Taking the Next Steps in Your Care

The Adult Cystic Fibrosis Program

Transitions

Cystic Fibrosis Center
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Welcome to the Adult Cystic Fibrosis (CF) Program
at the University of Michigan
We’ve been providing care for more than 25 years

One of our primary missions is to assume the care of patients with CF who have matured into adulthood. We currently work with about 150 patients. We view the important transition that you are about to embark on as a marker of the pediatric team’s and your success at managing CF from childhood through adolescence. As your adult care team, we take our responsibility to continue to successfully meet your needs very seriously.

For many, the thought of transitioning to adult care from the pediatric program can cause anxiety. We’ve created this booklet to introduce you and your family to the Adult CF Program and to address many of the questions and concerns that change naturally causes. On the following pages, we outline the transition process and explain how the adult program is organized and run for both outpatient and inpatient CF care.

A CF patient who recently transitioned to the adult care program.
Making the Transition

An important step in your transition to the Adult CF Program will be a “transition appointment” that occurs at one of your regular appointments in the pediatric CF clinic. At this appointment, your pediatric CF doctor will introduce you to the physician who will be assuming your adult care. Because good communication is important to a smooth transition, your new physician will spend time getting to know you and your family, answering questions, and explaining the adult care program during this initial meeting.

Your next appointment will be scheduled in the adult clinic with this physician. All of your medical records from the pediatric program will immediately be available to your new physician so no information will be lost during the transition. The quality of your care will remain our highest priority and no changes will take place without your full consent.

If the time for your transition is near and you need to be admitted to Mott Hospital, arrangements can be made for a nurse from University Hospital to visit you before you go home. At that time, the nurse will give you more information about the similarities and differences between the pediatric and adult CF programs.

Infection Control

Preventing the spread of germs between patients with cystic fibrosis is a primary concern for the Adult CF Program. We have instituted a set of infection control guidelines that are applied to both outpatient and inpatient areas. We monitor the success of our program carefully to detect any spread of potentially harmful bacteria, including Burkholderia cepacia. Our guidelines are similar to those that were adopted by the Cystic Fibrosis Foundation and take
into account the special needs of the adult program at the University of Michigan. We will outline some of these policies in this booklet as they apply to the outpatient and inpatient components of the program.

Dr. Samya Nasr, Director, U-M Cystic Fibrosis Center, and Dr. Richard Simon, Medical Director, the Adult CF Program.
The Outpatient Program

The adult CF clinic is located in reception area C on the 3rd floor of the Taubman Center, 2 floors above the pediatric CF clinic. The adult clinic meets regularly on Thursday afternoons, but you can be seen at other times when needed. The pulmonary function laboratory is located in the CF clinic area, blood drawing is just across the hall, and outpatient radiology is on the 2nd level of the Taubman Center, reception area A. The phone number for the adult clinic is 888-287-1085.

Addressing Problems Outside of Clinic Visits

You should contact the nurses if you are not feeling well, need prescription refills, or have other medical issues between your clinic visits at 888-287-1084.

Your privacy is important to us. It is our policy not to speak about your condition with anyone except members of your care team unless you first give us permission first.

Physicians
Richard Simon, M.D., Medical Director
Michael Coffey, M.D.
Cyril Grum, M.D.
Thomas Sisson, M.D.
Tammy Ojo, M.D.
Registered Nurses
Mary Ball, M.S.N., R.N.,
Coordinator, Adult CF Program
Barb Carpenter, R.N.
Karri Looker, R.N.

Nutrition Services
Hope O'Leary, M.S., R.D.

Physical Therapy
Geeta Peethambaran, P.T.
Jennifer Shifferd, P.T.

Social Worker
Carol Welsch, L.M.S.W., A.C.S.W.
Clinic Appointments

You will have your own outpatient CF physician who will see you at all of your regularly scheduled clinic visits. If a pulmonary fellow is part of your clinic team, you will also see a faculty physician at each visit.

