

Cystic Fibrosis Center Newsletter

Clinic visits during COVID-19

The world has certainly changed over the past six months due to the COVID-19 pandemic.

Your CF team remains committed to providing you the highest quality care. We would still like to see you for routine care every three months as recommended by the CF Foundation. However, depending on the local COVID-19 epidemiology, your personal health history and your comfort level, we recognize that some of you may wish to stay at home rather than coming to the hospital for routine care. We are excited to report that we are now able to do video visits! Thank you to everyone who helped trial this type of visit over the past few months.

In order to have a video visit, the first step is to make sure you have an OSF MyChart account. If you do not have an OSF MyChart account, please call the clinic and we can help get you set up. A video visit will allow you to see everyone from your multidisciplinary team. Each provider will meet with you over video, much like we already do during in-person visits. We will ask you about your symptoms, your medications, your general health and we will address any questions or concerns.

However, there are several things that cannot be accomplished over video. We will ask you to weigh yourself on your home scale so we can track your growth and/or BMI. If you usually perform a PFT in clinic, we can make arrangements for you to receive a home spirometer to track your FEV1. While the measurement is not as detailed as what we obtain in clinic, it can be used as a gauge of your lung function. Finally, we can make arrangements to mail you a sputum cup and instructions on how to collect and



return it. It is not possible (yet!) to listen to your lungs over video, and as such, if you are ill or having symptoms that concern you, an in-person visit is best.

We all look forward to the time when the COVID-19 pandemic is in the past. Until then, telehealth (video) visits will help us to bridge the gap. While there is nothing better than seeing you in person, we feel this care modality offers our patients and families flexibility during these uncertain times.

Home spirometry

The CF Foundation is partnering with ZephyRx LLC to bring PFT testing to your home. Some of you may have been contacted by the clinic about enrolling in this program. The spirometry, the MIR Spirobank Smart, requires the ZEPHRYX Breath Easy mobile application that you would install on an Apple or android cellphone or tablet. We are excited about this opportunity as it will help us continue to provide personalized CF care when using video visits. Home spirometry is flexible and can be done anywhere. It allows you another tool for managing lung function. The program is



restricted to those with CF who are greater than 5 years old and enrolled in the CF Registry.

Helpful tips for use of home spirometry:

- Initial testing should be done three times a week to get familiar with the software program.
- Your test should routinely be performed during same time of the day
- Do not share your home spirometer with another or allow others to use
- Replacement parts for Turbine sensor and mouth piece go through Zephyrx
- Clean after each use. Wash with warm soap water and rinse. Sanitize it by soaking in hydrogen peroxide for 30 minutes. Rinse with sterile water. Air dry. Do not use heat or flush turbine with high pressure water.

Home airway clearance

There have been some challenges lately with state insurance coverage of vests. Recently, OSF has been getting denials on reimbursement of the Afflovest after they have sent the units to patient's homes. To get vests covered, we have been asked for additional documentation on the use of the vest therapy. Information we need includes the number of hours used and improvement/stabilization of lung function. We also need documentation from a clinic visit.

What can you do to help? Use your vest so we can document at clinic that you are:

- o Using the vest two times a day as prescribe for 30 minutes each session
- o Using appropriate pressures as discussed with your respiratory therapist

Newly prescribed vest orders require a follow-up visit on duration of use, frequency and tolerance to therapy. Remember, your vest is a lifetime agreement with the initial consumer to cover the cost of a vest replacement and hoses. A replacement vest may be indicated if the current form of airway clearance is not working.

Reminders

FLU SHOT

Please remember to get your flu vaccine this year. It is very important to be vaccinated against influenza. You can obtain this from your primary care physician or your local pharmacy. Some workplaces also offer this at no charge.

CF MEDICATIONS

Most Cystic Fibrosis medications require prior authorization by insurance companies. This can take anywhere from one day to one month to obtain and may require an in-person visit as most authorizations require clinic notes. Please plan ahead so you're not left without medication.

YEARLY LABS

Due to the COVID-19 stay-at-home order, many have experienced changes in how often you come for CF clinic visits. This means many patients haven't had their yearly CF labs completed. If you need an order for yearly labs, please call the CF Center. It's important to get your yearly labs drawn as many prior authorizations for medications require lab work to have been completed.

Family Education Night

Since large gatherings are not recommended due to COVID-19, we've postponed the annual Family Education Night. We realize this event allows you to interact with CF product vendors and other CF families. This is a valuable event and we hope to have it next year.