

Why would my child need admission to Mott Children's hospital for their Cystic Fibrosis?

Your child may need admission for one of these reasons:

- Weight management - low weight, very decreased weight, feeding/eating problems
- **CF exacerbation** (ex-acer-ba-tion) - bacteria in the lungs increases, causing cough and breathing difficulty
- Other CF and not CF related reasons - Sinus problems, surgeries, blood sugar management, etc.

What is a CF Exacerbation?

A **CF exacerbation** is when the bacteria in the lungs of a person with CF increases and makes coughing and breathing difficult. Usually, we treat this with antibiotics by mouth first to fight the bacteria. If that does not work then a stronger antibiotic is needed, which is given in the hospital.

If symptoms are bad enough, we may start with admission to the hospital for stronger antibiotics, instead of starting with ones taken by mouth. Treating an exacerbation is important because they can cause harm to the lungs over time.

How would I be notified that admission is needed?

Either during clinic or over the phone with your CF care team nurses and doctor.

How long will we be in the hospital?

Admission for anything outside of an exacerbation is individualized for your child depending on the reason for admission. CF Exacerbations generally have two options:

- 14 days in the hospital - Used for young children or those that benefit from the close monitoring and treatment in hospital

- 3-5 days in the hospital with the remaining treatment done at home (totaling 14-21 days) – Used in older children who can follow the treatment plan at home.

Now is not the best time for an admission for us. Can we postpone it?

Admissions are only recommended when necessary. For the most part, they cannot wait. Speak to your doctor if you have specific concerns, so we can individualize your plan of care. Social workers in the CF clinic and on the CF home unit (12East Mott) will help you in any way possible to plan and prepare for the admission.

We're being admitted. Now what?

- Once you've been notified by the CF team of the admission, you will need to prepare your child and yourself.
 - If being admitted from clinic, prep can be done in the clinic with the team. You can always head back home or send someone to gather your needed items after your child is admitted to the hospital.
 - If being admitted from home, prep at home and await a call from the hospital with your room number on the day of your admission.
 - If being admitted for urgent symptoms, go directly to the ER for immediate evaluation and symptom management. You can always head back home or send someone to gather your needed items after your child is out of the ER and admitted to the hospital.
- Prepare your child – talk to your child about the admission, what it means, and why it is needed.
 - For example: “We’ll need to sleep in the hospital until the doctors tell us we can go home.”
 - Avoid blaming the child, as exacerbations are a part of having CF.
 - Explain who will stay with them, and when (only parents or caregivers can spend the night)
 - Allow and validate their feelings.
- If your child has procedural anxiety, avoid talking about specific tests or procedures and tell them: “We’ll have to see what the doctors say when we get there.”

- Child life, social work, and psychology can help depending on the severity of the anxiety.

Prep items

- Gather home items needed during an admission. See the list at the end of this handout as a starting point.
- Parents of children with CF recommend making a list somewhere that you can go back to with any admission (on paper, computer, phone, tablet). This would include things needed from the list at the end of this handout, but also unique items for your child like a special lovie, favorite board game, or special blankets/pillows.

Prep yourself

- Don't forget to pack items for yourself (see attached list)
- Contact your support system, asking for help if needed, or to express your feelings about the admission. This can include your CF social worker.

What team members will we see during an admission?

- Doctors
 - **Attending physician** - The Pulmonologists from the CF clinic. They take turns every week providing care to people in the hospital. This doctor may be your usual CF doctor or may be a different doctor on our team. They supervise all other doctors on your Pulmonology (lung) team.
 - **Fellow** - Doctor who has completed residency training and is now training to become a Pulmonologist. They train specifically in our clinic with our Attendings.
 - **Senior Resident** - Doctor in their last 2 years of post-graduate medical training.
 - **Intern/Resident** - Doctors in their earlier years of post-graduate training.
 - **Medical Student** - Student in training to become a doctor.
 - The entire doctor team works together to evaluate and treat your child with an individualized plan of care. If our team needs the expert opinion of another team, they will consult them and that team will come see you as well. Example: Gastroenterology (stomach/intestines), Pediatric

Surgery, Endocrinology (diabetes), Otolaryngology (ear, nose and throat), etc.

