



ST. JOSEPH'S • ST. MICHAEL'S • PROVIDENCE  
**UNITY HEALTH**  
TORONTO

# **St. Michael's Hospital**

## **Adult Cystic Fibrosis Program**

Smoothing the Transition for New Patients

Adult Cystic Fibrosis Program

St. Michael's Hospital, Respirology Clinic, 6th Floor, Donnelly Wing



30 Bond Street, Toronto, ON, M5B 1W8

(416) 864-5409 | <http://torontoadultcf.com>  TorontoAdultCFCentre

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## Welcome

Welcome to the Adult Cystic Fibrosis Clinic at St. Michael's Hospital in Toronto, also known as *St. Mike's*. The goal of the clinic is to provide expert care for adults with cystic fibrosis (CF).

St. Michael's Hospital is home to the largest adult CF program in North America. We care for over 550 patients, and also participate in clinical research and training.

We welcome new adults to our clinic for several reasons. Many are young adults who are transitioning from the Hospital for Sick Children or from a pediatric setting elsewhere in Ontario. This can be an exciting time as you leave the pediatric setting behind and look forward to having a **greater say in your own health care**. We appreciate that it can be a difficult time too, with facing challenges like meeting a new CF team, getting to know a new hospital, and **learning to make decisions** about your own health care. We also recognize that at this stage of your life, you may be experiencing other changes like gaining more adult responsibility, finishing up high school and moving onto further education or employment. Whatever your concerns, we are here to help!

Others are new to St. Michael's Hospital because they have re-located to Toronto, whether for work, school, or to be listed for a transplant. Again, the challenges of meeting a new CF team and getting to know a new hospital are there, along with the excitement, and sometimes anxiety of getting to know a new city.

Still others are completely new to the world of CF, having been diagnosed as an adult. For you, everything is new. While some feel relief at finally getting a diagnosis, we understand that there may be many changes to make and a lot of information to take in.

Whatever your reason for being new to the Adult Cystic Fibrosis Clinic at St. Michael's Hospital, this resource is one way we hope to welcome you and make this new experience a little easier.



## The Cystic Fibrosis Team

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

- 7 CF Physicians – Dr. Elizabeth Tullis, Dr. Anne Stephenson, Dr. Kieran McIntyre, Dr. Cecilia Chaparro, and Dr. Anju Anand, Dr. Giovanna Riolo, and Dr. Shazmeen Manji
- 3 CF Nurses – Sandee Westell, Stephanie Buschke and Amanda Santiago
- 2 Dietitians – Ronalee Robert and Lisa Mannik
- 3 Physiotherapists – Poonam Sisodia, Kevin Wood and Farwa Malik
- 3 Respiratory therapists – Brent West, Eva Leek and Ashley Bainey
- 2 Social Workers – Annie Thomas-Diceman and Anne Culligan
- 2 Pharmacists – Kevin Curley and Onella Pereira
- 1 Psychiatrist – Dr. Kien Dang
- 1 Endocrinologist – Dr. Julie Gilmour
- 3 Research staff – Katie Griffin, Jennifer Pike and Kamal Chokar
- 1 Care and Transitions Facilitator – Alicia Chibba
- 2 CF Administrative staff – Stephanie Leveiller and Sandra Falcao

In addition, on the ward there are a number of nurses who are all experienced in the care of adults with CF.



## Philosophy of Adult Care

St. Michael's Hospital is a teaching hospital associated with the University of Toronto. During your visit you can expect to be seen by a variety of health care providers dedicated to the care of individuals living with CF.

We expect the people we care for to **play an active role** in the management of their illness. We encourage support from family and friends and we aim for you to become **knowledgeable and engaged** with the CF team. The transition from pediatric care to adult care can be challenging and parents and loved ones often need support during the transition process. Cystic Fibrosis Canada and the Adult CF Team at St. Michael's Hospital are available for support and advice, if required.

### Our expectations

- Active participation in self-care



- Educated and informed about cystic fibrosis
- Ability to communicate with health care professionals
- Honesty and openness to the new team and adult approach
- Contacting the clinic if feeling unwell

## A message to parents

We recognize that your child's transition to St. Michael's Hospital can be difficult for you as well. Throughout the years, you have likely grown accustomed to being their primary care giver and providing for their needs, medical and beyond. We hope that you will continue to play a role in your child's health as a **member of our team**. However, we also hope that you see the importance of encouraging your child to take an active role in his or her health as they enter adulthood through **open communication** with the members of our team and **education**. Our team is here to support you throughout this transition to ensure it is as smooth as possible.

