UNIVERSITY OF MICHIGAN HEALTH
MICHIGAN MEDICINE

Cystic Fibrosis Care: Clinic Visits

How often do we come to clinic?

- Children 0-12 months old are seen every month.
    - This frequency is important due to the growth and development that happens in this time.
- Children 1 year and older are seen every 3 months.
    - For best outcomes, the CF Foundation recommends being seen every 3 months.
- Appointments are scheduled **1 year in advance** to block off your clinic time in the doctor's schedule. Be prepared to schedule appointments in advance when you check-out of your clinic appointments. You can always call and reschedule later if something in your schedule changes.
- Appointments can be long – bring snacks/food, drinks, enzymes, toys, books and anything you might need for a long appointment.

Waiting room safety

- Upon entering the hospital/clinic, please have your child wear a mask, or cover their infant carrier in a cotton blanket or cover.
- You can wait in the waiting area, by the elevators, or stand in the hallway if you do not want to sit in the waiting area.
    - Be sure to notify the check-in desk if you are going to wait down the hall.
- Our clinic sees many patients who have a cough every day, but they do not all have CF or a cold/virus. Staying 6 feet away from other patients is the safest way to protect your child with CF from potential exposure to other people with CF.

Who will I see each clinic visit?

Medical Assistant

- Measures height and weight
- Takes you to your room.

Respiratory Therapist (RT)

- If your child is 5 years or older, they will see respiratory therapy each visit for a breathing test to measure lung function (spirometry).
- An RT educator is available and may check in on children of any age.

Nurse or Patient Services Associate (PSA)

- Medication review
- Ask and answer general CF questions
- Collects the throat culture if you need one (usually every 3 months)

Pulmonologist, your CF doctor

- Will come listen to your child's lungs and do an exam
- Will talk in more detail about symptoms and address any medical concerns

Social Worker

- Assess for anxiety and depression, coping, resource needs, and can help with insurance.
- They can help through transitions (examples: new school, new friends, bullying, behavior changes, follow-through, cooperation with CF treatments, etc.)

Dietitian (licensed nutritionist)

- Will assess your child's growth, calorie intake, calorie needs
- Help adjust enzyme and vitamin doses, recommend supplements

Clinical Pharmacist

- Will assess your CF symptoms in relation to medication use
- Provides education and answers questions about medications (including prescribed and over-the-counter items)
- Checks for possible drug interactions and helps manage them
- Recommends new medications, or changes in medications
- Monitors labs for medication safety and efficacy
- Provides education on possible ways to optimize medication treatments

Will my visits be virtual or in-person?

Dietitians and Clinical Pharmacists might meet with you virtually in the days or hours leading up to your in-person appointment or in some cases, see you in clinic. Social Workers might see you in clinic but are available to meet with you virtually in the days or hours leading up to your in-person appointment if needed. If you are having a virtual appointment with your doctor, then the rest of the team will also schedule virtual visits.

- Communicate with them if you have a preference about how or when those visits are scheduled.
- You can always request to meet with any specialty specifically.

Additional team members

- Occasionally you may see a research coordinator, physical therapist, psychologist, or respiratory therapy educator during your visit as well, depending on your needs.
- A Child Life specialist is available for procedures – tell your nurse if interested

What tests or procedures happen with clinic appointments?

- **A throat culture** (swab of the back of the throat) will happen every **3 months** for all ages.
  - This tells your doctor what bacteria are likely living in the lungs.
  - It's normal to have bacteria in the lungs and does not always mean treatment is needed.
  - The culture helps your doctor know what antibiotic will work best when your child has a CF **flare** (infection).
- Once your child is able to cough up mucus into a cup, that will be collected instead

- **Blood work** (2nd floor Lab Draw Station) **and a chest X-Ray** (3rd floor Radiology) are needed **once every year.**
  - This helps your doctor monitor your child more thoroughly. Sometimes they may need additional blood work to monitor things as your child starts or stops new medications.

- Ask the lab about a "Poke Plan" to help make blood draws easier for your child.

- **Pulmonary Function Testing (PFT)**, also known as Spirometry, is a breathing test that is done at **every clinic visit** starting around the age of 5 or 6.
  - You can be present for this test and a respiratory therapist will coach your child through the breathing needed for the test.
  - This test helps your doctor monitor your child's lung abilities more closely.
  - Since your child will have to follow breathing directions, generally this test cannot be done on children 4 years and younger.

- **Oral Glucose Tolerance Test (OGTT)** is a test done **yearly** starting at age 10.
  - This test monitors blood sugar more closely because people with CF are at risk for developing CF-related diabetes. The test is done as follows:
    - Your child will have their blood sugar (glucose) level drawn after not eating for 8 hours (usually overnight).
    - Then they will drink a sugary drink provided by the lab.
    - After 2 hours, the lab will draw a glucose or blood sugar level again.
  - You can start this test before your clinic visit so your 2-hour wait will be during clinic. It can also be done at a lab close to your home, if doing it outside of clinic is easier for you or your child.
  - If your child's test is higher than expected, they will see Endocrinology for a diagnosis of CF-related diabetes and management.

- **Stool elastase**
  - We will ask you to collect a stool (poop) sample from your child's diaper as an infant to measure the amount of a specific enzyme in the stool.
  - If the amount is high enough, no treatment is needed, but we will re-check this test every year.
  - If the amount is low, we start pancreatic enzymes.
    - Pancreatic enzymes are capsules that can be opened and added to specific foods or applesauce to be given to infants or young children.

They are specifically designed to help people with CF breakdown and absorb carbohydrates, fats, and proteins.

- **Equipment evaluation**
  - Meet with the respiratory therapist **annually** to review all equipment and medication devices.
  - You can do them either virtually or in-person. If you choose an in-person visit, bring all nebulizers, spacers, and airway clearance devices to the appointment.
  - This appointment can take up to an hour. You can coordinate it with your doctor's appointment or do it on a different day, based on your preference.

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