Cystic Fibrosis Trust

Non-tuberculous mycobacteria (NTM) in cystic fibrosis

What are non-tuberculous mycobacteria (NTM) and how are they treated in cystic fibrosis (CF)?

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Patient Information Forum

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Contents

What does NTM mean?

NTM is an abbreviation for **non-tuberculous mycobacteria**. It describes a group of closely-related bacteria.

You'll see ***Mycobacterium abscessus*** and ***Mycobacterium avium*** written throughout this factsheet. These can also be written as:

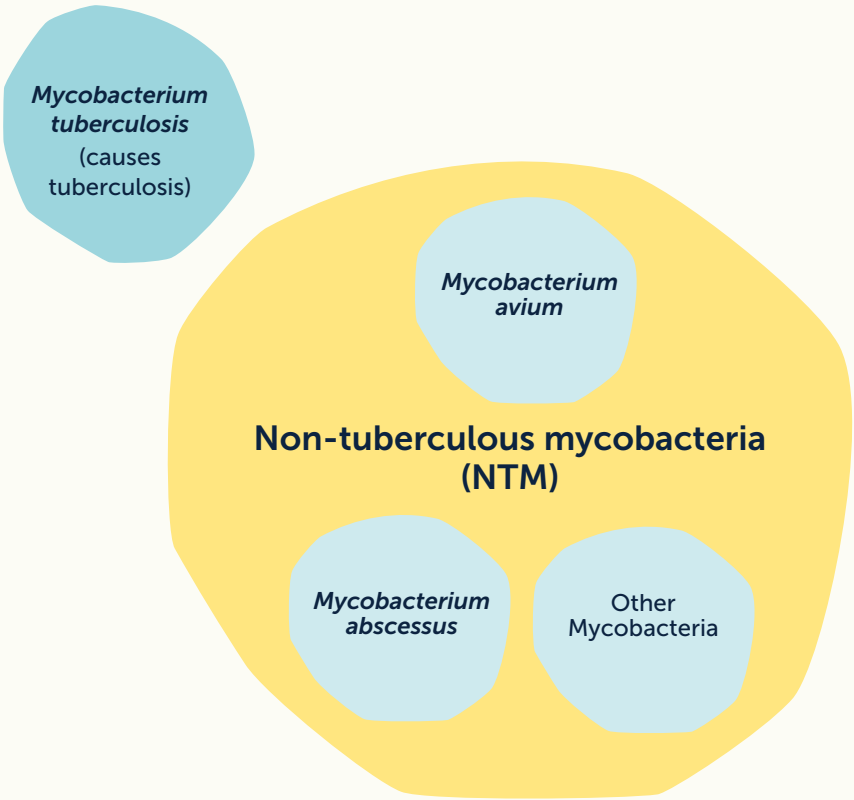
- ***M. abscessus*** or ***M. avium***
- ***Mycobacterium abscessus complex*** or ***M. abscessus complex***, which is sometimes abbreviated to **MABC**
- ***Mycobacterium avium*** complex or ***M. avium complex***, which is sometimes abbreviated to **MAC**

The word **complex** is used to describe a group of very closely-related bacteria. They are so closely related that it is sometimes hard to tell the difference between them.

NTM can infect the lungs of people with CF and other conditions where there is lung damage, difficulty clearing mucus from the lungs, or a weakened immune system.

A few NTM are found more often in the lungs of people with CF than others, such as ***Mycobacterium abscessus*** and ***Mycobacterium avium***.

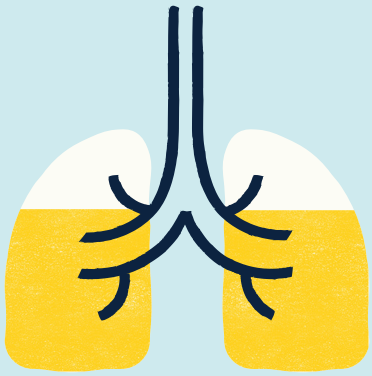
You may have heard the phrase **atypical mycobacteria**. This is the old name for NTM. NTM are not 'typical' because **they do not cause tuberculosis** (TB) like ***Mycobacterium tuberculosis***. ***Mycobacterium tuberculosis*** is a distant relative of NTM, but is very rare in people with CF.

