

CYSTIC FIBROSIS CLINIC STANDARDS OF CARE

THE CYSTIC FIBROSIS CARE MODEL REQUIRES:

- Seeing every cystic fibrosis patient four times per year
- Obtaining a full set of lab work once a year
- Liver function tests every 3 months for one year after starting any gene specific therapy, such as trikafta, and yearly thereafter
- Sputum cultures or throat swabs once a year and when you are having an increase in symptoms (we obtain at every in-person visit)
- Chest X-ray every 2 years or more if deemed necessary
- PFTs (spirometry) at every visit, either by the clinic spirometer or your home spirometer
- DEXA (bone density scan) once every 5 years or as needed
- Colonoscopy starting at age 40 and then every 5 years
- Annual mental health screening

CLINIC CARE

- We will continue to provide a hybrid model of care, which allows for two routine visits per year virtually (to be decided between patient and care team) and two routine visits per year must be an in-person visit. You may choose to do more in-person visits if you would like, however, we do not plan on scheduling more than two routine virtual visits per patient.
- **Medication refills will only be provided to patients who are up to date with their yearly labs and are maintaining routine CF clinic visits as outlined above.**
- **Trikafta, symdeko, and kalydeco will only be refilled at in-person visits.**
- Anyone who tests positive for any respiratory virus (flu, RSV, COVID), has a fever, or any NEW upper respiratory symptoms such as congestion or cough prior to their in-person clinic visit will be changed to a virtual visit or rescheduled.
- Anyone who arrives to clinic sick with active symptoms or fever will not be able to participate in pfts or sputum samples, however, will be able to see the team.
- We also will continue to offer respiratory education, social work/mental health counseling, and dietitian counseling visits outside of clinic visits either virtually or in-person.

VIRTUAL VISIT REMINDERS

- Please ensure your My Chart is active and that you have the zoom app downloaded on your phone or tablet.
- Please be available by phone 15 minutes prior to your scheduled appointment time so our medical assistant can call you for the check in/screening.
- Please find a quiet, private space where you can visit with the CF team without distractions. (i.e. not driving, in a store, or other public place)

HOME SPIROMETER

- You must be educated on and use a home spirometer device to participate in a virtual visit
- Please send Allison a screen shot of your FeV1 performed the day of or the day before your virtual or in-person visit OR bring your clean home spirometer to the visit ready to use.
- If using your spirometer during your visit, please ensure that the batteries are working and that your device is paired with the app PRIOR to your appointment. (i.e. Spirobank uses the Breath Easy app)

PRIMARY CARE PHYSICIANS

- Please make sure that you have a PCP, as the CF providers cannot serve as your primary care physician.
- If you would like a PCP in the Hartford HealthCare network, go to www.hartfordhealthcare.org and click on find a doctor, find by specialty, primary care.
- Please provide your PCP information when you check in for your appointment if we do not have it already.

FLU and COVID VACCINES

- Vaccines will not be available at CF Clinic.
- We strongly encourage you to get the both the flu and COVID vaccine.
- You can receive your vaccines from your PCP, local pharmacy, work or school if they offer it.

CONTACT INFORMATION AND INSURANCE

- Please make sure that we have all up to date contact information (email, address, phone/cell phone)
- Please provide any insurance updates as soon as possible to avoid gaps in refills, incorrect billing, etc.