 8/23/2017. Available at: <https://www.wolterskluwer.com/en/expert-insights/5-strategies-for-providing-effective-patient-education>

Assess Language and Comprehension Barriers

In the initial assessment, assess for and address any potential language and comprehension barriers and health literacy.

1. Ask every patient in what language they prefer to receive health information.
2. Assess the patient's ability to speak and understand instructions, including potential barriers, such as not speaking English as primary language, deafness, speech deficit, or learning disability.
3. Assess literacy in the patient's primary language.
4. Provide all instructions and communications in the appropriate language.
5. Use interpreters, visuals, TTY telephone or other educational methods to promote understanding. This is especially important in Washington due to the cultural diversity among our population.
6. Provide educational materials appropriate to the patient's language and reading level.



For more information on working with interpreters see the video: [Interpreter Services at Harborview Medical Center \(YouTube\)](#).



For more information on cultural sensitivity, refer to the [Participant's Workbook for Session 4: "Working with Culturally Diverse Populations" in the Directly Observed Therapy Training Curriculum for TB Control Programs \(Francis J. Curry National Tuberculosis Center Web site; 2003\)](#)



For information on country-specific TB epidemiology, common misperceptions, beliefs, attitudes, and stigmatizing practices related to TB and HIV/AIDS, general practices and cultural courtesies, translated educational materials available online, and references, refer to [country-specific guides \(Southeastern National TB Center\)](#).



For assistance with language issues, see the [Language Services Resource Guide for Health Care Providers \(The National Health Law Program Web site; 2006\)](#). Many LHJs have access to telephone services staffed with trained medical interpreters and translators similar to this: [UW Medicine Interpreter Services](#).



For information on assessing health literacy see: [Four Steps to Assess Health Literacy and Improve Patient Understanding](#) and [Measures of Individuals' Health Literacy](#).

TB Education Topics

Educate the patient as needed at **all available opportunities**. Take advantage of the time spent during the initial assessment, directly observed therapy (DOT) appointments, and monthly monitoring, to assess their educational needs and provide TB education. Spending time early in the relationship with the patient on all the education topics below will help in a patient's understanding of the importance of adherence to treatment, their responsibilities during treatment, and the consequences of nonadherence. In addition, it is important to:

- explain the importance of treatment and follow-up for active TB and the importance of regular monitoring visits.
- discuss the treatment plan (including DOT) and expectations. Advise the patient of their responsibilities and expected treatment adherence and follow-up activities.
- as needed, explain why you may offer incentives and enablers to ensure adherence to the treatment regimen.



For more information on case management activities, see [Chapter 10: Case Management](#)

Medical Diagnosis

In the initial interviews with the patient, provide information about TB and the patient's treatment plan. During DOT/VDOT appointments and monthly monitoring, confirm and reinforce the patient's understanding of these topics.

1. Discuss the difference between TB disease and TB infection.
2. Explain the signs and symptoms of TB, how TB is transmitted, prevention activities, and treatment.
3. Explain that TB is both treatable and preventable.
4. Explain the importance of completion of treatment.

Stress the importance of testing and follow-up. Discuss and explain diagnostic procedures used to make a diagnosis of TB such as:

- tuberculin skin testing and IGRAs
- chest radiography
- sputum microscopy (smear, culture, NAAT and drug sensitivity testing)

Discuss the current medical treatment plan and rationale.

1. Explain the need for regular medical monitoring and follow-up during the disease process. Discuss how treatment will be monitored (i.e., sputum testing, blood tests, vision screening, weight check, etc.) and adverse reactions to watch for, stressing the importance of reporting these to the case manager if they arise. Encourage the patient to be an active participant in care and treatment.
2. Discuss the roles of the patient (engage in treatment), the health department (case management, monitoring, contact tracing, and supervision of treatment), and the private

provider (treatment and monitoring). Encourage the patient to contact the case manager for issues and problems that arise during treatment.

3. Explain the risk of treatment failure, disease relapse, transmission, and drug resistance if treatment is not completed as prescribed.
4. Explain the signs and symptoms of possible relapse or failure and encourage the patient to report them immediately to the case manager.



