

What Happens Next: New Pseudomonas Positive Cystic Fibrosis Respiratory Cultures

What is *Pseudomonas*?

Pseudomonas (Soo-duh-MOAN-us) is a type of bacteria. It is the most common cause of lung infection in people with cystic fibrosis (CF). *Pseudomonas* infections tend to be more common as people get older. **Pseudomonas aeruginosa** (uh-roo-gin-OH-suh) is one specific kind of Pseudomonas. It is the most common of these infection types.

What does Pseudomonas do to my lungs?

It can cause chronic (long-term) airway infection, more frequent CF exacerbations, and decreases in lung function over time.

How was I exposed to Pseudomonas?

Pseudomonas can be found:

- In the environment, mainly in water and soil, such as public swimming pools that are not adequately chlorinated and in hot tubs.
- In hospitals and clinics (if infection control measures are not followed).
- In your home, particularly in kitchens and bathrooms, which is why sterilization of nebulizer equipment is important. Ask your CF team if you need more information about sterilizing equipment.

CF exacerbation - Increase in clinical symptoms or a “flare” of CF symptoms

Clinical symptoms - examples include increase in cough, sputum, or decrease in lung function or weight

Chronic airway infection - an infection of bacteria in the lungs that stays in the lungs even after treatment. This can be with or without clinical symptoms.

Can it be treated?

Yes, research studies have shown that there is often a benefit to treating *Pseudomonas* when it is first seen on culture, even if you have no clinical symptoms. **Eradication treatment** attempts to eradicate (remove) the bacteria in the lungs, with the hope that it will not be able to cause a chronic airway infection.

To identify the best antibiotic to treat it, healthcare providers will send a specimen (often called a culture) to the laboratory and test any bacteria that grow against a set of antibiotics to determine which antibiotics are active against the germ. The provider will then select an antibiotic based on the activity of the antibiotic and other factors, like potential side effects or interactions with other drugs.

What happens during eradication treatment?

Treatment is dependent on final culture sensitivity results, so is not started until your final culture report is available.

Inhaled tobramycin

- If you do not have any clinical symptoms, we treat you with 28 days of tobramycin inhaled through a nebulizer.
- **Inhaled tobramycin** (sometimes called TOBI) is an antibiotic inhaled twice daily.
- Take it after airway clearance, but before any steroid inhalers, if you are on these for asthma.

Inhaled tobramycin and oral antibiotic

- If you have clinical symptoms, we prescribe the inhaled tobramycin, but also include an antibiotic by mouth.
- If you were recently prescribed an antibiotic for a CF exacerbation (flare of CF respiratory symptoms), we may change the antibiotic to one that specifically targets bacteria like *Pseudomonas*.

If you have severe clinical symptoms, an admission to the hospital may be necessary for stronger antibiotic treatment, but your CF team will discuss with you.

How quickly will I receive the culture results and treatment plan?

In general, cultures take about a week to show final results and tests for antibiotic sensitivity. Once an organism grows on the culture, the lab must allow time to find out if it is resistant to any antibiotics and time to report it out to the doctor.

Does insurance cover this at-home treatment?

Yes! Insurances cover this treatment for *Pseudomonas*, although you may have a deductible, depending on your medication coverage plan. They usually require a **prior authorization** to show CF diagnosis and culture results. If you are unsure if treatment is covered, you can call your insurance company to find out.

<p>Prior Authorization - the process of insurance review of medication and need before approving it to be filled at a pharmacy.</p>

Do I need special equipment for inhaled medication?

Yes! The medication will need a **nebulizer compressor** and a specific nebulizer cup called a “**Pari LC Plus**” **nebulizer cup and tubing**. A durable medical supply company supplies these, and your CF nurse will send an order to them explaining which cup is needed.

How quickly will this medication be ready for pick-up?

Once the medication is ordered, our clinic begins the prior authorization process, which can take 1-2 business days. The pharmacy must run the medication through the insurance to trigger the prior authorization process that is needed in the insurance system. Our clinic submits an urgent prior authorization to your insurance, which usually has up to 2-3 business day turnaround time with your insurance.

Once we get the approval, we notify the pharmacy who typically has 1-2 business day turn-around for medication processing. It is a specialty medication, so will need to go to a specialty pharmacy, which needs time to deliver the medication. Typically, you will have the inhaled medication to treat *Pseudomonas* on or before 7-10 business days from the prescription order.

