# About my treatment for drug-resistant tuberculosis (TB)

**This leaflet is about rifampicin-resistant tuberculosis (RR-TB) and multidrug-resistant tuberculosis (MDR-TB)**

## What are RR-TB and MDR-TB?

RR-TB occurs when TB bacteria become resistant to rifampicin, one of the most powerful antibiotics normally used to treat the illness.

MDR-TB occurs when TB bacteria become resistant to rifampicin and isoniazid - the two most powerful antibiotics normally used to treat the illness.

This means that these medicines will not work effectively as they can no longer kill the TB bacteria.



## Information and support

**TB Alert information service:** for any questions or concerns about TB, email **contact@tbalert.org** or call **0330 102 2403**. This number is low cost or free to call by mobile phone, depending on your contract.

## What does it mean if I have RR-TB or MDR-TB?

RR-TB and MDR-TB are more difficult to treat than ordinary TB. You may need to take more tablets to treat this type of TB, and the medicines used against it have a greater number of side effects.

Many people may need to take antibiotics for 6 months, but some people may also have to take antibiotics for much longer - in some cases up to 20-24 months.

If you have RR-TB or MDR-TB, you may be infectious for longer, may feel more unwell and are more likely to be admitted to hospital for treatment. However, if you take all the medication for the full course there is a very high chance of a successful cure.



**Peer support:** talk to others who have been through TB online at: **healthunlocked.com/tb-alert**

Or email **contact@tbalert.org** to arrange direct support.

## What kind of drugs will I have to take?

You will be given a certain combination of drugs to treat your MDR-TB. Your doctor or nurse will tell you when and how to take them. On the following pages you can find reminders on how to take your medications and information about common and serious side effects. **See your TB Nurse if you are struggling with treatment.**

**Before you start taking your TB drugs, tell your doctor about:**

- all other medicines that you are taking including any that you buy over the counter in a pharmacy
- any previous allergy to any other medicines
- any history of other illnesses or conditions
- if you are pregnant or breastfeeding

## My TB treatment plan

Ask your doctor, nurse or pharmacist to write your treatment plan here. They should highlight the medications you are taking in the table below, which provides more information about each drug.

| Medication | Dose |
|---|---|
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| | |
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| | |

**Treatment start date:**

**Anticipated duration of treatment:**

| Medication | Warn your doctor...<br><br>...before treatment if you have ever experienced any of the following | Taking your medication | Side effects |
|---|---|---|---|
| Amikacin<br> | Allergies to other medications, kidney disease, hearing difficulties or tinnitus (ringing or buzzing in the ears), myasthenia gravis diagnosis | Given by a doctor, usually as an injection into a muscle or vein either as an injection or as a drip. It is usually given once every day to begin with. After two to three months, it may be given three times a week. | • ringing in your ears, or loss of hearing<br>• dizziness, or problems with your balance<br>• a decrease in the amount of urine you produce<br>• muscle weakness<br>• trouble breathing<br>• skin rashes and itchiness |
| Bedaquiline<br> | Allergies to other medications, kidney or liver disease, heart problems, thyroid problems | Best taken with, or after, meals. Swallowed whole with water. You should not drink alcohol while taking this medicine. | • headache<br>• dizziness<br>• pain or swelling in the joints<br>• stomach upsets such as nausea (feeling sick), vomiting and diarrhoea<br>• chest pain<br><br>**If you experience the following side effects, stop taking your tablets and contact your doctor immediately:** a racing heartbeat, a heartbeat that suddenly becomes more noticeable (palpitations), or if you faint |
| Clofazimine<br> | Allergies to other medications, peanut or soya allergy, kidney disease | Best taken with meals, or with milk to prevent stomach upset. Avoid strong sunlight and wear sunscreen. The drug may make your skin more sensitive to sunlight than normal, causing a rash or severe sunburn. | • pink, red or brownish-black colouration of the skin and body secretions. This should go away after stopping the medicine, but may take a long time<br>• skin rashes and itchiness<br>• stomach upsets such as nausea (feeling sick), vomiting and diarrhoea<br>• reduced visual acuity, dry or irritated eyes<br>• bloody or black stools or diarrhoea |

| Medication | Warn your doctor... | Taking your medication | Side effects |
|---|---|---|---|
| Cycloserine or Terizidone  | Allergies to other medications, epilepsy or convulsions, mental health problems, kidney disease, porphyria | Best taken before or after meals. You must take pyridoxine (vitamin B6) while taking this medicine. | Side effects may include:<br>• skin rashes and itchiness<br>• sleepiness<br>• confusion<br>• agitation, depressed mood, or changes in behaviour or personality |
| Delamanid   | Allergies to other medications, kidney or liver disease, heart problems, low levels of albumin, potassium, magnesium or calcium in the blood | Best taken with meals. Swallowed whole with water. | • stomach upsets such as nausea (feeling sick), vomiting and diarrhoea<br>• dizziness<br>• tinnitus (ringing in your ears)<br>• headache<br><br>**If you experience the following side effects, stop taking your tablets and contact your doctor immediately:** a racing heartbeat, a heartbeat that suddenly becomes more noticeable (palpitations), or if you faint |
| Ethambutol   | Allergies to other medications, colour blindness or visual disturbances | Can be taken before or after meals. | • skin rashes and itchiness<br><br>**If you experience any of the following side effects, stop taking your tablets and contact your doctor immediately:** visual disturbances (blurred vision, colour disturbance). These are rare.<br>Your doctor or nurse will arrange for you to have an eye test before you start taking ethambutol. |