## Visiting the Clinic

### How clinic works

The Adult CF Clinics are held in the Respiriology Clinic area, which is on the 6th floor of the Donnelly Wing. There are a number of CF clinics organized to take account of infection control measures.

- The **Tuesday Clinic (Non Cepacia Clinic)** is for people who are not growing *Burkholderia cepacia* complex in their sputum (**see infection control for details**). Appointments are available from 8:30 am until 2:30 pm.
- The **Wednesday Clinic (Home IV Clinic)** is for people who are receiving intravenous



antibiotics at home. Appointments are available from 8:00 am until 12:00 pm.

- The **Friday Clinic (Cepacia Clinic)** is for people who are growing Burkholderia cepacia complex in their sputum. This clinic is separated into a “Burk” clinic and “Cenocepacia” clinic held on **opposite weeks to ensure patients** who have grown specific strains of Burkholderia cepacia complex are seen on the appropriate day. Appointments are from 8:30 am until 12:00 pm and these are held on alternating weeks from CF GI clinic.
- The **CF GI Clinic** is held approximately one time per month on Friday afternoons and for people who have nutritional, gastrointestinal, or liver related medical problems. Appointments are from 1:00 pm until 3:00 pm.

The CF Clinic is a very busy place! Your clinic visits may take up a whole morning or afternoon to allow us to provide the treatment you need and to get to know you a bit better. It is very important that you arrive promptly.

Allowing yourself 30 minutes prior to your scheduled appointment time, can help. We will do everything that we can to ensure your first visit goes smoothly as your CF care is important to us.

[Please remember to bring your OHIP card with you each time you come to the hospital.](#)

## Your first visit

For your first visit, you have the option to come during a non-clinic time to meet with the CF Nurse/ Social Worker who will help orientate you with the Adult CF Clinic.

[After that, your clinic day will be on](#)

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The CF secretary will book your first appointment. Please contact (416) 864-5409 or [cfclinicbookings@smh.ca](mailto:cfclinicbookings@smh.ca) if you have not heard from us within 2-3 weeks of your final visit at SickKids. **Please identify yourself as being new to the clinic.**

On your first or second appointment, you will start to be introduced to other members of





the Allied Health Team such as the dietitians, pharmacists, social worker and physiotherapists, in addition to seeing the nurse and doctor.

To book appointments after your first visit, do so at the end of your clinic visit or contact our Booking

## Infection Control

Infection control is a method of protecting people with CF, healthcare workers, and visitors from getting infections in the hospital and in the home.

Infection control is important because people with CF can spread germs (bacteria) unknowingly to others with CF and also can pick up infections from the hospital environment or other patients.

Persons with CF should be aware that their lungs may become infected with potentially harmful bacteria including *Staphylococcus aureus*, *Pseudomonas aeruginosa*, Methicillin-resistant *Staphylococcus aureus* (MRSA), and *Burkholderia cepacia* complex (*B. cepacia*). Some bacteria may be spread between people with CF and can cause serious illness in some individuals, quality of life and may impact life expectancy. It is important to adhere to the infection control practices and attend clinic on your designated day.

## How are these bacteria transmitted? How could I get infected?

There are a few ways that bacteria can enter the lungs of someone with CF:

**Environment:** Some bacteria grow in the environment (in soil and water) and there are some places that are more likely to be contaminated with bacteria (e.g., hot tubs).

**Direct Contact:** With another person with CF (e.g., shaking hands, hugging, or kissing)

**Indirect Contact:** Through touching a surface or object that has germs on it. For example,



door handles respiratory equipment, toys, computer, etc.

**Droplet Transmission:** Coughing or sneezing creates droplets, which contain bacteria. These droplets are projected to a distance of up to 2 m (or 6 ft) and can enter the eyes, nose, or mouth of another individual and fall onto surfaces such as tables.

## What is *B. cepacia* and what could happen to me if I get it?

Burkholderia cepacia complex (*B. cepacia*) is a group of bacteria living in soil or water (streams and ponds), causing rot in plants such as onions. ***B. cepacia* is unusual as it rarely causes illness in people unaffected by CF.** We know that there are many different kinds (species) of *B. cepacia* and we call this group of bacteria *B. cepacia* complex (BCC).

