

Respiratory Team

Non-Tuberculous Mycobacteria (NTM)

Information for Parents and Carers

Introduction

This factsheet is aimed at providing parents and carers with information about bacteria called non-tuberculous mycobacteria (NTM).

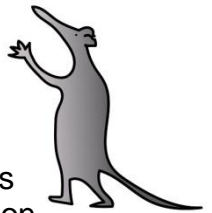
What causes this condition?

Non-tuberculous mycobacteria (NTM) are a group of bacteria that are commonly found in the environment - in soil, water sources, plants and animals. Although they are from the same family as the tuberculosis bacteria (like 'cousins'), they behave differently and cause a different type of lung disease from tuberculosis. There are lots of bacteria in the NTM group; some of the more frequent ones causing problems are *mycobacterium abscessus* and *mycobacterium avium intracellulare*.

We are all exposed to these bacteria and people with normal immune systems are usually able to handle these germs without becoming unwell. However, people who have difficulties in clearing respiratory secretions (for example, bronchiectasis or cystic fibrosis) or who have problems with their immune system (immunodeficiency or whilst receiving chemotherapy) can be more susceptible to lung disease with these bacteria.

Signs and Symptoms

The signs and symptoms of NTM lung disease can be variable and non-specific. Patients usually have a chronic or recurring cough. Other symptoms can include sputum production, malaise, fatigue, weight loss, breathlessness, fever, chest pain, coughing up blood. In children with cystic fibrosis, NTM infection can cause worsening lung function and persistence of chesty symptoms despite standard antibiotic treatment. Infection with these bacteria can cause changes on chest Xray and chest CT scans.



How is NTM infection diagnosed?

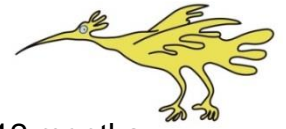
NTM infection is diagnosed by analysing special cultures of sputum. This can include sputum that is coughed up spontaneously, induced sputum (using hypertonic saline nebulisers) or from bronchoscopy samples (when a camera is passed into the lungs to get samples). To help make sure the test is accurate, the samples must be from the lower airways and not from a throat swab.

NTM are very slow-growing bacteria and can be hard to detect and treat. It usually takes a while to get the results of the culture as it can take up to 6-8 weeks to grow.

All children with cystic fibrosis who produce sputum get a routine yearly screening for NTM as part of their annual review investigations. Extra cultures for NTM are also requested in CF patients with worsening lung function and clinical symptoms despite conventional antibiotic treatment.

It is important to remember that even if NTM is found in your child's sputum culture, it does not mean that he or she has NTM lung disease. If NTM cultures are repeatedly positive, then further investigations will be undertaken to confirm NTM infection and to rule out other causes of

worsening lung disease (such as other bacteria, CF related diabetes, ABPA) before commencing on treatment for NTM. These investigations are likely to include a bronchoscopy and chest CT scan.



What treatments are available?

NTM can be treated with a prolonged course of 3 or more antibiotics for at least 12 months. Treatment is usually started with an intensive phase using oral and intravenous antibiotics and this will be as an inpatient in hospital for 2-3 weeks. This will be followed by a continuation phase with oral and inhaled (nebulised) antibiotics.

The exact combination of antibiotics will depend on the exact type of NTM causing infection. Your child will be monitored for side-effects or allergies that may develop during the course of the treatment. He or she will continue to have NTM cultures sent every few months to monitor response to treatment and a CT scan and bronchoscopy will probably be performed near the end of the course of treatment.

Does anything increase the risk of acquiring NTM?

NTM are bacteria that are present everywhere in the environment (our surroundings). Infection is not due to poor hygiene or cleaning but is due to risk factors in the patient such as lung disease or problems with the immune system.

NTM acquisition is associated with increasing age in people with CF with prevalence increasing from 10% in children aged 10 years to over 30% in adults aged over 30 years.

CF lung disease is a risk factor for development of NTM lung disease due thick walled and enlarged airways (bronchiectasis) and poor clearance of secretions.

Other risk factors that predispose specific individuals with CF to acquire NTM or develop NTM lung disease are poorly understood. There is a lot of research underway worldwide looking at the relationship with other bacteria and medicines used in CF.

Person-to-person transmission of NTM may be possible in patients with lung disease and it is very important to protect other patients with lung disease from cross infection.



What are the implications for others? (risks of infection to other people)

Patients with CF with NTM infection should be segregated from each other and from other CF patients and immunocompromised patients. (There is little evidence of harm to people with healthy lungs and immune systems). We will arrange for your child to be seen last in clinic or on a different day to the usual clinic so that there is no contact between them and other patients who may be at risk.

Infection control recommendations from the CF Trust include use of well-ventilated rooms, use of gloves and full length aprons during patient contact and hand-washing with soap and water before and after patient contact. Specific precautions will be taken by staff in physiotherapy and in lung function where your child will be breathing out more than normal. If your child needs hospital admission, he or she may need to be admitted to a special cubicle (negative pressure room) on the ward which has special airflow to preventing airborne spread of bacteria. You can still visit and stay with your child as normal and staff will explain the infection control measures.

How long will my child need special precautions around infection control?

For the purpose of infection control measures, special precautions (as above) are recommended until a minimum of 4 negative NTM cultures over a period of 12 months.

What are the risks to other family members?

Most people with healthy lungs are not at risk of NTM lung disease. However people who are immunocompromised (those with a primary immunodeficiency or those receiving chemotherapy for cancer) can be susceptible. Some children with normal immune systems may get infection limited to swollen lymph nodes in the neck without any chest symptoms.

Are there any common problems that may occur?

Some of the medicines used for treatment can cause allergies or side effects and your medical team will discuss these with you and your child.

Who to contact for further information or support?

For further information, please speak to the Cystic Fibrosis team or Respiratory Consultant looking after your child.

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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