



Preparing for a Cystic Fibrosis Clinic Appointment

It's a good idea to plan for your CF clinic appointment and make the most out of your visit. Start thinking about what you'd like to learn or share before the actual day. These simple tips can help you organize your thoughts ahead of time and make it easier to cover important health or wellness topics with your care team.



MAKE A LIST & PRIORITIZE YOUR CONCERNS

- Don't put off topics that are on your mind until the end of your appointment - bring them up right away!
- What are the top 3 concerns you want to address at your next visit?
- Do you have a new symptom?
- Are there changes in your health?
- Are you concerned about how a treatment is affecting your daily life?
- Have you had a major life event?
- Has your insurance changed since your last appointment?



KEEP THE CARE TEAM UP TO DATE WITH NEW INFORMATION

- Let the care team know what has happened in your life since your last visit.
- Have you experienced a major medical event such as, being hospitalized or treated in the emergency room?
- Are you seeing a new doctor or a specialist?
- Mention any changes you have noticed in your appetite, weight, sleep or energy level.
- Discuss recent changes in any medications you take or the effects they have had on you.



PRESCRIPTIONS & MEDICATIONS

- Bring a list of your prescriptions.
- Do you carry a list of your medications with you in case of emergency?
- Do you know how to store medications properly?
- Do you review medication expiration dates?
- Are you able to access prescribed medications?
- Do you need medication refills?
- Are you taking any over-the-counter medicines?
- Do you take vitamins, herbal remedies or supplements?
- Have you experienced side effects?
- Have there been any drug interactions?
- Review the order of your treatments
 - Bronchodilator
 - Hypertonic Saline
 - Mucolytic
 - Antibiotic
 - Corticosteroid



RESPIRATORY EQUIPMENT

- Sign up for an airway clearance treatment and equipment evaluation with the respiratory therapist.
- Which airway clearance methods are you using? What works best?
 - Huff cough
 - Manual percussion
 - Flutter
 - PEP valve
 - Vest
- How is your vest working?
- What are your vest settings?
- How is your compressor?
- How is your nebulizer?
- Do you use oxygen?



CLEANING & STERILIZATION

- How old are your neb cups? Should they be replaced?
- What is your sterilization protocol?
- Do you use an Acapella?
- How is this device sterilized?
- Do you use a Flutter valve?
- How is this device sterilized?



NUTRITION

- Are you getting enough calories to maintain a healthy weight?
- Do you use a food diary or tracker?
- Have you experienced a change in BM's, cramps or abdominal pain? Or any unusual GI symptoms?
- Do you use a symptom diary or tracker?
- Food
 - Have you worried that your food supplies or supplements would run out before you obtained more?
 - Are you in a position to eat at home so you can better track what you are putting into your body?
 - Do you have access to fresh, healthy food?
- Do you take additional supplements to support your nutritional needs?
- Tube feeding
- Have you had any trouble with dehydration or maintaining salt levels?
- Do you have CF related diabetes?
- Have you had any symptoms of high or low sugar levels?



SCHOOL / COLLEGE

- Are your child's educational needs being met at school?
- Do you need assistance or information about an Individualized Education Plan, Student Support Plan or 504 Plan for your student? - [LINK](#)
- Information and help with understanding IDEA Section 504 - [LINK](#)
- Child Life Specialists at Phoenix Children's - [LINK](#)
 - What school resources are available at the hospital for inpatient stays?
 - How to help your child catch up after being absent for a hospitalization?
 - What are steps for re-entry into school after being in the hospital?



WELLNESS RESOURCES

- Do you visit a primary care doctor, dentist, or other health care providers for routine care and monitoring beyond CF?
- Personalized Patient Assistance Service



- CFF Compass Program - 1-844-COMPASS (844-266-7277) - [LINK](#)
- Legal - CF RoundTable - 1-800-622-0385 - [LINK](#)
- Do you set aside quality time to spend with family and friends?
- Do you make time to go to places where you can meet new people and socialize?
- Do you volunteer or connect with others on important issues?
- Family Resources
 - My family needs diapers, clothing, car seats and/or back to school supplies.
- Food insecurity
 - Have you worried that your food supplies or supplements would run out before you obtained more?
- Housing
 - In the last 30 days have you slept at a friend's home, slept outside, in a shelter or in a place not meant for sleeping?
- Utilities
 - Do you have trouble paying your heating bill for the winter?
 - Do you have trouble paying your cooling bill for the summer?
- Transportation
 - Do you have access to transportation for appointments?
 - Do you put off or neglect going to the doctor because of distance or transportation?
- Are you planning any future travel? Domestic or abroad?