*B. cepacia* can be linked with poor health in CF and it will affect each person differently. Some people will have a slow and gradual decrease in lung function after becoming infected with *B. cepacia*, while others may have a rapid decrease in lung function and significant health complications. *B. cepacia* is naturally quite resistant to antibiotics so it can be difficult to treat.

## Is *B. cepacia* complex the only bacteria that can be harmful to people with CF?

No. There are other bacteria that can also be harmful to people with CF. **It is very unpredictable how a person with CF will respond to infection with a particular bacteria.** In addition, some strains of bacteria can be more harmful than others. It is advisable to minimize the chance of becoming infected with any of these bacteria.

## Protect yourself and others. What can you do?

1. Know what type of bacteria grows in your lungs so you can attend clinic on your appropriate day
2. Be sure to maintain a distance of 6 feet or more from others with CF
3. Do not share personal items such as cups, utensils, toys, computer, compressors,



and nebulizers with other people with CF

4. Avoid people who are sick whenever possible
5. Wash your hands or use alcohol-based hand sanitizers:

- Before, throughout and when you leave your clinic visit
- After coughing, sneezing, and blowing your nose
- After using ATMs, touching handrails, grocery carts, etc.
- Before and after eating
- Before and after using the washroom



## Cleaning with hand sanitizers:

1. Put a nickel sized amount in palm of hand

## What does the CF clinic do for infection control?

In 2014, the CF Foundation had experts in CF infection update the Infection Control guidelines. These guidelines are available on Cystic Fibrosis Canada website <https://www.cysticfibrosis.ca/about-cf/living-with-cystic-fibrosis/infection-prevention-and-control>

- When you come to your appointment, you may ask for a mask at the information desk on the ground floor if you identify that you have CF. If you choose not to do this, we will provide you with a mask when you check in at the clinic which you will be asked to wear while you are in the shared hospital spaces (clinic area, halls, cafeteria, coffee shop, etc). You can remove this mask when you are in your own clinic room. This practice will protect you from airborne bacteria in the hospital.
- All staff providing care in the CF clinic and on the ward will wear a hospital gown, which is changed between patients.
- All staff will wash or disinfect their hands then put on gloves before coming in to see



you. They will also wash or disinfect their hands after they remove their gloves on leaving your room.

We will do our best to put you in a clinic room as soon as you arrive in clinic. If there is no clinic room available, we recommend that you not use the waiting room. You can provide a cell phone number to the CF Administrative staff or one of the clinic nurses and you will be called you when a clinic room is ready for you.

During your clinic visit you are asked to stay in your room. All members of the team will come and see you. You may also have your lung function tests done in your room as well as your follow-up appointments confirmed before you leave. Please be aware that, the surfaces in each clinic room are cleaned between patients.

People with CF admitted to hospital should stay in their room and not go into the hall or waiting area. Patients may leave the inpatient unit to go to the cafeteria/ coffee shop, however not in the company of another person with CF.

## Feeling Unwell


### What do I do if I am feeling unwell?

If you are feeling unwell, please call the CF Office at (416) 864-5409 and the secretary will connect you with the CF nurse.

### Office Hours

**Monday to Friday:** 8:00 am – 4:00 pm

**CF Office:** (416) 864-5409

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- If the matter is urgent, and it is during evening, weekend or holiday hours, you can reach the CF doctor on call through hospital locating: (416) 864-5431.
  - If you are extremely ill and it is of an urgent nature, we recommend that you go to your nearest Emergency Department. It is advisable to also call the CF doctor on call at St. Michael's Hospital through locating so they can discuss the medical problem with the doctors at your present location.

## Hospital Admission

### What happens if I need to be admitted?

St. Michael's Hospital has a Respiriology inpatient unit on the 6th floor of the Peter Gilgan Tower (known as "6 PGT). Our secondary unit that cares for CF patients is on the 8<sup>th</sup> floor of the Peter Gilgan Tower (known as 8 PGT)). On each of these units, you will be cared for by the CF team. This team includes staff doctors, medical residents, nurses, physiotherapists, dietitians, respiratory therapists, social workers, pharmacist, and a care and transitions facilitator. There are 5 specialized CF doctors who take turns looking after people with CF admitted to the hospital.