- Nurses
 - Registered nurses who provide direct care and education at the bedside.
 - They give medications and monitor your child.
- Pharmacist
 - Reviews your child's medication list for appropriate therapy and doses
 - Checks for possible drug interactions and helps manage them.
 - Recommends antibiotics and monitors lab tests for safety and effectiveness.
 - Provides education and answers questions about medications (prescribed and over-the-counter items).
- Dietitian
 - Checks on your child's intake and makes recommendations if changes are needed to your child's diet during admission.
- Respiratory Therapist
 - Gives inhaled medications and helps with airway clearance.
- Physical Therapist
 - Focuses on airway clearance methods and helps with movement activities to do while in a hospital room.
- Social Worker
 - Checks on emotional wellbeing of you and your child.
 - Can offer some assistance with hardships related to being admitted.
 - Can complete federal Family Medical Leave Act forms for parental time off work.
- Psychology
 - Does not see every patient but is available for those who need them.
 - Helps with procedural anxiety, behavioral concerns, and any other concerns related to emotional wellbeing.
- Child Life
 - Available for procedural anxiety.
 - Offers activities and things to occupy your time.
- Various services available
 - School teacher

- Music therapy
- Lego and Robotics
- Gaming consoles
- Get Well Network - TV in the room offers education, games, internet access, and access to TV and movies for free
- Canine Therapy - unfortunately, due to special infection control precautions we have for the safety of people with CF, the dogs are not allowed to enter the room. They can say hello from the hallway if you would like.
- Med buddies - Medical students who come play with your child to lessen fear around medical personnel and provide a break for parents. This program is on hold during the COVID pandemic.
- Refrigerator in the room
- Private patient rooms with private bathrooms

What procedures will be done while we are in the hospital?

Your team will discuss treatment and procedures with you thoroughly. If you have questions or concerns about any procedure, ask your team.

Intravenous catheter (IV)

IV stands for Intravenous catheter. This catheter is a short, thin, flexible tube that is inserted into a vein usually on an extremity like an arm or hand. The IV is designed to allow medications and fluids for hydration to be safely given directly into the patient's blood system. These must be replaced regularly and usually do not last more than a few days.

Peripherally Inserted Central Catheter (PICC)

PICC stands for Peripherally Inserted Central Venous Catheter. This catheter is a long, thin, flexible tube that is inserted into a vein above your elbow. The PICC is designed to reach a larger vein in your chest, however you will only be aware of a small length of line resting on your arm.

PICC lines are often used if you are going to receive IV medications that can cause damage to the smaller veins in the arm. They are also used for blood

draws or infusions for people whose veins are difficult to access. PICC lines stay in place for as long as needed.

Depending on the age and your child's preference, this can be inserted while awake and in the hospital room. Another option is a procedure that uses medication to make them unconscious during the insertion.

Port placement

A **port** is a disk-shaped device that is placed under the skin. It is used for people who need medication or fluids through a vein for a long period of time. It may also be used for drawing blood. A small flexible tube called a **catheter** connects the port to a large vein near the heart. The port has a raised center called a **septum**. A special needle with an extension tubing is inserted into the septum and is then covered with a dressing to hold it in place and to protect the site from infection.

Blood draws

During an admission, there will be multiple occasions where blood will be drawn to assess your child's status. For cystic fibrosis, we collect blood at admission, and must continue to periodically check blood levels of certain antibiotics in the blood to determine if we need to adjust the treatment.

Chest x-ray

In order to see a picture of the lungs or check placement of a PICC line, your team may order a chest x-ray. If your child is too young to follow directions, there are specially designed tools used to safely hold them still for the image if needed. Parents can usually be present for the entire procedure if desired and patients are awake for this test.

Spirometry

This is a test to show how well the lungs are functioning. Your child will follow a series of directions from a respiratory therapist while blowing into a tube that measures the breath. Due to the need to cooperate and follow directions, this test cannot be performed on children younger than 5 or on people who cannot close their mouth around a tube and follow directions at the same time.

Physical therapy evaluations

Our physical therapists will see you in the hospital and can offer a variety of resources for better movement of mucous out of the lungs. This can include different airway clearance techniques and age-appropriate ways to exercise while in the hospital and at home.