That seems like a long time for something so serious. Is there concern about this time without treatment?

Cultures are a simple way to sample what is in the lung, but it is hard to say when *Pseudomonas* got into the lungs and how long it has been there. You may have gotten it last week, last month, or 6 months ago and this is the first time we could see it in the culture. If you are free of clinical symptoms, the wait time to receive the medication is okay.

If you have clinical symptoms, you will receive an antibiotic to take by mouth sooner, which treats the bacteria as well. Once you have inhaled tobramycin , you will take it in addition to the medication by mouth.

Is there anything I can do to speed up the process?

Yes! If you want to, you can call and ask your insurance provider for 3 things:

1. The specialty pharmacy they require you to use if you do not already know.
2. An urgent turnaround time for this medication. Sometimes they will start the prior authorization process with you over the phone or connect directly with us for quicker authorizations. This is not required though. You will receive the medication even if you do not call your insurance to try to speed up the process.
3. The durable medical supply company they prefer us to send your nebulizer compressor and supplies order to.

Okay, I have taken all 28 days of the medication. Now what?

After you have completed the 28-day course, we wait until your next scheduled

clinic visit (within 3 months) to get another culture. There is no need to come in before that appointment.

→ **What if that culture is negative for *Pseudomonas*?**

We continue to monitor cultures, and remember it when treating any CF respiratory flares.

→ **What if that culture is positive for *Pseudomonas*?**

We consider it a chronic airway infection and start the inhaled tobramycin antibiotic twice daily every other month. If we alternate 28 days on, followed by 28 days off, repeating over and over, then we lessen both the chances for developing resistance and the amount of bacteria in your lungs. Sometimes that treatment may lead to eradication over time.

Once I have had *Pseudomonas* once, can I get it again, even after successful eradication?

Yes. Unfortunately, the lungs of people with CF make an environment that *Pseudomonas* can thrive in. Depending on how recently you underwent the eradication treatment, we will come up with a plan to treat your new infection and optimize your airway clearance.

Are there other treatments that help, besides the antibiotics?

- Stick to your daily CF treatment and airway clearance plan to minimize lung infections. This is very important. Our physical therapist can talk to you about other airway clearance techniques if you need more.
 - Doing airway clearance twice daily when well and four times daily when sick is ideal.
- Continue to sterilize your nebulizer equipment daily. Our respiratory therapists have resources and can provide you with education on this. Ask your CF care team if needed.
- If you do not take any inhaled medications daily (example: Pulmozyme and Hypertonic Saline), we likely will start daily or twice-daily inhaled medications that can help break up the mucus in your lungs. These are not antibiotics. This can be helpful even if you do not have clinical symptoms. If

the lungs can get infected with *Pseudomonas*, then we assume they have some thick, sticky mucus that might need help getting cleared. Your CF care team will discuss these other inhaled medications with you.

- Take your **CF modulator** if prescribed. If you are not currently on a CF modulator talk with your CF team to find out if you are eligible for one.

CF modulator - A medication taken by mouth that directly treats the underlying cause of CF in the body.

I have contact with other people with CF. Should I stay away from them if I have a *Pseudomonas* infection?

If other people with CF live in your home, there is no need to stay away from them. Exposures are similar when living together, so we will watch the other person's cultures and will consider their likely exposure, should they get sick and need antibiotics. Otherwise, you should not be in contact with other people with CF.

If you are in an area where there are other people with CF, like school:

- Avoid direct contact
- Maintain 6-foot distance
- Use separate bathrooms or stalls if able
- Wear a mask around them

If you have concerns about school separations, your CF social worker may have resources.

I still have questions. Who can I contact?

- **8:00 am - 5:00pm**
 - Call our nurse line at (734) 764-4123
- **Afterhours and weekends**
 - Call (734) 764-4123 and follow prompts for the on-call doctor for pediatric pulmonary.
 - Use only if you:
 - Need a medication sent to a new pharmacy urgently

- Have sudden change in clinical symptoms, like increase in cough or sputum, and need advice now.
- Other needs, like prior authorization issues, can only be addressed during business hours (8:00am-5:00pm).

→ **Any time of the day or night:**

- Send a message through your MyUofMHealth.org portal account
- The nursing staff reviews these messages during business hours and within 3 business days, so urgent needs should only be sent on the portal if they are follow-up with a phone call to our nurse line at (734) 764-4123.

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