As part of your adult care:

- We recommend that you visit the CF clinic every 3 months and more frequently, if needed.
- You will meet with one of our CF dieticians, social workers, and physical therapists at least once a year, and more often when needed. The dietician and social worker will see you during one of your regular CF appointments. The physical therapy appointment will be scheduled separately, but will occur immediately before your appointment. The Physical Therapy Department on the first floor of University Hospital.
- We also recommend that you have blood tests and a chest x-ray to identify potential problems before they cause you symptoms at least once per year.
- We will review the list of medications that you are taking and ask if you need any refills at each clinic visit. Whenever appropriate, we try to use medications that are covered by your insurance company in order to reduce out-of-pocket expenses. We will also get prior authorizations from your insurance company, if needed.
- At the conclusion of each visit, your next appointment is scheduled. If you need to reschedule an appointment, call: 888-287-1084.
Physical Therapy

You will be seen by a physical therapist at least once a year, either in the outpatient clinic or during hospital admissions, to review your long-term exercise and chest physiotherapy program. Your physical therapy prescription will have several components to help you maintain healthier lungs, gain muscle weight, build stronger bones, develop better posture, and maximize your cardiac conditioning. Your program may include exercises that focus on:

- Aerobic or endurance fitness
- Strength or power
- Flexibility
- Relaxation
- Balance and coordination
- Airway clearance and breathing

To maintain interest and participation in your physical therapy program, it is critical that you and your therapist find a combination of treatments and activities best suited to your preferences and lifestyle.

Infection Control in the Outpatient Clinic

To limit the spread of germs in the outpatient clinic, we avoid having two patients with CF use the same exam room on a single afternoon. Each night, the rooms undergo additional cleaning before the next day. We have waterless alcohol-based hand sanitizers placed in the exam rooms in the clinic. These measures have been quite effective in preventing the spread of germs at our adult CF center clinic program.
The Inpatient Program

Adult patients with CF are admitted to ward 6C in University Hospital. Ward 6C is a 32-bed, inpatient unit that provides care for general medical patients and has special expertise in pulmonary-related problems and cystic fibrosis.

The Adult CF Inpatient Program is managed by:

**Nurse Manager**
Diana Cprek, R.N.,B.S.N.

**Clinical Nurse Supervisor**
Cathy VanCamp, R.N.

**Clinical Nurse III**
**CF Adult Inpatient Coordinator**
Veronica Downer, R.N.

Ward 6C Phone: 734-936-4602

A CF patient arrives at the adult inpatient program.
Admitting Procedures

If you are sick and feel you might need to be admitted for inpatient therapy, please call the nurse in the Pulmonary Clinic (888-287-1085). If it is a weekend or after hours, the emergency room is always available.

Your home floor for inpatient care will always be 6C. If for some reason you are admitted elsewhere in the hospital, please tell your nurse to call 6C and we will arrange for your transfer to us.

On some occasions, you may be admitted to the hospital as a “direct admission.” This means that after the decision is made to admit, you will go to the admitting lounge on the first floor of University Hospital. There, they will direct you to 6C when a room is clean and available. Another route for admission is through the emergency room. The decision of whether to admit you by “direct admission” or via the emergency room will be made by your physician, the nurse, and you.

Routines and Expectations

In the hospital, your care will be provided by members of a large medical team. Because University Hospital is a teaching hospital, medical and nursing students may be part of your team. Many of the physicians in the Pulmonary Division take turns being an attending physician (doctor in charge) on 6C. They usually rotate this responsibility among faculty members every few weeks. All of these physicians have extensive experience taking care of patients with CF. Your regular clinic physician will also have input to your care, but he/she may not be the attending physician during your hospitalization. Although there are many caregivers on the team, it is the ultimate responsibility of the attending physician to make decisions about your care with you.
First thing each day, a member of the physician team will stop in to check on how you are feeling and to perform a brief physical exam. Later in the morning, the team will come around together and discuss the plans for the day including any testing and changes in treatment with you. Although getting rest is very important, you will need to be awake and participate in these morning rounds so that full and accurate information can be obtained. This is also the best time for you to ask your care team questions.

During your hospitalization, aerosolized treatments will be provided by members of our Respiratory Therapy Department. The therapists who work on 6C have a lot of experience with CF. Chest physiotherapy will be provided by members of the Physical Therapy Department and the 6C nurses. The physical therapy treatments will be tailored to meet your specific needs. Because secretion clearance is a critical component of the treatment program, we will attempt to plan your day so that you can participate fully in it.

