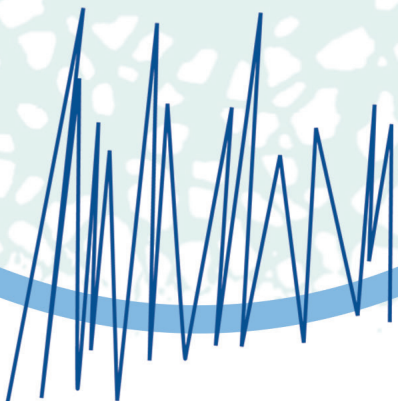
NHS
Royal Papworth Hospital
NHS Foundation Trust

Information following positve result for Mycobacterium abscessus

A patient's guide



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Why am I receiving this leaflet?

As part of your care with us at Royal Papworth Hospital NHS Foundation Trust, your clinical team will have requested a number of investigations, eg, sputum samples.

One of these tests has come back to confirm you have tested positive for Mycobacterium abscessus (M. abscessus).

What is M. abscessus?

M. abscessus is a type of bacteria commonly found in water, soil, and dust.

It can enter people's lungs and other organs naturally through exposure in the environment. Although it is not usually harmful to the general population, it can cause lung infections in some people who already have underlying respiratory conditions or who are immunosuppressed.

M. abscessus has been seen in a growing number of people with cystic fibrosis worldwide since the 1990s. It is therefore normal practice for our teams to regularly test for it as part of our standard patient care. The people we consider most susceptible / vulnerable to M. abscessus are:

- Pre and post-transplant inpatients.
- People with cystic fibrosis.
- Lung defence/ immunology patients and people with bronchiectasis.
- People with interstitial lung disease.

Symptoms of M. abscessus

Symptoms vary between patients.

Some people will have no symptoms at all despite the positive result, while others may show various respiratory symptoms such as breathlessness or increased sputum production.

As usual, any change in symptoms should be discussed with your clinical teams.

Incidence of M. abscessus at Royal Papworth Hospital

In 2019, we found higher than expected numbers of these bacteria in our water supply. Our investigations into this issue have been, and remain, extensive and we have taken many measures in response. These included:

- Putting specialist filters (called point of use or POU filters) on taps and showerheads in the relevant clinical areas.
- Providing bottled water to our most susceptible patients.
- Doing additional water tests.
- Treating our water with ultraviolet light and hydrogen peroxide.

Through these control measures, we know this has greatly reduced the risk of transmission.

Does this mean I caught M. abscessus at Royal Papworth Hospital?

At the moment, we do not know where you acquired the bacterium.

All patient samples that test positive for M. abscessus are sent for further testing to see if the source can be identified. This testing is done off-site and can therefore take several months to be completed. We will inform you when your results are available.

The number of cases linked to our hospital water have fallen significantly since our additional measures were put in place in 2019 and 2020.

What happens now?

Your clinician will discuss with you whether you need treatment and, if you do, what the best treatment is for you.

Some patients who acquire M. abscessus need no treatment at all. If someone

does need treatment, this can be effective, while for others it can be difficult to treat and have serious effects on quality of life, health and survival.

Your treatment plan is not affected by where you caught the bacteria. This means that we do not need to wait for the result of that further testing before beginning any required treatment.

Your clinician will decide how frequently further testing of your sputum should be done. In some cases, patients only ever have one positive sample and all subsequent samples are then negative.

Infection prevention and control precautions

You will be cared for in a single room when you are in our hospital or are attending outpatient appointments. This is known as isolation or barrier nursing. Keeping the door closed will help to prevent the spread of bacteria.

Hospital staff will need to follow infection control precautions, which will include wearing gowns when in your room and maintaining excellent hand hygiene.

Is there a risk to my family and friends visiting me in hospital?

It is usually quite safe to be around your family and for you to receive visitors in hospital. This is because M. abscessus is not usually harmful to healthy people.

However, if you have a relative who is within the vulnerable groups identified (see above on page 2), then please contact the infection prevention and control team for advice prior to their visit: 01223 638052 (08:00 - 16:00, Monday to Friday).

What do I need to do?

It is still very important that you follow the additional precautions and guidance we have put in place while you are receiving care with us.

Drinking water

Please only drink the tea, coffee and bottled water provided to you by staff during your stay. Please do not drink any tap water (tea and coffee are ok because the water has been boiled). The ward staff will not supply jugs of tap water to you for this reason.

Water filters

You will be placed in an area with POU filters fitted to taps and showers. If you are unsure whether your room has a filter fitted, please ask your clinical team before using the water.

Sinks

Each patient room has two sinks - one in the bedroom and one in the bathroom.

The bathroom sink is for your personal use. Please keep the sink area clear and avoid storing any items on it. Toothbrushes and toiletries should be kept in your toiletry bag on the shelf.

The bedroom sink is for staff handwashing only and should not be used for any other purpose.

Cleaning teeth

You must use only bottled water when brushing your teeth. You may do this at the sink in your bathroom or by using a separate bowl. Do not use your bedroom sink (see 'sinks' above).

Showers

It is safe to wash using water from taps and showers with the POU filter in place. If you are unsure whether your room has a filter fitted, please ask your clinical team before using the water.

If you do not wish to use the shower, cleansing wipes are available from ward staff for you to use.

If you have wounds post surgery, do not shower until you are told it is safe to do so. This is usually 72 hours after your operation, when the wound is dry and healing well.

If you have had a lung transplant, we recommend you do not use the shower during your stay. Wipes are available as an alternative – please ask the ward team caring for you.

Nebulisers and other equipment

If you use nebulisers, there will be information available in your room. Nebulisers must be cleaned using bottled sterile water (this is different to bottled drinking water) and a disposable bowl. Your ward team will then discard this water outside your room. Do not empty the bowl of water into the sink in your room.

Hand washing

It is safe to wash your hands at the sink in your bathroom. We strongly encourage you to regularly wash your hands with soap and water as part of general infection control measures to keep your hands clean. This will reduce your risk of all other infections.

If you have questions or concerns

We appreciate that you may also have further questions about this. You can find more information about our management of M. abscessus on our website: **royalpapworth.nhs.uk/mycobacterium-abscessus**

Please do not hesitate to ask any member of staff if you have any concerns about this.

Your specialist nurse or doctor will be very happy to speak with you and answer any additional queries you might have.

You can also contact our Patient Advice and Liaison Service (PALS) on 01223 638963 / 01223 638896, or you can email us on papworth.pals@nhs.net.

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Author ID:	Deputy director infection and prevention control
Department:	Infection prevention and control
Printed:	April 2026
Review date:	April 2028
Version:	2
Leaflet number:	PI 301

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