

PATIENT INFORMATION

Information Sheet for Patients with Non-Tuberculous Mycobacterium Infections (NTM)

What causes Non-Tuberculous Mycobacterium infections?

Non-tuberculous mycobacterium (NTM) infections are caused by mycobacteria that are found in water and soil. These mycobacteria do not usually make people unwell and are part of the broader family of bacteria which includes the mycobacteria that causes tuberculosis.

It is not known why NTM infects some people and not others. It is believed, however, that people who get these infections already have some lung damage, an underlying illness, or a problem with their immune systems.

NTM infections are not contagious and cannot be passed from person to person.

How serious are NTM infections?

Some patients with NTM infections do not require treatment. The medical team looking after you will make an assessment which takes into account any other medical conditions including background lung disease.

What are the symptoms of NTM infections?

Symptoms can be similar to other lung infections and may develop slowly, including:

- Fever
- Cough (and coughing up blood)
- Weight loss/loss of appetite
- Fatigue
- Night sweats
- Swollen lymph nodes

How are NTM infections treated?

NTM infections are treated with a combination of strong antibiotics.

Due to the length of time required to kill the NTM bacteria, treatment may last a full year or two.

In some cases, the NTM infection becomes chronic (long term) and requires continuous treatment. It is also possible that you may get another NTM infection following treatment completion.

Important information about medications used to treat NTM infections

If you forget or stop taking your NTM medication, the infection may return. This is very serious and may mean:

- It will be harder for the doctor to treat the infection because the NTM bacteria can become resistant to the antibiotics prescribed
- An increased amount of medication will be required
- You may need to have injections as well as tablets to treat the infection.

Side effects

The antibiotics used can cause severe side effects, therefore doctors carefully monitor patients being treated for NTM Infections.

The medicines used to treat NTM infections have some common, occasional and rare side effects. If you suffer from any of the potential side effects, it is important that you tell your doctor.

The following side effects may occur with NTM medication:

The following side effects are very common and to be expected. There is no need to contact your doctor/nurse if this encountered:

- If you are taking Rifampicin, your urine, stool, saliva, sweat, and tears may go a red-orange colour. (If you wear soft contact lenses, tell your doctor before starting your treatment as contact lenses may be permanently stained.)

The following potential side effects only occur occasionally. If these are noted, please contact your doctor/nurse if there is no improvement within 48 hours:

- Vomiting (being sick)
- Nausea (feeling sick) – this may improve by taking tablets with food
- Diarrhoea
- Loss of appetite

The following potential side effects are usually rare but can be serious. Please contact your doctor/nurse immediately if you experience any of the following:

- Eye sight problems can occur with Ethambutol treatment; in particular blurring of vision, pain in the eyes or green/red colour blindness. You should stop taking your tablets if this occurs and inform your doctor/ nurse immediately.
- Rash or itchy skin
- Flu-like symptoms: Chills, fever, etc.
- Bruising more easily
- Liver problems: Yellowing of the skin (jaundice) or the whites of the eyes.
- Numbness or tingling in the fingers or toes

Please Note

You should always inform your doctor or pharmacist of any other medicines you are taking.

If you think you are pregnant, continue taking your prescribed medication and consult your doctor as soon as possible.

It is safe to drink alcohol in moderation while taking NTM medicines. Drinking in moderation means:

- 3-4 alcohol units on 2 or 3 days of the week for a man
- 2-3 alcohol units on 2 or 3 days of the week for a woman

N.B: alcohol unit = 1/2 pint beer/ larger; 1 pub measure of spirit; 1 small glass of wine.

What to do if you forget to take your medication

It is recommended that you take it as soon as you remember **unless** it is nearly time for your next dose. If this happens, miss out the one you forgot. **Do not double up doses.**

For further assistance or to receive this information in a different format, please contact the department which created this leaflet.