

PATIENT INFORMATION

FOR PATIENTS WITH NON- TUBERCULOUS MYCOBACTERIUM INFECTIONS (NTM)



Patient Information leaflet for patients with Non-Tuberculous Mycobacterium Infections (NTM)

What is NTM and why have I got this Infection?

Non-tuberculous mycobacterium (NTM) infections are caused by a group of bacteria that are commonly found in the environment - in soil, water sources, plants and animals. Although they are part of the same broad family of bacteria as *Mycobacterium tuberculosis* which cause tuberculosis (TB), they behave differently and cause a different type of lung disease. There are more than 160 different types of NTM that are found naturally in the environment. The most common species causing disease is called *Mycobacterium avium complex*. The next most common are *mycobacterium abscessus complex* and *Mycobacterium kansasii*.

It is not known why NTM infects some people and not others. However, people with an underlying lung problem such as bronchiectasis, cystic fibrosis, COPD (chronic obstructive pulmonary disease) or a weak immune system are more at risk of NTM infection. NTM most often cause lung problems but they can affect other parts of the body such as the skin and the lymph nodes (glands).

Can I pass it on to my friends and family?

NTM infections are not thought to be transmissible between individuals except in very specific circumstances (For example *M.abscessus* infection can pass between people with cystic fibrosis).

In order to reduce cross infection it is sensible to adopt good hygiene precautions, such as coughing into a tissue and disposing of it in a covered bin.

How serious are NTM infections?

Some patients with NTM infections do not require treatment and are not associated with ill health. 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 lung infections?

The signs and symptoms of NTM lung infections can be variable and non-specific and can include:

- chronic or recurring cough
- sputum production
- coughing up blood
- increasing shortness of breath
- fever
- fatigue
- night sweats
- weight loss

How are NTM infections diagnosed?

NTM infections are usually diagnosed using a combination of investigations, in addition to carefully assessing symptoms and medical history. In patients who produce sputum three samples will be sent for NTM culture. The samples are collected in the early morning on three consecutive days. The sputum is examined under a microscope and then put in a culture to grow any bacteria that may be present. This can tell your doctor what type of NTM it is and what drugs will work on your strain of NTM. In those who find it difficult to produce sputum other methods of obtaining samples for culture may be discussed with you (such as sputum induction

using nebulised saline or bronchoscopy, which involves inserting a flexible camera through the nose or mouth into the lungs). A CT scan is usually recommended to look for changes consistent with NTM disease. A CT scan is a three dimensional image of the lungs which is more useful than a chest x-ray to assess the state of your lungs. Lung function tests may also be requested – these are a variety of tests that look at how well your lungs work.

How are NTM infections treated?

NTM antibiotic treatments differ according to the species being treated, but usually involve three or more strong oral antibiotics for 12-24 months, which can be extended in some circumstances to many years. These usually include the antibiotics clarithromycin or azithromycin, rifampicin and ethambutol. These antibiotics may be given daily or 3 times a week – Monday, Wednesday and Friday. Combinations of antibiotics work better because they attack the mycobacteria in more than one way – this stops the NTM becoming resistant to any particular antibiotic.

Why do I have to take treatment for so long?

NTM infections require prolonged treatment because they are more resistant to antibiotic therapy than conventional chest infections. It is very important that you follow your doctor's instructions for taking the antibiotics. If you forget or stop taking NTM medication, the infection may return. This is very serious and may mean:

- it will be harder for the doctors to treat the infection because the NTM bacteria can become resistant to the antibiotics prescribed
- an increased amount of medication may be required
- You may need to have inhaled or intravenous medicines in addition to oral antibiotics.

Side Effects

The antibiotics used can cause severe side-effects; therefore doctors carefully monitor patients being treated for NTM infections. Although some people can take tablets without any difficulty, most find that they have side effects, at least at the start of treatment.

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 or your nurse.

The following side-effects may occur with NTM medication:

The following side-effect is very common and to be expected.

