PUBLIC HEALTH DIVISION
HIV, STD, & TB Program
Kate Brown, Governor

Oregon Health Authority

800 NE Oregon Street, Suite 1105
Portland, OR 97232

# Recommendations regarding people with TB disease receiving end of life care

## Background

Deciding if a person should continue TB treatment at end of life is a difficult ethical decision. It is important for the local public health authority (LPHA) to work with the person living with TB, the family, and the care team to individualize TB treatment to meet end-of-life needs and protect public health.

## Terminology

**End of life care**: The term used to describe the support and medical care given during the time surrounding death. People may receive end of life care in the hospital, through hospice services or at home.

**Hospice:** Hospice services are provided for a person with a terminal illness whose doctor believes they have 6 months or less to live if the illness runs its natural course. Hospice provides comprehensive comfort care for the person as well as support for the family. Attempts to cure the person's illness are stopped.

**Palliative care:** Palliative care is for anyone with a serious illness. Palliative care can be helpful at any stage of illness. In addition to improving quality of life and helping with symptoms, palliative care can help people understand their choices for medical treatment. Palliative care can be provided along with curative treatment and does not depend on prognosis.

## Rationale for continuing TB treatment

People living with TB often report feeling better in the weeks following initiation of treatment. Initiating or continuing TB treatment at end of life might benefit the person and improve their quality of life. The person may start to feel better or improve while on treatment and infectiousness will be less of a concern.

## Factors to consider when a person with TB disease is at end of life

- What are the person's goals of care? What are their end of life goals?
- What is the person's life expectancy and what interventions besides TB treatment are continuing?

- How sick and likely infectious is the person with TB (Sputum smear+? Cavitary CXR?)
- Is the TB drug-resistant?
- For people with pulmonary TB, how will their infectiousness be monitored if the treatment is discontinued and how long should this monitoring continue?
- If a person with pulmonary TB cannot produce sputum, should airborne isolation be maintained?
- Is the person able to swallow pills? If not, will an invasive procedure be required to keep them on treatment (NG or PEG tube, PICC)?
- What labs are needed if TB medications are continued and how can sample collection be minimized to avoid discomfort from blood draws?
- Will there be visitors who have not yet been exposed to TB?
- Are there immunocompromised individuals staying with the person?
- Will home health or hospice staff enter the home to provide care if the person living with TB is not on treatment?
- Are home health or hospice staff equipped with fit-tested N95 masks or PAPRs? If not, can the LPHA help with PAPR loans or help with fit-testing?
- Will the person living with TB need to go outside their home for care?

**General guidance:**

- A case conference between all providers is recommended to ensure joint decision making. Consider including the family in a case conference with providers as appropriate.
- Often it is best to keep the person on TB treatment if tolerated. In some cases, a modified regimen with a decreased pill burden is appropriate. Consult OHA TB program or Curry International TB Center to discuss a modified regimen.
- Remember there may be new visitors to the home. Determine how visitors can be protected from TB while still allowing the person living with TB to see their loved ones.
- When possible, assist hospice and home health to obtain appropriate PPE and education about TB (e.g. assist with N95 fit testing or provide a PAPR) so hospice care can continue.
- If the person has extrapulmonary TB, medications can be stopped without monitoring for infectiousness.
- If a person with pulmonary TB discontinues medications, weekly sputum collection is advised. People entering the home (healthcare workers, new visitors) should wear appropriate PPE. Open windows to allow in fresh air and sunlight.
- A person with pulmonary TB who has discontinued medication and is unable to produce sputum or reports no cough should be considered infectious. Healthcare workers and new visitors should wear appropriate

PPE. Consult OHA TB Program or your health officer if you believe an exception is warranted (e.g. pleural TB or miliary CXR).

- When TB medication is stopped, the LPHA should remain in contact with the person living with TB or their family during the remainder of the person's life. If their condition improves, consider asking them to try TB treatment again. Consult OHA TB program or Curry International TB Center for more guidance on frequency of monitoring.
- Assure household members and family that public health will continue to support them after their loved one has died. Those living with an infectious family member should be tested 8-10 weeks after their last exposure.

**Resources and References**

Clinical Practice Guidelines for Providing Palliative Care to Patient with Tuberculosis. Kyrgyzstan Republic Ministry of Health.

Providing Care and Comfort at the End of Life. National Institute on Aging.