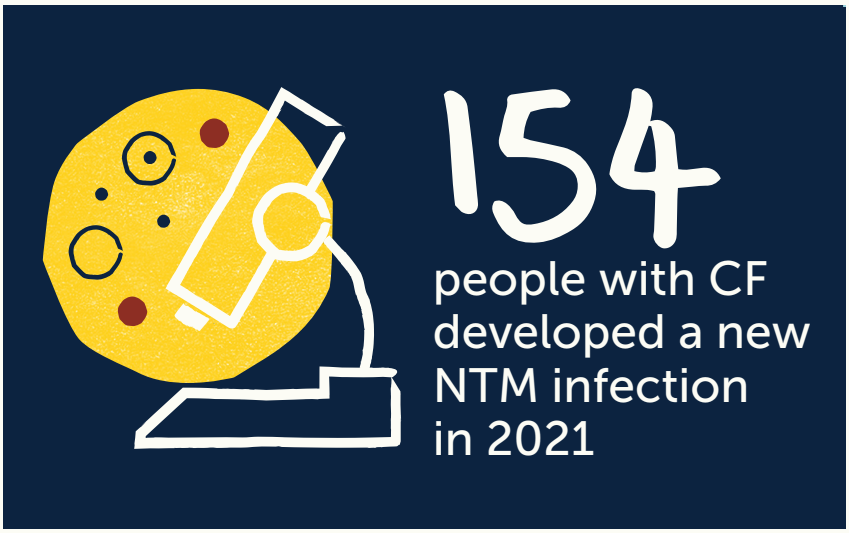


In 2021, around

4%

of people with CF had an active NTM infection, with over 58% of them having treatment for this infection





Figures taken from the UK CF Registry Report 2021

How can I reduce my chances of getting an NTM infection?

NTM are found in many places – we will all be exposed to NTM at one point or another. There is no evidence that avoiding certain activities or places lowers the risk of NTM infection. We don't fully understand why some people with CF get NTM lung infections while others do not.

Can I get an NTM infection from another person with CF?

There have been a small number of reports of NTM infections spreading between people with CF, called cross-infection. People with CF should not meet one another in person. Learn more at **cysticfibrosis.org.uk/crossinfection**.

CF centres have strict infection control measures to minimise any risk of cross-infection. It is very important to attend your CF clinics despite any minimal risk of infection. Avoiding attending your CF clinics is likely to be more harmful to your care than any potential infection risk.

What are some early symptoms of NTM infection?

Symptoms of NTM infection can be difficult to tell apart from the symptoms of other CF lung infections and exacerbations. Symptoms of an NTM infection can include:

- cough
- weight loss
- fever
- night sweats
- decreased energy levels.

Your CF team can also pick up on **signs** like a drop in lung function or new changes on a chest X-ray or lung CT scan. However, just like the symptoms of NTM infection, CT scan changes can also be caused by other CF lung infections.

An NTM lung infection can sometime be picked up if infection symptoms and signs do not clear after a standard course of antibiotics.

Sometimes NTM can be picked up in sputum from people with CF who are well or have no increase in infection symptoms.

What if NTM is found in my sputum?

If your CF team find NTM in a sputum sample, this does not mean you have or will have an NTM lung infection. This is because NTM growth is often temporary and will clear on its own, without treatment. Your team will ask you for more sputum samples to test for NTM and will monitor your symptoms.

Even if NTM is found in several sputum samples it does not always come with symptoms or signs of lung infection, and you and your CF team may choose to monitor it closely without treatment.

A CT scan can pick up signs of changes to the lungs that may be due to infection with NTM. Your CF team may arrange for you to have a CT scan if a NTM is found in your sputum samples, or if they suspect you may have NTM infection for any other reason, such as your symptoms.

Being told you have an NTM infection or that NTM is found in your sputum can understandably be scary and stressful. You can talk to anyone in your CF team about how you're feeling, including a CF psychologist if you have one. Your CF team can also refer you for psychological help.

"When the doctor first told me I had NTM I was relieved, because I had felt so poorly and hadn't any idea why. I soon realised that treating this infection wasn't a quick fix and came with a lot of challenges. I did feel worried and it did feel a little scary."

