

# Treatment of NTM

## Tips & Information



This informational booklet was developed and led by the Chairs of the NTM Network UK Pharmacist Subgroup with support from the NTM Network UK Pharmacist Subgroup members, Chair of NTM Network UK, NTM Patient Care UK and most importantly our patient stakeholders.

# Treatment of NTM

## Tips & Information

Not everyone with Non-Tuberculous Mycobacterial (NTM) disease needs to take specific antibiotic treatment. However, if they do, this is often a combination of several drugs taken for months and sometimes years. This leaflet has been written to provide you with information about the treatments for NTM

It also includes top tips to help with taking your medication and manage possible side effects that can occur when on treatment

You will also find links to further information about each of the commonly used drugs, including how to take them, possible interactions with other medication you might use, side effects and any necessary monitoring your clinical team will perform. This information can be found at the NTM Patient Care website ([www.ntmpatientcare.uk](http://www.ntmpatientcare.uk)) or by using the QR code shown here



We hope that by providing this information you will feel more informed, more comfortable with the medication and able to speak to others including your health care providers about any concerns that you may have

Please do let us know what you think of this leaflet as we are always looking to improve it!

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## How is Non-Tuberculous Mycobacterial disease treated?

- NTM can cause disease anywhere in the body, but most often this is in the lung. Treatment includes both non-antibiotic approaches, such as sputum clearance for NTM lung disease, and antibiotics that target the specific NTM thought to be causing the disease. People will be asked to take several antibiotics together for several months or more. A combination of three or four antibiotics is generally used to treat the NTM bacteria in different ways and prevent the bacteria from becoming resistant to antibiotics
- Your NTM treatment is specific to you. Not all NTM infections are treated the same way, and this is dependent on the species of bug (strain), where in your body it is causing disease, and how badly the illness is affecting you. You may be prescribed, therefore, a different combination of antibiotics to other people with NTM. Most antibiotics are taken by mouth (orally), though in some instances, depending on the specific NTM, you may be offered antibiotics given intravenously (by a drip into the arm), or breathed in through a nebuliser
- As with all medications, some people may experience side effects during treatment. In many instances, these may be mild and/or short-lasting and can be managed easily. In the event of a serious adverse reaction, please notify your clinician immediately. Serious adverse reactions may also be reported to the MHRA (national medicines surveillance group) via a "yellow card" report. The form can be accessed via [yellowcard.mhra.gov.uk](http://yellowcard.mhra.gov.uk) and will usually be completed by a pharmacist or doctor involved in your care
- Before starting treatment tell your clinician about any medications you are taking including over the counter medicines, herbal medicines, any allergies and if you are pregnant or intending to become pregnant, or breastfeeding

## Duration of treatment

- It takes a long time to kill NTM bacteria, so treatment durations are usually for months or years. For example, if you have NTM lung disease, treatment is for at least 12 months after your sputum samples have stopped growing NTM bugs (often called 'culture conversion'). For NTM skin disease this may be for just a few months. Your NTM team will advise you for how long you need to take your treatment
- It is important that you take your antibiotics regularly as prescribed even if you feel well. This will help to treat the bug, reduce the chance of it coming back, and will also help to prevent it becoming resistant to the drug treatments

## Stopping or changing treatment

- Your NTM team will advise you if you need to stop or change treatment
- Your NTM team will advise you when you have completed your course of treatment
- Your NTM team may also change your treatment depending on your response to the prescribed medication
- If you have any serious side effects, your NTM team will be able to provide advice on switching to alternative antibiotics

## Monitoring

- For people with NTM Lung Disease, it is really important that you produce regular sputum (phlegm) samples. These will provide your clinical team with more information about the bug growing, which treatment is best and how it is working for you
- Your NTM team should check your sputum (phlegm) every 4–12 weeks during treatment and for 12 months after completing treatment if you are still productive

## Staying on track with your treatment

- It is very important that you take your medicines every day or as prescribed by your healthcare team. As you will be taking your NTM medications for a long period of time, here are some suggestions to help you get into a routine:
  - Take your tablets at the same time every day
  - Put your tablets in a weekly dispenser. Medication organisers, e.g. a pillmate® or dosette®, are helpful for some patients and are available from local pharmacies
  - Mark off each day on a calendar once you have taken your medicines
  - Set a reminder on your phone/use a phone app
  - Request support from your NTM clinical team to write a medication card which lists all your NTM medicines along with how and when to take these
  - Ask a friend or relative to help you
  - Use a combination of the above

## Missed doses

- It is very important that you take your medicines every day to ensure the infection is treated and reduce the risk of antibiotic resistance
- If you don't take your medication regularly the bacteria can become resistant to antibiotics, making the infection more difficult to treat now and in the future
- If you do forget or miss a dose:
  - If a once daily regimen and still the same day, take the dose as soon as you remember. If the day has passed, skip the missed dose and take your next scheduled dose
  - If a twice daily or more frequent dosing regimen, take that dose as soon as you remember and then continue to take your antibiotics as normal. But if it's almost time for the next dose, skip the missed dose and continue your regular dosing schedule
  - Do not take two doses at the same time
- Always let your clinician know if you do not remember to take your tablets
- If possible, bring your tablets with you to your NTM clinic as this can help your healthcare team ensure you are getting the most from your drug therapy

## Drug interactions

- Drug interactions should be checked before treatment initiation and when there are any new medication changes
- Please make your NTM team aware of all your prescribed medicines (from your GP, other hospital clinics etc.) and any over-the-counter medicines (including vitamins and supplements). Your NTM team will check for interactions and manage these appropriately. Some of the common interactions can be found in the individual drug information leaflets

## Known side effects of medications used in treatments for NTM

[\* uncommon; \*\* common]

It is important to report any new symptoms that you experience to your NTM team.