- If you are taking rifampicin, your urine, stools, saliva, sweat and tears may go a red-orange colour. If you wear soft contact lenses, tell your doctor before starting treatment as contact lenses may be permanently stained.
- Rifampicin also reduces the effectiveness of hormonal contraceptives – if you are using this form of contraception you should use additional means of contraception

You may also experience:

- Loss of appetite and/or indigestion when you eat

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

- Vomiting (being sick)
- Nausea (feeling sick)
- Diarrhoea
- Abdominal pain

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

- Eye sight problems can occur with ethambutol, in particular blurring of vision, pain in the eyes or red/green colour blindness. **You should stop taking your tablets if this occurs and inform your doctor/nurse immediately.**
- Hearing problems such as “ringing in the ears” may occur with azithromycin.
- Balance problems associated with azithromycin
- Liver problems – yellowing of the skin or the whites of the eyes (jaundice)
- Severe upper abdominal pain
- Flu-like symptoms: chills, fever etc.
- Bruising more easily
- Rash or itchy skin

Special instructions for taking your medicines

Rifampicin should be taken on an empty stomach, either one hour before food or two hours after. Azithromycin, clarithromycin and Ethambutol can be taken with or without food. All of the tablets can be taken together. It is very important to remember to take the antibiotic when it is due as regularly forgetting to take the tablets may mean the bacteria become resistant. Establish a routine that works for you – taking the medicine at the same time each day may help you to remember. Alternatively, you may find it helpful to have your medicines in a weekly dosette box. 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 the next dose. If this happens, miss out the one you forgot. **Do not double up doses.**

Monitoring during treatment.

Your doctor will monitor your blood count and liver and kidney function at least monthly at the beginning of treatment to make sure they are not causing harm and to regulate your dose if required.

The antibiotics may very occasionally cause changes to your hearing and eyesight so you will have eyesight and hearing tests before starting treatment. Some medications (including the antibiotics azithromycin and clarithromycin) can affect the electrical activity of the heart so you may have an ECG at the start of treatment and then from time to time if necessary.

You will be asked to give regular sputum samples to monitor the effect of treatment on the number of NTM bugs present in your sputum.

Your TB nurse will provide you with their contact details – they will aim to contact you monthly to offer advice and support.

Useful information

Please contact your TB nurse if you would like further information.

Telephone number 01562 512316 or email wah-tr.tbnursingteam@nhs.net

The TB service is available Monday to Friday 08:30-16:60

An answerphone is in operation outside of these hours and on Bank holidays – if your call is urgent please contact your GP and if out of hours NHS 111.

Other sources of information

Non-tuberculous mycobacterial infection (NTM) www.blf.org.uk

Patient Care UK – www.ntmpatientcare.uk

References

BTS Guidelines for the management of non-tuberculous mycobacterial pulmonary disease (NTM-PD)

If your symptoms or condition worsens, or if you are concerned about anything, please call your GP, 111, or 999.

Patient Experience

We know that being admitted to hospital can be a difficult and unsettling time for you and your loved ones. If you have any questions or concerns, please do speak with a member of staff on the ward or in the relevant department who will do their best to answer your questions and reassure you.

Feedback

Feedback is really important and useful to us – it can tell us where we are working well and where improvements can be made. There are lots of ways you can share your experience with us including completing our Friends and Family Test – cards are available and can be posted on all wards, departments and clinics at our hospitals. We value your comments and feedback and thank you for taking the time to share this with us.

Patient Advice and Liaison Service (PALS)

If you have any concerns or questions about your care, we advise you to talk with the nurse in charge or the department manager in the first instance as they are best placed to answer any questions or resolve concerns quickly. If the relevant member of staff is unable to help resolve your concern, you can contact the PALS Team. We offer informal help, advice or support about any aspect of hospital services & experiences.

Our PALS team will liaise with the various departments in our hospitals on your behalf, if you feel unable to do so, to resolve your problems and where appropriate refer to outside help.

If you are still unhappy you can contact the Complaints Department, who can investigate your concerns. You can make a complaint orally, electronically or in writing and we can advise and guide you through the complaints procedure.

How to contact PALS:

Telephone Patient Services: 0300 123 1732 or via email at: wah-tr.PALS@nhs.net

Opening times:

The PALS telephone lines are open Monday to Thursday from 8.30am to 4.30pm and Friday: 8.30am to 4.00pm. Please be aware that a voicemail service is in use at busy times, but messages will be returned as quickly as possible.

If you are unable to understand this leaflet, please communicate with a member of staff.