Cystic Fibrosis Inpatient Guide

Your guide to our adult cystic fibrosis inpatient unit
St Michael’s Hospital is home to the largest adult cystic fibrosis (CF) program in North America. We care for over 400 patients, and also participate in clinical research and training.

Introduction
This guide will help you find your way during your time at the hospital. Please ask any staff member for help if you have questions or concerns.

Our Team
You will be cared for by an interdisciplinary team of healthcare professionals:

Nurse Practitioner (Kate Gent)
Dietitians (Ronalee Robert and Lisa Mannik)
Physiotherapists (Erika Szego, Kenneth Wu, Farwa Malik, Polyana Mendes)
Respiratory Therapists (Brent West and Eva Leek)
Social Workers (Annie Thomas-Diceman and Anne Culligan)
Pharmacists (Daniel Cortes and Kevin Curley)
Psychiatrist (Dr. Kien Dang)
Research coordinators (Leena Rizvi, Katie Griffin, Jennifer Pike, Lesley Gaskin).
Clinic Nurses (Janelle Lopez and Sandee Westell)
On the ward there are a number of nurses who are all experienced in the care of adults with CF. The charge nurse is Sarah Sweetman.

Our Unit
Our respirology inpatient unit is on the 6th floor of the Bond wing (“6 Bond”). The patients on this floor may have other lung illnesses besides CF. CF patients with all different types of germs/bacteria including B. cepacia are admitted to same unit.

On 6 Bond, there are 9 private rooms and 3 semi private rooms for a total of 15 beds. If you are placed in a semi private room, the other patient in the room will NOT have CF. In semi-private rooms the bathroom is shared with your roommate.

There are specific showers designated for your use. For infection control reasons please speak with your nurse before using a shower. See section on Infection Control on page 3.

When being admitted to St. Michael’s Hospital we ask that you bring your physiotherapy devices and a list of your medications so they can be reviewed with you. When you are admitted to hospital, all your medications will be supplied for you.
Being Admitted

It is important for your care team to get a clear picture of your health at the beginning of your admission.

A nurse will assess you initially, including a full review of your medications. You will also be given a wristband. You should keep your wristband on for the duration of your admission.

You may also need to:
- Have a baseline chest X-Ray done when you arrive in hospital
- Have a baseline lung function done when you arrive in hospital
- Do MRSA skin swabs (these will be done in your room)
- If you are having symptoms of a viral (flu-like) illness, you may need a nasopharyngeal swab (NP swab) at time of admission

Infection Control

- Nurses that care for B. Cepacia-positive patients will not care for B. Cepacia-negative patients.
- There are specific showers designated for your use according to which microorganisms you grow in your sputum. Please speak with your nurse upon arrival to find out more about which showers to use and where they are located.
- All people with CF, regardless of their respiratory tract culture results, must be separated by at least 6 feet (2 meters) from other people with CF in all settings, to reduce the risk of droplet transmission of CF pathogens. This does not apply to members of the same household.
- We do encourage patients to leave their room and to engage in physical activity, however we strongly advise against being in the inpatient ward hallway or lounge areas.
- Patients can leave the floor to go to the cafeteria or coffee shop but not in the company of another person with CF.
Nutrition

Patient Food Services at St. Michael’s Hospital provides balanced, nutritious meals that accommodate a wide variety of diets.

The standard CF diet is a high fat, high-energy diet that provides 3 meals and 3 snacks daily. **If you have dietary allergies or restrictions**, inform your nurse as soon as you arrive at the Hospital.

You will receive a menu with your breakfast tray, to be filled out for the following day’s meals. Please place your completed menu in the box outside of the nursing station **no later than 5pm** in order to ensure the diet office receives your selections. A **menu substitution list** is available that provides additional food options that you can write on your menu. If you are on special infection control precautions, you may not receive a printed menu; instead, the diet office will phone you every day for your meal selections.

All private rooms and some semi-private rooms contain refrigerators. You are welcome to bring into hospital your own food from home, or have visitors bring in food when they visit. There is a microwave in the pantry that can be used to re-heat food.

Nutritional supplements such as EnsurePlus, Scandishakes, and Boost pudding are available to help meet your nutritional needs. Please inform your dietitian or nurse if you would like to receive supplements.

If you have a G-button for enteral feeding, please **bring your adaptor** with you when you come to hospital.