Side effects	Rifampicin/ Rifabutin	Azithromycin/ Clarithromycin	Ethambutol	Clofazimine	Doxycycline/ Minocycline
Gastrointestinal: nausea, vomiting, diarrhoea	**	**		**	**
Reflux	*	*			**
Headache; dizziness	**	**			**
Reduced appetite; altered state	**	**			*
Fatigue; malaise (flu like)	**	*			
Visual impairment (acuity/colour)	Risk of uveitis (inflammation of the middle layer of the eye) with Rifabutin	*	*		
Hearing impairment		*			
Photosensitivity				**	**
Prolongs QTc: i.e. prolongs the time it takes for the heart's electrical system to recharge between beats		*		*	
Discoloration of body fluids e.g. tears, sweat, urine	**			**	
Skin pigmentation				**	*

Side effects	Moxifloxacin/ Ciprofloxacin	Isoniazid	Linezolid	Cotrimoxazole	Nebulised Amikacin
Gastrointestinal: nausea, vomiting, diarrhoea	**	**	**	**	**
Reflux	*		*		
Headache; dizziness	**		**	**	**
Reduced appetite; altered state	*		**	*	**
Fatigue; malaise (flu like)	**	*	*		**
Visual impairment (acuity/colour)			**		
Hearing impairment/ Tinnitus	*		*	*	**
Photosensitivity	**			*	
Prolongs QTc: i.e. prolongs the time it takes for the heart's electrical system to recharge between beats	**				
Sensation of numbness, pins and needles of extremities	*	**	**		
Others	Tendonitis risk and muscle pain	Dry mouth	Affect blood counts such as low platelets, anaemia	Affect blood counts such as low platelets, anaemia	Cough, chest tightness, sore throat and mouth, altered voice, coughing up fresh blood

## Managing side effects

- Stomach-related side effects including nausea, vomiting, diarrhoea, bloating and reflux (indigestion) can be common with NTM treatments. In most instances these can usually be easily managed in discussion with your team
- If you're struggling with nausea, consider taking your medicines at night before going to bed
- Ginger sweets or tea can sometimes be helpful to overcome the feeling of nausea. Like all remedies they should be used in moderation
- Peppermint tea can sometimes be helpful to relieve the feeling of bloating
- If your nausea does not resolve using the above methods or if you are vomiting (being physically sick), please contact your NTM clinical team to see whether an antiemetic (anti-sickness tablet) may be appropriate. There are different types of antiemetics available, therefore your NTM team will be able to advise whether there is a suitable antiemetic for you, taking into account any other medical conditions and drug interactions
- More serious symptoms of reflux can be managed with lifestyle changes such as having your last meal of the day much earlier before bedtime, avoiding alcohol, caffeinated drinks and spicy foods and stopping smoking. In some cases, medication such as proton pump inhibitors may also be prescribed. Please speak to your NTM team before starting any new medications
- You may experience diarrhoea or frequent loose stools which occur due to the change in balance of good bacteria in your gut. Ensure you are well-hydrated and consider buying probiotic drinks/yoghurts or supplements. One of the most common live cultures available includes *Lactobacillus acidophilus*. Avoid taking probiotics at the same time as your antibiotics. Tell your NTM team if you have severe persistent diarrhoea or blood in your stools
- Skin rashes or itching may occur. Make your NTM team aware if you experience a rash. Sometimes rashes go away on their own accord or your team can provide you with some medication to help with this

- Thrush is a yeast infection which can commonly occur in the mouth or vagina. This is due to the overgrowth of a fungus. Oral thrush can present as a sore mouth with a white, furry coating on your tongue and back of your throat. Vaginal thrush symptoms include creamy abnormal discharge, itch and irritation of the vulva region and pain on urination. Consult your NTM team if you experience any of these symptoms. In some instances, over-the-counter/pharmacy treatments may be recommended to help resolve the infection
- While trying to take all your medications at the same time each day may help with remembering to take all your treatments, if you experience side effects, discuss with your NTM team how splitting the timings of some of the antibiotics could help you tolerate them better
- Some medications can cause less serious side effects including a change in colour to body fluids or skin pigmentation. This may make patients feel more self-conscious and can impact on wellbeing. This can also cause staining to lighter-coloured fabrics e.g. clothes and bedsheets; for drugs which cause changes to body secretions it is suggested to avoid white or pale colour clothing and use darker colour bed sheets
- Fatigue is common due to both the NTM disease and the medications. We recommend good nutritional intake, adequate hydration and building exercise tolerance to help overcome fatigue
- A new diagnosis and/or a number of new treatments can cause feelings of worry and anxiousness. If you are finding it hard to cope with your mental health, please speak to your clinical team

You may also find support managing your NTM treatment by discussing with other patients with NTM through the Zoom calls which are held regularly. To attend these Zoom meetings, contact us at [info@ntmpatientcare.uk](mailto:info@ntmpatientcare.uk).