Because we want you to get the maximum benefit from your hospitalization, we do not provide temporary passes to leave the medical center, except for very special circumstances such as family emergencies.
Making the Most of Your Care

While you can expect the highest dedication to your care from the medical staff, we also need your full participation to make the most of your treatment program. Although there are many parts to your care, each is important and deserves its full share of effort. We place special emphasis on good nutrition, secretion clearance programs, and control of blood sugar for those who have CF-related diabetes.

Nutrition

The head dietician on 6C is Carrie Faut. She has many years of experience helping patients with cystic fibrosis. During your hospitalization, one of the dieticians will visit you to provide information on your diet, as well as guidelines to maximize your oral intake. A dietician assistant will also visit you to pick up your daily menu and to help you with your meal and snack choices. They can also provide you with meal passes for the cafeteria, if you prefer, and/or a write-in-list of foods that are available but may not be on your menu. If you are not able to satisfy your nutritional needs through regular diet and food choices, then liquid nutritional products are recommended. We can provide you with: NuBasics Juice Drink, Boost, Boost Plus, Replete, Carnation Instant Breakfast, or Scandishake.

Controlling Blood Sugar

For those who have cystic fibrosis-related diabetes, excellent blood glucose control is important to speeding recovery. To achieve this, the care team will emphasize the need to follow the recommended diet as closely as possible.
Frequent blood sugar tests, usually before each meal and at bedtime, will be needed to adjust insulin doses correctly.

**Comfort**

Every effort will be made to make you comfortable while you’re in the hospital. When your condition allows it, we will use a “sleep protocol” at night that minimizes the number of times you need to be awakened for medical care. Medications for pain and anxiety will be used when needed. We have developed a special program for people with CF who have chronic problems with pain. The pain will usually be treated with oral medication that is adjusted to meet the severity of the problem. Intravenous pain medication will be provided for acute problems or if medications cannot be given by mouth.

**Social Work**

In the hospital, you will be visited by Carol Welsch, the CF social worker (or April Hicks if Carol is not available). Her role is to assist you with coping and social support needs and to make the admission and discharge process go as smoothly as possible.

Sometimes it is helpful to see a familiar face and have a “friendly visit” for emotional and moral support while hospitalized. The social worker can also make sure that:

- One care team member has communicated with another in order to answer questions and increase confidence for patients with the treatment planning.
• They can coordinate meetings between the patient, family members, and the medical team during the hospital stay to talk about important medical decisions or problems.
• They can also assist in providing information about advanced directives to help you and your family navigate the decision-making process for your medical care in general.

Infection Control in the Inpatient Program

On 6C, you will have your own private room, telephone, and bathroom. Nursing assignments are designed to reduce the chance that a single nurse will be taking care of more than one patient with CF at a time.

Because adults can control their respiratory secretions much better than children, surgical masks are not required when you are outside your room in University Hospital. As in the pediatric program, we strongly discourage you from visiting directly with other hospitalized CF patients at any time, including when you are in your hospital room or in public areas of the hospital.

Patients who have the bacteria Burkholderia cepacia in their respiratory secretions receive special attention. The registration card of patients with cepacia will have the code “BC” imprinted on it to let hospital staff know that cepacia has been detected. For those with cepacia or with bacteria that are resistant to many antibiotics, “Special Contact Precautions” will be used by staff to limit the spread of germs. Staff will wear gowns and gloves for all direct patient care or when working within 3 feet of the patient.

Patients are encouraged to wash their hands frequently and to use the waterless alcohol-based hand sanitizers to reduce the chances of picking up germs from others and to prevent them from leaving germs that others might
come in contact with.

**Discharge Planning**

Allison Wilson, or another discharge planner, will set up what is needed to continue your recovery after going home.

- If home intravenous antibiotics are needed, the appropriate nursing company, infusion company, and equipment suppliers will be contacted.
- When needed, the discharge planner will also set up home physical therapy for teaching you and any helpers about ways to promote secretion clearance and physical therapy.
- If supplemental oxygen is needed, the discharge planner will order it, and a company will bring it to your home and teach you how to use it.

The discharge planner will review your insurance coverage and work to decrease any of your out-of-pocket costs where possible. All discharge plans will be coordinated with you and your attending physician.