If you monitor your blood sugars regularly at home, please **bring your glucometer and test strips with you**.

If you have any questions about nutrition, please speak with Ronalee or Lisa and they would be happy to help you!

Please also see our Menu Substitution List to avail of these options for patients with cystic fibrosis.
Tests and Procedures

During your stay in hospital, you may have to do some tests and procedures in order to help inform your care.

Your doctor will decide what tests are needed for you. However, these are some very general guidelines regarding tests and procedures on our inpatient ward:

- **Bloodwork**: blood tests are generally done on Mondays and Thursdays, however you may need additional bloodwork and this would be explained to you by your doctor
- **X-Ray**: An X-Ray is done when you are admitted, and usually again after 7-10 days of treatment
- **Lung Function**: Similar to x-ray, lung function tests are done upon admission and then repeated after 7-10 days of treatment
- **Sputum Samples**: You may be asked to provide a sputum sample so that your team can determine which therapies are best for you
- **Six Minute Walk tests and lower limb strengthening exercises** may be done with you while you are in hospital. Please speak with your physiotherapist to learn more.
Medications and Coverage

The cost of CF medications can be covered through different ways.

Some CF medications (such as enzymes, vitamins) are paid for by the Ontario Special Drug Program. These medications do not require paying a dispensing fee, but must be dispensed at The Prescription Care Centre at St. Michael’s Hospital in order for the cost to be covered by the Ontario government.

Some people with CF may have private insurance to cover the costs of their medications. This could take the form of private coverage through plans held by their parents, spouse or through their work. The coverage of medications may be complete or there may be a deductible (for example, 80% of the cost of the medication is covered). If you are using private insurance, you can get many of your medications through the Prescription Care Centre at St Michael’s Hospital or at your local pharmacy.

The Ontario government has a drug insurance plan called the Trillium Drug Program, which can also cover the costs of CF medications not covered by the Special Drug Program or fully through private insurance. The deductible, the amount you pay to the Trillium Drug Program, is calculated based on your income.

Please note that medication coverage may be different or change for those over the age of 18.

Although medication coverage can be complicated, it is important to get it sorted out so that you always have access to the medications you need. Please speak with the CF team about this, as we can help you. Also please look at our adult CF clinic website www.torontoadultcf.com for more information.

You can get many of your medications at a local pharmacy near to your home, but there are several medications that are best to get at our outpatient pharmacy at St. Michael’s Hospital, because these medications require special ordering or may be unavailable in the community.
The pharmacy is located on the ground floor of the Donnelly (Queen St) Wing Room B1034. The head pharmacist is Jeff Petten.

The Prescription Care Centre team is available to help with your medication needs. They also carry a variety of over-the-counter medications and nebulizer supplies.

**Directions:** From the Queen Street Entrance, walk straight down the hall, past the 2nd set of Queen elevators. The pharmacy will be on your left.

**Hours:**
Mon - Fri: 8:30 a.m. - 6:00 p.m.
Saturdays: 10:00 a.m. - 3:00 p.m.
Sundays and holidays: closed

**Contact Info:**
Phone: [416-864-5110](tel:416-864-5110)
Fax: [416-864-1962](tel:416-864-1962)
Email your prescription or refill request to: prescription@smh.ca

**Tips for picking up medications:**
To avoid long wait times, you should call/email one to two weeks before your scheduled clinic appointment to order your maintenance/regular medications. That way, your medication order will be ready for you to pick up when you come to your appointment.

This includes patients transitioning from the Hospital for Sick Children who are coming to a clinic at St. Michael’s for the first time.

If you run out of medication before a clinic visit, please call/email the Prescription Care Centre directly (not the CF office) and order your medication for pick up. Please give the Prescription Care Centre staff 1 week to have your order signed and ready for you. More than 1 week’s notice may be required for medication quantities greater than 3 months supply.

Please call the CF office directly at [416-864-5409](tel:416-864-5409) if you wish to have medication ordered at your local pharmacy. We will arrange for the CF nurse to call in your order. Again, please give the office a few days to call your order into your local pharmacy as the CF nurses are very busy but they will try to accommodate your request in a timely manner.