Sara, who lives with CF

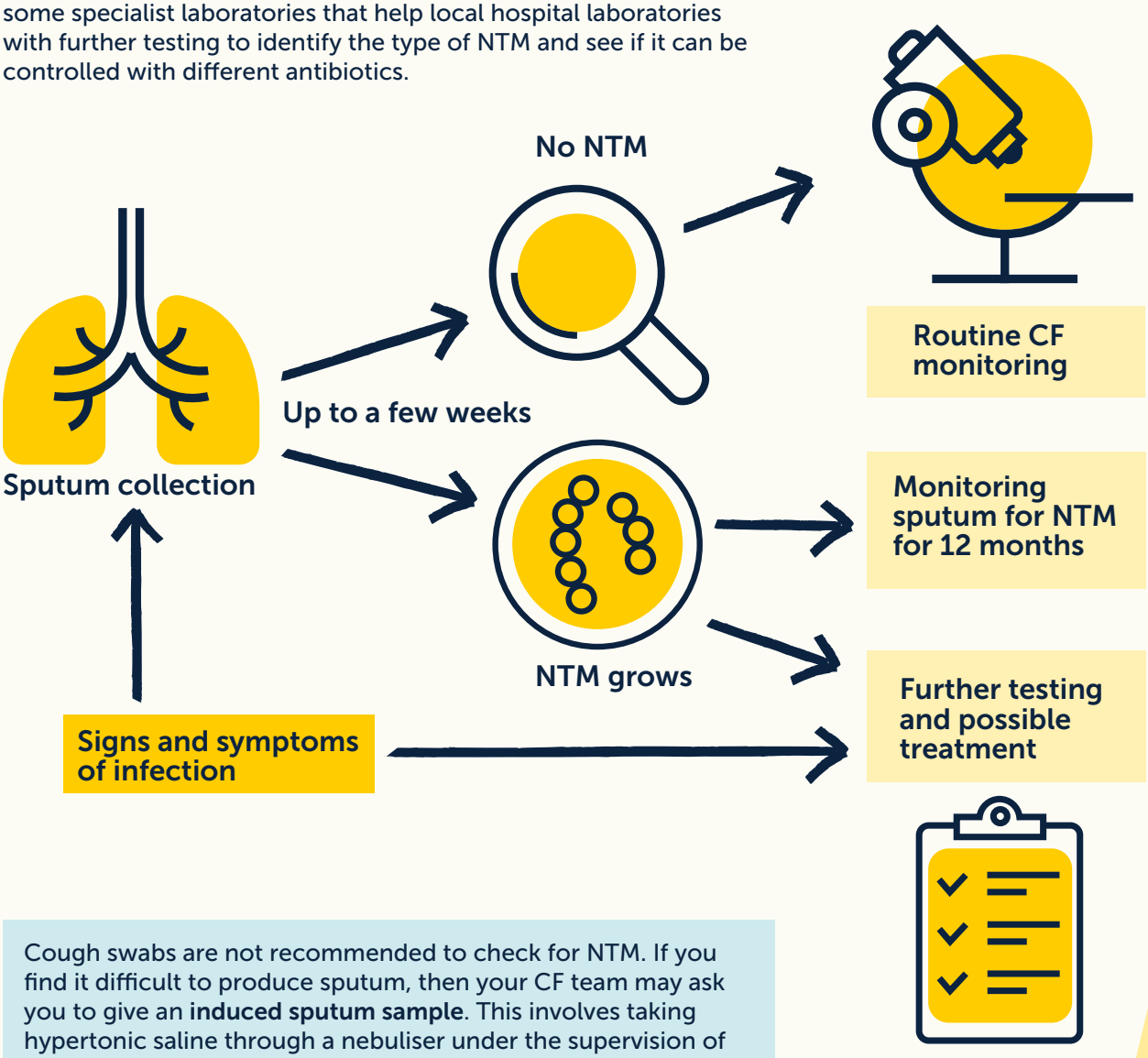
"He received no treatment, and although it scared us at the time, we were very fortunate, and [the NTM] disappeared again."

A parent of a child with CF

How will my team find out if I have an NTM infection?

Your team can find out if you have an NTM infection by sending your sputum to the hospital's microbiology laboratory. There they will check if NTM grows from your sputum samples. They may also check your sputum under a microscope.

NTM are difficult to grow and tend to grow slowly, so sometimes it takes a few weeks to get a result. If an NTM grows, the laboratory will then do tests to identify the type of NTM. In the UK there are some specialist laboratories that help local hospital laboratories with further testing to identify the type of NTM and see if it can be controlled with different antibiotics.



Cough swabs are not recommended to check for NTM. If you find it difficult to produce sputum, then your CF team may ask you to give an **induced sputum sample**. This involves taking hypertonic saline through a nebuliser under the supervision of a CF physiotherapist, which should help you cough up a sputum sample.

Another way of collecting a sputum sample is to have a bronchoscopy, which involves inserting a flexible telescope through the nose or mouth into the lungs. Your CF team will talk to you about this in much more detail if they think you need to have one.

How will I be treated for an NTM infection?

If your CF team recommends treatment, it will be very individual to you and the type of NTM. Your CF team may need to change the original treatment plan if you experience side-effects that you cannot tolerate, or if the NTM becomes resistant to an antibiotic.

- **How long will treatment be?**

  NTM infections usually need a long treatment period because they are more resistant to antibiotic therapy than most lung infections. The treatment is for at least one year and often longer.

- **How many antibiotics?**

  At least three antibiotics and sometimes more are combined to treat NTM infection. For some types of NTM, such as *Mycobacterium abscessus*, your CF team may recommend an initial course of intravenous (IV) antibiotics (usually for 2–12 weeks) alongside oral antibiotics or nebulised antibiotics, or both. You will continue any oral and nebulised antibiotics after the IV treatment has finished.