**Remember, your TB doctor or nurse is there to help you.**

| Medication | Warn your doctor... | Taking your medication | Side effects |
|---|---|---|---|
| Levofloxacin or Moxifloxacin   | Allergies to other medications, liver disease, heart problems, tendon problems from quinolone antibiotics, epilepsy or convulsions, myasthenia gravis, enlargement or "bulge" of a large blood vessel (aortic aneurysm), glucose-6-phosphate dehydrogenase deficiency | Can be taken before or after meals. You should not drink milk, or take antacids, vitamin supplements or sucralfate within two hours of taking levofloxacin and moxifloxacin. Avoid direct exposure to either extensive sunlight or UV irradiation during treatment. | • stomach upsets such as nausea (feeling sick), vomiting and diarrhoea<br>• skin rashes and itchiness<br><br>**If you experience any of the following side effects, stop taking your tablets and contact your doctor immediately:**<br>• jaundice (yellowing of the skin or eyes)<br>• a racing heartbeat, a heartbeat that suddenly becomes more noticeable (palpitations), or if you faint<br>• tendon pain or swelling – if this happens, rest the painful area until you can see your doctor<br>• pain in your joints or swelling in joints such as in the shoulders, arms, or legs<br>• abnormal pain or sensations (such as persistent pins and needles, tingling, tickling, numbness, or burning), weakness in the legs or arms, or difficulty walking<br>• severe tiredness, depressed mood, anxiety, problems with your memory or severe problems sleeping<br>• changes in your vision, taste, smell or hearing |

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| Medication | Warn your doctor... | Taking your medication | Side effects |
|---|---|---|---|
| Linezolid<br> | Allergies to other medications; if you are taking other medicines (especially decongestants or those for depression or Parkinson's); high blood pressure, overactive thyroid, adrenal gland tumour or carcinoid syndrome, kidney or liver disease, epilepsy or convulsions, anaemia | Can be taken before or after meals. Avoid eating large amounts of mature cheeses, yeast extracts or soya bean extracts (such as soy sauce), or drinking large amounts of alcohol. | • stomach upsets such as nausea (feeling sick), vomiting and diarrhoea; or a metallic taste<br>• skin rashes and itchiness<br>• bloody or black stools or diarrhoea<br>• headaches<br>• unexplained bruising or bleeding<br><br>**If you experience any of the following side effects, stop taking your tablets and contact your doctor immediately:**<br>• pain, numbness, tingling or weakness in your fingers or toes<br>• visual disturbances (blurred vision, colour disturbance). These are rare. Your doctor or nurse will arrange for you to have an eye test before you start taking linezolid. |
| P-aminosalicylic acid<br> | Allergies to other medications, kidney or liver disease, thyroid problems, gastric ulcer | P-aminosalicylic acid must be stored in your refrigerator. Do not use if the packets have become swollen, or if the granules have lost their tan colour and are a dark brown or purple colour. Sprinkle the granules over apple sauce or yogurt, or swirl in juice (tomato, grape, grapefruit, cranberry, apple or orange). Do not chew the granules. The skeleton of the granules may be seen in your faeces. This is normal. | • stomach upsets such as nausea (feeling sick), vomiting and diarrhoea<br>• skin rashes and itchiness<br><br>**If you experience the following side effect, stop taking your tablets and contact your doctor immediately:**<br>jaundice (yellowing of the skin or eyes) |

| Medication | Warn your doctor... | Taking your medication | Side effects |
|---|---|---|---|
| Pretomanid<br> | Liver or kidney disease, heart problems, thyroid problems, low calcium/magnesium/potassium, epilepsy or convulsions | Best taken with, or after, meals. | • stomach upsets such as nausea (feeling sick), vomiting and diarrhoea<br>• pain, numbness, tingling or weakness in your fingers or toes<br>• unexplained bruising or bleeding<br><br>**If you experience any of the following side effects, stop taking your tablets and contact your doctor immediately:**<br>• jaundice (yellowing of the skin or eyes)<br>• a racing heartbeat, a heartbeat that suddenly becomes more noticeable (palpitations), or if you faint<br>• visual disturbances (blurred vision, colour disturbance). These are rare. Your doctor or nurse will arrange for you to have an eye test before you start taking pretomanid. |
| Prothionamide<br> | Allergies to other medications; liver disease, diabetes, gastric ulcer, thyroid problems, epilepsy or convulsions or a condition that makes convulsions more likely; mental health problems such as depression, anxiety or psychosis | Best taken with, or after, meals. You must take pyridoxine (vitamin B6) while taking this medicine. | • stomach upsets such as nausea (feeling sick), vomiting and diarrhoea<br>• a metallic taste in your mouth<br>• agitation, depressed mood, or changes in behaviour or personality<br>• dizziness, headache<br><br>**If you experience the following side effect, stop taking your tablets and contact your doctor immediately:**<br>jaundice (yellowing of the skin or eyes) |
| Pyrazinamide<br> | Allergies to other medications, liver disease, acute porphyria; hyperuricaemia and/or acute gouty arthritis | Can be taken before or after meals. | • stomach upsets such as nausea (feeling sick), vomiting and diarrhoea<br>• skin rashes and itchiness<br>• pain or swelling in the joints<br>• flu like symptoms such as chills, fever, dizziness and bone pain<br><br>**If you experience the following side effect, stop taking your tablets and contact your doctor immediately:**<br>jaundice (yellowing of the skin or eyes) |