For more information on TB education, DOT and treatment agreements, contact investigation, side effects and potential drug interactions, and adherence with the treatment regimen, [Chapter 10: Case Management](#).

Isolation

If isolation is necessary, educate the patient about how to take proper precautions and restrictions that will be in place. Have them sign an [acknowledgement of TB counseling](#) and [Isolation Instructions](#).

1. Explain the [behavior changes needed for infection control](#). Discuss permitted and prohibited activities, limiting and excluding visitors, covering the mouth and nose when coughing and sneezing, and using a mask. Encourage going on a walk or sitting outside on weather appropriate days.
2. Explain the [home environmental changes](#) needed for infection control. Discuss the affect ventilation and sunlight has on transmission.
3. Discuss the requirements for [release from isolation](#). Advise the patient that clearance is contingent upon clinical condition and continued adherence to the treatment regimen.



For more information see the [Case Management Tracker on the WA State TB SharePoint site](#)

Side Effects and Adverse Reactions

Educate all patients taking anti-TB medications about the medications' potential side effects and adverse reactions.

1. Explain names, dosages, and rationale for the drug treatment plan and the importance of treatment.
2. Explain the common side effects and options to improve symptoms.
3. Explain signs and symptoms of drug toxicity.
4. Direct the patient on actions to take if side effects or signs and symptoms of toxicity appear.
5. Explain potential effects of alcohol and/or drug use on treatment and the increased risk for side effects and toxicity.
6. Review other medications, both prescription and non-prescription including over-the-counter medications, supplements, homeopathic treatments, the patient is taking to identify potential drug interactions.
7. Remind patients to inform their other healthcare providers that they are taking TB treatment so those providers can look out for drug interactions and remind them to report to the TB case

manager any new prescriptions or over-the-counter medications they may start while also still taking TB treatment.



For more information on side effects and adverse reactions see the related sections in [Chapter 6: Treatment of TB Disease](#), and [Chapter 8: Treatment of Latent TB](#).



[Nursing Guide for Managing Side Effects to Drug-resistant TB Treatment \(Curry International TB Center; 2018\)](#).

Contact Investigation

When a contact investigation is necessary, educate the index patient about the process and confidentiality.

1. Discuss the contact investigation process.
2. Reinforce the confidentiality of investigation but warn the patient of the potential for contacts to guess the patient's identity.
3. Gauge the patient's comfort and desire to be involved with notifying those exposed. If the patient wants to be involved in the process, provide education regarding how they can best assist.



For more information on contact investigation see [Chapter 11: Contact Investigation](#).

Treatment Completion

Although cured and left with a low probability of recurrence, TB survivors completing treatment commonly experience chronic morbidity related to the site of disease. They may also experience an increase in post-treatment mortality over the next several years. The site of disease producing the greatest number of lasting consequences is the chest. Common manifestations include dyspnea, chronic cough and sputum production associated with bronchiectasis as well obstructive, restrictive, and mixed pulmonary dysfunction. Frequency and severity of these sequelae appears proportional to the extent of lung damage at the time of diagnosis. CNS disease may be associated with the most severe long-term impacts among those with unresolved neurologic deficits, but skeletal and pericardial cases—among others—also are at notable risk for chronic post-treatment morbidity.

People who have survived TB disease have advocated for comprehensive and holistic care beyond treatment completion to increase their quality of life. This might include referrals to primary care, pulmonary function testing, mental health, rehabilitation, and social support services. As completion of treatment approaches (and in some cases during TB therapy) patients at risk for or exhibiting such likely-to-be chronic morbidity should be educated about the condition and alerted to the potential value of obtaining additional follow-up through their personal health care system to address safety, comfort and function going forward. Treatment completion summaries should include statements about known or anticipated post-TB health concerns and possible complications as well as recommendations for age-appropriate screening for cardiovascular disease, lung cancer and depression.



