



# Patient Care UK

Raising awareness of Non-Tuberculous Mycobacteria (NTM) and providing a voice for NTM Patients in the UK

## Non Tuberculous Mycobacterial (NTM) infection

Have you been diagnosed with NTM?

Do you want to find out more about NTM and its management?

Would you like to hear from other people with NTM?

**If you have answered yes to any of the questions above, then NTM Patient Care UK is here for you!**

*The term NTM covers a range of bacteria. The most common species are M. avium complex (MAC), M. kansasii, M. malmoense, M. xenopi and M. abscessus.*

## What is NTM Patient Care UK?

NTM Patient Care UK is a patient association and registered charity that is working to improve the lives of people with non-tuberculous mycobacterial (NTM) infection in the UK. We are doing this by providing education and information to increase understanding of NTM in both the clinical and patient communities. We are also working hard to improve support for NTM patients, their carers and families.

## What is NTM (non-tuberculous mycobacterium)?

NTM are common bacteria in our environment that very occasionally lead to health problems. The term NTM covers a wide range of Non-Tuberculous Mycobacteria. The most common species causing lung infection are *M. avium complex* (MAC), *M. kansasii*, *M. malmoense*, *M. xenopi* and *M. abscessus*. Do ask your doctor for more information if this would help you.

## Questions that you may have about NTM

We know that newly diagnosed NTM patients will often have lots of questions about NTM, and those that may have been living with the condition for some time can still have many unanswered questions as well. Therefore, please find below the answers to some frequently asked NTM questions (*more information can be obtained from our website or discussions with your consultant, nurse or GP*).

### What illness can it cause?

The main form of NTM infection is lung disease. However, NTM can also cause skin, joint and other infections.

### Who catches NTM lung disease?

This usually occurs in people with damaged lungs such as in bronchiectasis – a long-term lung condition in which the airways are inflamed, widened and mucous collects, leading to infections. It also affects older people, and those with low immunity.

### How common is it around the world?

We don't know, as it is often not recognised. However, it is found everywhere and may be more common in humid climates.

### Why does NTM contain the term "nontuberculous"?

NTM is a relative of the bug that causes tuberculosis, a serious infection that passes from person to person. Except in very rare instances, NTM is not passed from person to person. A better name for NTM might be Mycobacterial Lung Disease.

### What do I say to my family and friends?

Say your infection is like chronic bronchitis, but needs longer treatment to have a good effect. Tell them NTM is not infectious and is not TB.

### Do I need to tell colleagues at work?

No. If you want to talk, say you have a form of chronic bronchitis that needs regular treatment.

### ●● Might my close friends and family catch it? ●●

No. Just like bronchitis, you can't catch NTM lung disease nor pass it on to others.

### ●● What can I tell my GP? ●●

Educate your GPs by showing them this leaflet or directing them to the NTM Patient Care UK website

### ●● What are the commonest symptoms? ●●

A stubborn cough that produces phlegm, a slight fever, breathlessness, tiredness and weight loss. These are just like the symptoms of bronchiectasis and so doctors often miss it.

### ●● How is NTM lung disease managed? ●●

Physiotherapy to increase lung health, diet to keep a normal body weight, exercise for fitness. Antibiotics may be used if indicated.

### ●● Does everyone need antibiotics? ●●

No. Many doctors wait and only give them if:

1. NTM is found in your sputum repeatedly and
  2. your symptoms, examination, chest X-rays, scans, and blood tests show you need them.
- It also depends on your other medicines.

### ●● Does everyone get side effects? ●●

No - or just a few at the start. Main side effects are nausea, poor appetite and bowel upsets. Very rarely, changes may occur to your eyesight or hearing that return to normal if caught early. Thus, regular tests of blood, eyesight and hearing will help to ensure all is well.

### ●● For how long might I need treatment? ●●

Your doctor will usually ask you to take three antibiotics daily for around 18 months or until your sputum has no NTM for a year. Take them regularly to stop NTM getting resistant.

### ●● Do I need physio? ●●

Yes. You will learn how to breathe and puff to get rid of sputum, and reduce cough and breathlessness. NTM grows in sputum so getting it out means you may not need antibiotics.

### ●● Do I need a special diet? ●●

No, but a dietician's advice is helpful, especially if you have lost weight or are underweight, because a normal weight can help your immune system fight NTM.

### ●● How much exercise should I take? ●●

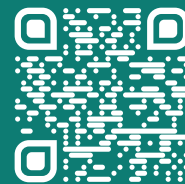
As much as you can. Exercise helps muscles and lungs to work well. Coughing up sputum after exercise is great – it is not a reason to stop! Any exercise like walking or climbing stairs helps. A brisk daily walk is a goal for people with no physical disability. Talk to your doctor before starting new, energetic exercise.

### ●● Can NTM be in my lungs without causing a problem and then flare up at a later date? ●●

Yes, NTM infection may not always result in symptoms, and so if it is identified it is important to try and get further samples to see if it persists. You may also need other tests such as CT chest scans if you have not had these recently. People with NTM may also have symptoms from an underlying respiratory illness such as bronchiectasis, and so it can be difficult to distinguish whether having the NTM in your lung is actually the cause of your symptoms. Obtaining repeated sputum samples means that if you do get a worsening in your health this can be related to whether or not the NTM persists. If so, this may be an indication for treatment.

### ●● Will I recover? ●●

Yes! Up to 80% of people recover from NTM infection. They may have ongoing problems with bronchiectasis or chronic bronchitis, but NTM lung disease rarely kills people.



NTM Patient Care UK is a patient association providing information and support for NTM patients.

Please visit our website;

[www.ntmpatientcare.uk](http://www.ntmpatientcare.uk)

Alternatively you can contact us on  
[info@ntmpatientcare.uk](mailto:info@ntmpatientcare.uk)