Bronchoscopy

In some situations, your doctor may recommend a bronchoscopy. This is a procedure that requires your child to be sedated, or safely made unconscious using medications. Using a flexible tube with a camera and light on it, the doctor can look into the lungs while your child is breathing. They will also flush out some of the mucus in the lungs to test it to better guide their treatment. If this procedure is recommended, the doctor will discuss thoroughly and answer all your questions beforehand.

CT Scan

Computed tomography, called **CT or CAT scanning**, is an x-ray system that uses a computer to take detailed images of the chest or other areas of the body. These pictures look like cross-sections or “slices” of the body that are then put together by the computer. This test can show more details than a regular chest x-ray but is only recommended on occasion.

To produce the scans, we will ask your child to lie on a table. The table slides into the doughnut-shaped ring in the center of the scanning machine. An x-ray tube rotates around the area of the body that we need to scan. Sensors in the ring detect x-rays passing through your body. Information from the sensors is processed by a computer and displayed as an image on a video screen. Parents can usually be present for this procedure.

G-Tube or NG Tube

If feeding or growth is a concern, your team may recommend placing a flexible tube either in the nose or through the abdomen to provide a way to get nutrients into the stomach.

NG Tube stands for **nasogastric tube** and means that the tube goes through the nose and into the stomach. This is usually inserted while the patient is awake and is taped in place. They can be changed daily or stay in for longer periods as tolerated.

G-Tube stands for **gastrostomy tube** and means a tube is inserted into the stomach through the abdomen (belly) during a surgery. Then a connection point, or “button,” is left on the surface of the abdomen that a feeding tube can be connected to when needed and disconnected when not in use. These are used when long term tube-feeding is required. Once inserted, the dietitian helps manage feeding plans and troubleshooting.

What will our day look like?

Your team in the hospital will help develop a schedule for your stay.

The team will do “Rounds” each day. Rounds are the time when the doctors and other team members come to the hospital room to discuss the treatment plan and progress. These rounds are patient-centered, so we want the parents and patient to engage, listen, and provide input to develop the plan and have questions answered.

In general, your schedule will include some variation of these activities:

1. Wake up
2. Hygiene
3. Rounds
4. Airways clearance 4 times per day (Respiratory and physical therapy)
5. Airway medications
6. Medications by mouth
7. Breakfast/lunch/dinner/snacks
8. Tests and procedures
9. Blood draws
10. Child life activities
11. Sleep

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Packing checklist for a CF admission:

Child packing list:

- Regular clothes and pajamas
- Underwear
- Fun sock to use to cover PICC line or IVs
- Socks
- Slip on shoes
- Sandals
- Favorite pillow
- Favorite stuffed animal/toy
- Sound machine or ear plugs
- Vest wrap/jacket if Hillrom Brand (otherwise hospital will provide a temporary vest wrap/jacket and compressor)
- Electronic devices with chargers if needed (safety of devices not guaranteed)
- Enzymes for the first day (in case there is a delay getting them to the hospital unit before your child needs to eat)
- Extra bag for bringing home things you receive there (toys/art/supplies/etc)
- Portable wagon to haul everything

Not recommended to bring:

- All medications – only need enough enzymes for a meal/snack or two
- Game consoles or other expensive devices (safety cannot be guaranteed)

Parent packing list:

- Regular clothes and pajamas
- Underwear
- Socks
- Slip on shoes
- Sandals
- Favorite pillow
- Toiletries specific for you if needed (hair care, make-up, etc)
- Sound machine or ear plugs
- Eye mask if needed (for darkness)
- Electronic devices with chargers if needed (safety of devices not guaranteed)
- Note pad or electronic note taker app

Items offered in the hospital:

- Toothbrushes, toothpaste, floss
- Simple shampoo, conditioner, soap, brushes, combs
- Washcloths and towels
- Sheets, pillows, blankets
- Non-slip socks
- Gowns
- Meals and snacks (for parents as well – charged to insurance)
- Drawing materials
- General Cable TV
- On demand movies via the TV
- Internet access via the TV
- Video Games and consoles
- Diapers and wipes (Bring your own if child requires specific brand)
- Refrigerator in the room
- Private room and bathroom