For more information see: [Improving post-tuberculosis care in Canada](#) and [Emphasis on post-TB lung disease and other sequelae of TB is good but as a public health approach to TB is morally ambitious](#)



For a template of a treatment summary see: [\(47\) TB Treatment Summary.docx](#) and [\(47\) TB Treatment Summary_Spanish.docx](#)

Patient Education Materials & Resources

Washington State Department of Health

TB Program SharePoint Site

- [TB Newsletter](#)
- [TB Partners SharePoint: Clinical Resources page](#)
- [TB Partners SharePoint: BPaL](#)
- [TB Partners SharePoint: Case Management Tools](#)
- [TB Partners SharePoint: Clinical Resources](#)
- [TB Partners SharePoint: Other Program Resources](#)

TB Program Website

[TB Program Home Page](#)

Refugee Health Program Website

[Ukrainian, Afghan and other new arriver patient education materials.](#)

CDC, Division of TB Elimination

[Education and Training Materials](#)

[Find TB Resources](#)

[Patient and General Public Materials](#)

[Self-Study Modules on Tuberculosis.](#)

- [Module 6: “Managing Tuberculosis Patients and Improving Adherence.”](#)
- [Module 4: “Treatment of Latent Tuberculosis Infection and Tuberculosis Disease,”](#)

[“Targeted Tuberculin Testing and Treatment of Latent Tuberculosis Infection” \(MMWR 2000;49\[No. RR-6\]\).](#)

[Think, Test, Treat TB.](#)

[Train Learning Network of web-based courses](#)

Other Sites for TB Patient Educational Materials

[TB Centers of Excellence for Training, Education, and Medical Consultation \(TB COEs\)](#)

[COE TB Training and Education Products, Southeastern National TB Center](#)

The four TB COEs are:

- [Curry International Tuberculosis Center](#)
- [Global Tuberculosis Institute at Rutgers, The State University of New Jersey](#)
- [Heartland National Tuberculosis Center](#)
- [Southeastern National Tuberculosis Center](#)

Minnesota Department of Health Website: [Tuberculosis: Patient Education Materials](#). Patient educational materials in multiple languages.

National Tuberculosis Controllers Association, National Tuberculosis Nurse Consultant Coalition: [Tuberculosis Nursing: A Comprehensive Guide to Patient Care](#). (as of August 2022 this resource is currently under revision and unavailable.)

Official American Thoracic Society/Centers for Disease Control and Prevention/Infectious Diseases Society of America Clinical Practice Guidelines: [Treatment of Drug-Susceptible Tuberculosis, Clinical Infectious Diseases, Volume 63, Issue 7, 1 October 2016, Pages 853–867](#)

EthnoMed:

- [Patient Education Resources: All Languages](#).
- [Tuberculosis Series – Intro](#)

TB Survivor Stories and Support Networks

[TB Personal Stories](#)

[TB PhotoVoice](#)

[We Are TB: TB Survivors and Advocates](#)

[We Are TB Facebook](#)

Other Resources

American Academy of Family Physicians. Am Fam Physician. **Patient education**. 2000 Oct 1;62(7):1712-4. Available at: <https://www.aafp.org/pubs/afp/issues/2000/1001/p1712.html>.

CDC. **Measures of Individuals' Health Literacy**.

<https://www.cdc.gov/healthliteracy/researchevaluate/measure-peoples-skills-experiences.html>

Long R, et al. **Emphasis on post-TB lung disease and other sequelae of TB is good but as a public health approach to TB is morally ambitious**. Intl J Tuberc Lung Dis 2024; 28(2):70–72.

National Tuberculosis Controllers Association (tbcontrollers.org) NTNC. **Tuberculosis Nurse Case Management: Core Competencies**. <https://www.tbcontrollers.org/resources/core-competencies/tb-nurse-case-manager/>

Romanowski K, Amin P, Johnston JC. **Improving post-tuberculosis care in Canada**. CMAJ. 2022 Dec 5;194(47):E1617-E1618.

Washington State Tuberculosis Law Manual for Health Officers. **Acknowledgement of TB Counseling**. Available at: <https://doh.wa.gov/sites/default/files/legacy/Documents/Pubs/343-116-TBLawManual.pdf?uid=634877062e576#page=41>.

Wolters Kluwer. **Five strategies for providing effective patient education**. Available at: <https://www.wolterskluwer.com/en/expert-insights/5-strategies-for-providing-effective-patient-education> Accessed June 30, 2022.