**Medication Delivery:**
Medications can be delivered by Canada Post COD (charge on delivery) or Purolator. Delivery times depend on the method and delivery address and can range from next day (GTA) to 7-10 business days turn-around times.
Physiotherapy

We ask patients to bring with them into hospital:
- All physiotherapy/airway clearance devices they have at home (even ones you are not using), for use in the hospital, as well as for assessment by physiotherapists
- Walking/running shoes (for exercising and functional/strengthening tests)

If you have questions about physiotherapy techniques or want to learn more, please ask to speak with one of the CF physiotherapists.

Equipment

**PICC Lines**

If you have a PICC (peripherally inserted central catheter) line placed, it is important to learn some guidelines on PICC care. For instance, you will need to cover your PICC line when showering. Several options are available to you for this:

- Saran wrap with tape to secure
- A large biohazard bag with a hole cut at end, secured with tape
- Commercially available covers such as DRYPro (www.drycorp.com)

Ask your inpatient nurse to tell you more about how to care for and protect your PICC site. You can read more about PICC care at: [http://www.torontoadultcf.com/daily-living/picc-lines](http://www.torontoadultcf.com/daily-living/picc-lines)

**Respiratory Equipment**

Be sure to ask your respiratory therapist (Eva or Brent) for a nebulizer cleaning kit. You can also ask them any questions you have about how to clean your nebulizer.

**IV**

If you wish to go for a walk, you can ask your nurse to be de-accessed from your IV pole, so that you can walk with more freedom. Please see section on Infection Control.
For your reference
We want to make your stay as pleasant as possible. If you have questions or concerns, talk to your CF care team. We are here to help!

WIFI/ELECTRONICS
Wifi is available to patients and family. Under wifi/internet settings, select “Other” and enter: SMH_Guest. No password is needed. We strongly discourage bringing expensive electronics or other items into hospital in order to avoid theft/damage.

VISITING HOURS
11 a.m. to 9 p.m., seven days a week.

Be sure to check with your CF team about infection control measures if you are not sure.

TELEVISION
Each television has 3 free channels: 3, 75 and 81. Channel 75 is the St Michael’s Hospital channel airing evenings.

Other channels can be turned on for a charge. Dial 2400 from your patient phone to activate these channels using

LEAVING THE HOSPITAL
Patients should discuss with their physician if they wish to leave the hospital for any reason. We expect patients to be in their rooms, available for treatments when the members of the CF team arrive to see them. Please sign out with the nurses station, and be sure to return by 9pm.

STAYING NEARBY
If you are being admitted to St. Michael’s Hospital and don’t live near Toronto we might be able to help your family stay close to you! Be sure to ask your social worker for information about discounted medical rates for hotels nearest the hospital.
A message from our Patient/Family Advisory Board

Who we are:
In January 2008, the CF clinic at St. Michael’s Hospital in Toronto initiated the first Patient/Family Advisory Board (PFAB) in Canada, to ensure patients’ needs are met with the highest standards of results. Our group is comprised of CF patients and family members, with support from two clinic staff in an advisory capacity. PFAB conducts monthly meetings via teleconference, in addition to having regular ongoing communication.

What we do:
The aim of PFAB is to act as an advisory resource to the St. Michael’s CF care team. We collaboratively work with the CF team to actively participate in the development of new programs, review recommendations and provide input with the ultimate goal of shaping a service system (the clinic) that is patient/family centered, efficient, and cost effective.

In addition, PFAB promotes improved relationships between patients, families and staff. This partnership allows PFAB and the CF care team to foster a partnering relationship in which concerns are listened to and addressed. This will result in more effective planning to ensure that services really meet the needs of CF patients.

If you are interested in joining PFAB or learning more about this initiative, please contact us at cf.pfab.toronto@gmail.com

Inpatient Housekeeping Survey

One of PFAB’s current initiatives involves an anonymous, brief survey online in order to obtain feedback about the level of satisfaction patients have with the housekeeping service while in hospital. We hope to continue to provide a clean environment for patients and their families.

You can complete the survey online: https://www.surveymonkey.com/s/KQRCQ9P

Thank you, and we wish you a speedy recovery!
Before you go...

Before you leave the hospital, be sure to know the answers to the following:

- What medicines you will be taking and any related instructions.
- Be sure to ask for any prescriptions you may need, and which pharmacy to fill them at.
- When to follow-up in CF clinic.
- The date of any other follow-up appointments.
- Instructions related to any equipment or devices you may be using.

Ask your CF team member if you are not sure about next steps.

**Discharge time for inpatient units is 11 a.m.**

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