

Going to the Hospital for a CF Lung Exacerbation

What to expect when staying at Seattle Children's Hospital

Sometimes, your lungs need a tune-up. This may require a one- or two-week hospital stay. There, they can give you lung treatments 4 times a day, high calorie foods and IV antibiotics to get you back on track.

Many people will take care of you

We want you to be as comfortable as possible when you get to the hospital and to know what's going on with your care. Members of the CF team are happy to answer any questions or address any concerns that come up during your stay.

Because Seattle Children's is a teaching hospital, your medical care will be provided by a team of doctors, some who are in training. A lot of staff may come and go in your room from lung doctors in training to respiratory therapist to dieticians. If you would like to know the role of each care provider, ask your nurse for our handout "Welcome to the Medical Unit"

seattlechildrens.org/pdf/PE077.pdf

During your hospital stay, you will likely:

Get a PICC line

You will likely receive IV antibiotics for about 14 days. Because of this, we often place a special, longer lasting IV in your arm, called a PICC (pronounced "pick") line. The very skilled staff on the Interventional Radiology team will put in this IV in your arm. Getting an IV placed can make anyone anxious. To help ease the poke, a numbing cream called LMX can be rubbed on your skin any time from 30 minutes to 3 hours before the IV is started. Be sure to ask about LMX if we don't bring it up. Sometimes your doctor may also prescribe a medicine to help you relax.

The nurses will provide information about how your PICC line will be cared for. This information will include dressing care and hygiene practices such as daily linen changes and daily chlorhexidine (CHG) wipes to decrease the chance of infection from your PICC.

Be started on IV antibiotics

You will likely get 2 antibiotics in your IV. One is given 3 to 4 times a day, 6 to 8 hours apart. Sometimes this means you will have to get an antibiotic during the night. The other is given once a day, or every 24 hours. If you are on tobramycin or amikacin, we will take some blood samples from you to check your dosage level. After you have been on this IV for a full day (24 hours), we need to draw blood at 2 hours and then at 6 hours after you get a dose. We will do all we can to avoid a blood draw at night when you're trying to sleep. If we need to adjust your dose, on day 3 or 4 of the IV

To Learn More

- Cystic Fibrosis Clinic
206-987-2024
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.



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antibiotic, you may need to have the 2-hour blood level test repeated. Unfortunately, these antibiotic levels cannot be drawn through your IV. Don't forget to ask for the numbing cream a couple of hours before blood draws. If we need to have your blood for other tests, we will try to get that blood when your IV is started or when we are also drawing blood for the antibiotic levels. Child Life Specialists are staff who focus on your emotional needs to help reduce the stress of being in the hospital. They can help develop a support plan for you for your blood draws.

Have respiratory therapy 4 times a day

Lung treatments are an important part of helping you to get better. Nebulizers, inhaler treatments and Airway Clearance Techniques (ACTs) are done 4 times a day, but not at night. These treatments are a key part of getting better. You will need to be in your room and awake when it is time for your treatments. Pulmonary Function Tests (PFTs) are most often done twice a week, on Mondays and Thursdays, so we can check your progress.

Eat a lot to get strong

Eating continues to be important when you are in the hospital. The effort you use for breathing takes a lot of calories! When you are admitted, a CF dietician will come and ask you about the foods you eat and can help you pick high calorie food from our menu. From your room, you can call 7-MENU (7-6368) and order your meals and snacks between 6 a.m. and 9 p.m. It takes about 45 minutes for food delivery. You may also pre-order your meals and snacks and request delivery times. You will be weighed every other day.

You should order 3 meals and 3 snacks a day to be delivered to your room. Your diet order will be "Modified Diet, Cystic Fibrosis." This means you will get whole milk instead of low fat and full fat salad dressings, etc. Be sure and tell them when you order to put extra butter pat and salt on your tray. Your nurse will bring your enzymes to you for each meal and snack. We have all the types of feeding supplements you use at home, so you won't have to change products while you're here. High calorie shakes, commercial oral supplements, and tube feeding products are available while you are here.

Have to stay in your room most of the time to control germs

Our hospital follows the infection control guidelines of the CF Foundation. We place all patients with CF in what is called "contact isolation." Contact isolation means we take measures to protect you from germs that are easily spread through touch or "contact." Contact isolation means that you will need to stay in your hospital room as much as possible unless you are going to a test or procedure. Your nurse can talk with the infection prevention nurse to create an activity plan for your hospital stay.

Please wear a mask when you are outside of your hospital room. This helps to protect you and other patients and is required by our infection control policy. Change your mask each time you leave your room or after a coughing episode.

Hospitals are full of germs. Be sure to wash your hands or use a sanitizing gel (like Purell) every time you leave your room and when you return to your room. Gel in - gel out! Sorry, you are not allowed to go visit other patients with CF in their rooms, and we ask that you stay at least 6 feet away from other CF patients.

When you can go home

Most likely you stay in the hospital for about 14 days. Some stay 10 days; some stay up to 21 days. This time frame is the amount of time needed to give all the IV antibiotics and respiratory therapy treatments you need to get better. The decision of when to stop your therapy is based on a number of things, but mainly:

- Your lung tests. We want your PFTs to improve. You will be treated until your PFTs return to baseline or stop improving. This test is our main way of reading what's going on in your lungs. If you are too young or can't do the pulmonary function tests because of other reasons, we may keep you longer to watch for lung improvement in other ways.
- Your weight. If you have lost weight, we wait for you to gain it back.

When PFTs and weight are improved, you will be ready to go home.

Home IVs

Some patients come to the hospital only for a few days to get their IV therapy started, and then return home to finish their therapy. To be able to do IVs at home, certain criteria must be met, so some people prefer to stay in the hospital. The CF team will talk with you about your wishes and whether doing IVs at home is an option for you.

After you go home – a follow-up visit to the CF Clinic

If you finish your IVs while you are in the hospital, we will want to see you in clinic again in 1 month. If you go home on IV antibiotics, we will want to see you in clinic 2 weeks after you started the antibiotics. We will try to schedule the return clinic visit before you leave the hospital. If not, call us to make this appointment at 206-987-2024 ext 1.

To contact someone from our CF Team for any reason while you're in the hospital, dial these extensions:

- CF Nurses: 7-3316
- Dietitian: 7-1744
- Respiratory: 7-2258
- Scheduling: 7-2024, ext. 1
- Social Work: 7-4144
- To order your meals: 7-MENU (7-6368)