## Drug monitoring

This table shows the tests and frequency of monitoring that you might expect while on treatment for NTM

Monitoring	Blood tests (Full blood counts, liver and kidney function)	Vision (Visual acuity - Snellen chart and colour differentiation - Ishihara plates)	Heart tracing ECG for QTc measurement	Audiometry
Frequency	Baseline, within 4 weeks of initiation and each clinic	Baseline and each clinic	Baseline, within 4 weeks of initiation and each clinic	Baseline and when needed
Rifampicin/Rifabutin	*	* For Rifabutin		
Azithromycin/ Clarithromycin	*		*	*
Doxycycline/ Minocycline	*			
Ethambutol	*	*		
Clofazimine	*		*	
Isoniazid	*			
Moxifloxacin/ Ciprofloxacin	*		*	
Linezolid	* May need more frequent weekly bloods in the first month	*		
Co-trimoxazole	*			
Nebulised Amikacin	*			*

## Further information

### Diet

- It is important to ensure a well-balanced diet and good nutritional status during and after treatment completion
- Vitamin and Mineral Supplements: Most vitamin and mineral supplements can be taken safely to help supplement your diet, however, some do interact with several of the antibiotics used to treat NTM. Therefore, if you do take or plan to take any vitamin or mineral supplements, please check in advance with your NTM team that the preparation(s) are compatible with your treatment

### Alcohol

- Alcohol consumption should be limited (or avoided where possible) while taking NTM treatment
- It is recommended that you do not exceed the national guidelines, which is that men and women are advised not to drink more than 14 units a week on a regular basis
- If you are prescribed bedaquiline, alcohol should be avoided

### Smoking

- All patients who smoke are encouraged to stop. If you would like help to stop smoking, please speak to your clinical team or GP who can refer you to a local stop smoking programme

### Vaccinations

- Please ensure you are up to date with your vaccinations where possible. These include:
  - Flu (influenza) annually
  - Pneumococcal once as an adult (or if repeat boosters have been recommended by your NTM team)
  - Covid-19 vaccinations (as per government guidelines)



## Further information [continued]

### Pregnancy and Breastfeeding

- Please make your NTM team aware if you are or plan to become pregnant or plan to breastfeed so they can advise appropriately about the medication you are taking

### Myasthenia Gravis

- Please inform your NTM team if you have Myasthenia Gravis (a form of muscle weakness) as some medicines may worsen the Myasthenia Gravis symptoms

### Travelling

- When you travel, plan to keep your antibiotics in your hand luggage in case of lost checked in luggage
- Plan to take extra medications in case of disruption or delays to your travel plans
- Always inform your NTM team of travel plans in advance to allow for clinic appointments and prescriptions to be organised as needed

### Costs

If you are finding it difficult to pay for your medication, please speak to your NTM team to see if you qualify for an exemption from prescription costs

For patients who are not exempt, you can purchase a prepayment certificate (PPC) for 3 or 12 months. This works out that if you require 4 or more prescriptions in 3 months, or 12 or more prescriptions in 12 months, it may be cheaper to buy a PPC

There is also the option to pay in 10 monthly instalments if you buy a 12-month PPC

This can be accessed via: <https://www.gov.uk/get-a-ppc>

## PLEASE NOTE:

We do hope the information provided in this leaflet is useful to both NTM patients and their wider care community, however we should highlight that this information is provided for guidance only. Please be aware that each person's NTM treatment journey may differ, with treatment usually tailored to the individual patient. However, if you are concerned that any information we have provided here is different to that which has been recommended to you, please speak to your NTM team

More specific information on the most widely prescribed NTM treatments (detailed in the appendices list below) can be found at the NTM Patient Care UK website at the following link: [www.ntmpatientcare.uk/coping-with-the-medicines](http://www.ntmpatientcare.uk/coping-with-the-medicines) or by using the QR code shown here



## Appendices

**Appendix 1:** The Big Three (Azithromycin or Clarithromycin, together with Rifampicin/ Rifabutin and Ethambutol)

**Appendix 2:** Clofazamine

**Appendix 3:** Ciprofloxacin & Moxifloxacin

**Appendix 4:** Co-trimoxazole

**Appendix 5:** Doxycycline & Minocycline

**Appendix 6:** Isoniazid

**Appendix 7:** Linezolid

**Appendix 8:** Nebulised Amikacin (using the intravenous preparation as the inhaled drug)

**Appendix 9:** Nebulised Liposomal Amikacin (Arikayce®)

## References

British National Formulary. <https://bnf.nice.org.uk/> Accessed 2022

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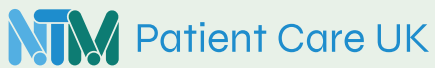
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Version 4 - March 2024