Talk with your team about all the treatment options, for example what can be done at home and what must be done in hospital.

"NTM medications are really tough on your body and you have to treat your body with as much kindness as possible to get through it."

A person with CF

"At the beginning, my treatment for NTM was pretty intense. Over time, treating this infection got easier and it is not as intense as it once was. Now I have home IVs about once a year and take nebulised meropenem twice a day, plus a couple of oral antibiotics which seems to be enough to keep my NTM from flaring."

Sara, who lives with CF

Are there any side-effects of the treatment?

As treatment will involve a combination of antibiotics, side-effects are relatively common. Ask your CF team about the side-effects of the antibiotics they choose for you and if there are any side-effects that you should particularly watch out for. You will be asked to have regular blood tests and, depending on which antibiotics are used, possibly eyesight and hearing tests too.

Your CF team may need to change the antibiotics you are taking if you experience side-effects.

How will my team check if the treatment is working?

Your CF team will:

- regularly ask you about your symptoms
- monitor your lung function
- monitor your weight, appetite and nutritional intake
- ask you to give regular sputum samples to look for NTM, during your normal clinic appointments
- do a CT scan of your lungs after treatment has finished.

NTM cannot always be completely cleared from the lungs. It may depend on the NTM type and its sensitivity to antibiotics. You can talk about this with your CF team when they have all the information about your NTM type.

Your CF team are aware of how intense an NTM treatment regime is – you can talk to them about your experiences and worries. They will try to support you in any way they can.

Will my CF appointments and hospital stays change after an NTM diagnosis?

If an NTM is found in your sputum or you've been diagnosed with an NTM lung infection, there may be some changes to your clinic appointments and hospital stays. These are precautions to reduce the risk of NTM passing between people with CF who attend clinics.

- Your appointment times are likely to be on a different day or at a different time, usually later in the day.
- You might be seen in a different clinic room. This could be a **negative pressure room**, which means that air pressure inside the room is kept lower than the air pressure outside the room. When the door is opened, air from inside the room will not flow outside.
- For an inpatient stay, you might be on a different ward or different area of the CF ward.
- Your team may have to wear extra PPE (personal protective equipment like gloves, masks and aprons).
- You might not be allowed to go to certain places in the hospital.

Every CF clinic will have their own rules, so ask your CF team what will apply to you.

Will I still be eligible for a lung transplant if I have an NTM?

Some NTM types can cause problems around the time of a lung transplant because they can be difficult to clear from the airways. After a lung transplant, the organ recipient will take medicines that suppress the immune system to stop their body from rejecting the new lungs. If the NTM is still in the airways after a lung transplant, it can grow very quickly while the immune system is suppressed.

Lung transplant teams usually want someone to have had treatment for NTM before they are listed for a transplant. Your CF team and the lung transplant team will discuss each case individually. Speak to your CF team if you have questions or concerns about this.

How will modulators like Kaftrio affect my chances of getting an NTM or getting rid of an NTM infection?

We don't know yet if CFTR modulators such as Kaftrio reduce the risk of developing an NTM infection, or improve the success of treatment. We will learn more as CF teams continue to collect information.

What research is being done on NTM?

There is a lot of research being done to help improve the diagnosis and treatment of NTM in CF. Cystic Fibrosis Trust is helping to support several of these research projects.

The **UK Cystic Fibrosis Innovation Hub** at the University of Cambridge is focused on improving lung health for people with CF. It is also a **Strategic Research Centre** looking at *Mycobacterium abscessus* in CF lungs. Lead by Professor Andres Floto, the research aims to better understand how ***Mycobacterium abscessus*** spreads, and to improve how infections are treated.

You can **read more** about Professor Floto's research on our website.

Cystic Fibrosis Trust is also involved in an international clinical trial called **FORMaT**, which is looking for the best treatment for ***Mycobacterium abscessus***.

"When you or a loved one are first diagnosed with NTM it can feel quite scary. My message to those who have it would be that you can still lead a great life and do all that you want to do."

Sara, who lives with CF

Further information

Find more information resources about living with cystic fibrosis at **cysticfibrosis.org.uk/information**.

Our Helpline is open 10am – 4pm Monday to Friday. It's available to anyone looking for information or support with any part of cystic fibrosis, a listening ear, or just to talk things through.

How to reach us:
- Call **0300 373 1000** or **020 3795 2184**
- Email **helpline@cysticfibrosis.org.uk**
- Chat with us on **Facebook**, **Twitter** or **Instagram**
- Message us on WhatsApp on **07361 582053**

Visit **cysticfibrosis.org.uk/helpline** for more information.

We welcome your feedback on our resources.

You can also ask for this resource in large print or as a text file. Email **infoteam@cysticfibrosis.org.uk**.

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Cystic Fibrosis Trust

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

cysticfibrosis.org.uk

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