



## **Beginning and monitoring your treatment for NTM disease.**

The following refers to lung disease due to NTM. However, the comments about drug monitoring and avoiding side effects also relates to treatment for NTM arising elsewhere in the body.

Not everyone will need antibiotic treatment for their NTM infection. You may have an additional infection that is often better to treat first, and sometimes this alone will reduce your symptoms. Or the NTM infection may sometimes improve by itself. You will, however, continue to be monitored regularly using some of the investigations described below. Remember that NTM lung disease varies a lot. What happens to one person may be different from what happens to you.

### **Chest X-rays and CT Scans**

Both chest X-rays and CT scans help your doctor to make the diagnosis of NTM lung disease. However, they are also important in assessing how things change over time. You will first have a chest X-ray and/or CT scan to assess the extent of NTM disease and whether you might need antibiotic treatment. How often you have follow-up X-rays or scans will depend on the nature of the disease and how unwell you are. Generally, a repeat X-ray will be carried out within the first 2-3 months. CT scans are usually done less often than X-rays.

### **Blood tests**

How many blood tests are done before your doctor starts medical treatment will depend on the type of treatment planned for you. It will also depend on your general health. Many older patients have other medical problems and take other medicines. So, your doctor will want to check that there is no clash between the antibiotics you are about to start and the medication you are already taking. For most people this is not a major problem.

A general recommendation for patients starting out on triple antibiotic therapy is to obtain tests of your liver and kidney function - as well as testing the blood itself, for example to make sure you are not anaemic. These will be carried out when you first see the specialist, 2 weeks after starting the antibiotics and then monthly for three months. If all is well, this testing could then take place every 6 months or so. This will vary according to your general health at the start of treatment and any subsequent adverse effects that arise, including if you need to change your medication.

### **Eyesight and hearing tests**

The antibiotics may very occasionally cause changes to your eyesight and hearing. These rare side effects are usually reversible when caught early. Thus, you will undergo eyesight and hearing tests before starting and then about twice a year thereafter.

**Electrocardiogram (ECG)**

Some medications (including the antibiotics azithromycin and clarithromycin used to treat NTM) can affect the electrical pattern of the heart, and so recording an ECG is a precaution to make sure all is well and stays well. You may therefore have an ECG at the start of treatment to check this, and then from time to time if necessary.

**Lung function tests**

You will usually have had your lung function measured while your doctor was making the diagnosis of NTM infection. Knowing about the function of your lungs at the start of treatment also helps your clinicians monitor your improvements. It will also help the physiotherapist who advises you (see below).

**Physiotherapy**

Your clinician should refer you to a respiratory physiotherapist, who will make a personalised assessment of your breathing and how to improve it. This can include advice on clearing sputum, managing cough and breathlessness, exercise programmes and living with a chronic illness. There is much more on our *www.ntmpatientcare.uk* site about how physiotherapy can help to keep your lungs healthy.

**Sputum (phlegm) tests**

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. The length of antibiotic treatment is usually guided by whether and for how long these are no longer found. Generally, treatment is continued for a year once the sputum becomes free of NTM bugs.

**Dietary advice**

Advice on diet and maintaining a healthy weight can be crucial, especially as many patients are underweight at the time of diagnosis. Maintaining a normal weight will help you to fight the NTM infection as well as preventing its return when you finish your course of antibiotics. Ask to be referred to a dietician, who will help with this, as well as advise on maintaining intake of important vitamins such as Vitamin D.

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