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 and review your medications. The CF team will also meet with you to better understand what has brought you to hospital and determine what interventions could assist you to return to your usual level of functioning. You will be given a wristband that you are asked to wear 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)
- Have a nasopharyngeal swab (NP swab) if you are having symptoms of a viral (flu-like) illness at time of admission

The patients on 6 PGT may have lung illnesses other than CF. CF patients with all different types of germs/bacteria can be admitted to the same unit however people who grown a particular strain of B. Cepacia (ET12) will be admitted to 8 PGT. Due to infection control, all people with CF are asked not to socialize with other patients on the unit.

On both 6 PGT and 8 PGT, there are 16 private rooms with access to private washrooms/showers.

Adults with CF (non-ET12) are admitted to 6 PGT, unless there is no bed available, in which case you will be placed temporarily on any another unit in the hospital (except for 8 PGT). Even if you are admitted to a different floor, the CF doctor will direct your care and the CF team will still be **actively involved**.

If you are colonized with B. cepacia ET12, you will ONLY be admitted to 8 PGT and cared for as above by the CF team.

When being admitted to St. Michael's Hospital we ask that you bring your medication, physiotherapy devices (nebulizer, insulin pens, glucometer, etc) and a list of your medications so they can be reviewed with you. When you are admitted to hospital most of your medications will be supplied for you.

## Medications

### How do I get my medications?

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



Some CF medications (e.g., enzymes and vitamins) are paid for by the Ontario government. These medications must be dispensed at [The Prescription Care Centre \(PCC\)](#) at St. Michael's Hospital in order for the cost to be covered by the government. This is similar to the process through Shoppers Drug Mart at SickKids. At your final visit at SickKids, it is a good idea to refill 3 months of your CF medications to ensure you have adequate supply until you are seen at St. Michael's.

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 parents, spouses, or through personal employment. Many parental plans cover people up until the age of 25 or until an individual is finished school. The coverage of medications may be 100% complete or there may be a deductible (e.g., 80 % of the cost of medication is covered so 20% is left to pay). If you are using private insurance you can get your medication at your local pharmacy or through the PCC at St. Michael's Hospital.

[Ohip + \(Plus\)](#), is a plan that allows for anyone 24 years and under who are not covered by a private plan to receive coverage under the Ontario Health Benefits Plan (ODB). Coverage will be automatic, with no upfront costs. Coverage will stop on an individual's 25<sup>th</sup> birthday or if a person becomes covered by a private plan.

<http://www.health.gov.on.ca/en/pro/programs/drugs/ohiplus/#covered>

The Ontario government also has a medication insurance plan called the [Trillium Drug Program](#) for people over the age of 25. This covers the cost of many CF medications with a deductible based on the household income. This program is available through the PCC at St Michael's hospital or through your local pharmacy.

**Note that medication coverage may be different for those over the age of 18 years.**

Although medication coverage is complicated, it is important to get it sorted out so that you can have access to the medications you need. Please speak with a member of the CF team (social worker, pharmacist, MD, nurse), as we can help you. Please visit the Toronto Adult CF Clinic website [www.torontoadultcf.com](http://www.torontoadultcf.com) for more information.



## Where can I get my medications?

You can get many of your medications at your local pharmacy or at the Prescription Care Centre (PCC) at St. Michael's Hospital however there are several CF specific medications that are best to get at the PCC as they require special ordering or may be unavailable in the community.

### Prescription Care Centre (PCC)

The pharmacy is located on the ground floor of the Donnelly Wing, Room B1-034. From the Queen Street entrance, walk straight down the hall, past 2 sets of Queen Wing elevators. The pharmacy will be on your left. The Pharmacist Manager is Jeff Petten.

The PCC team is available to help with your medication needs. They also carry an assortment of over-the-counter medications, nebulizer supplies and physiotherapy devices.

Monday to Friday:  
8:30 am – 6:00

am

### Tips for picking up medications

To avoid long wait times, call/email the PCC 1-2 weeks before your scheduled clinic appointment to order your maintenance/regular medications. Your medication will be brought to your clinic for pick up or you can arrange for home delivery\*(\*speak with the pharmacy to determine if you qualify for free delivery). By doing this, your medication order





will be ready for you to pick up when you come to your appointment and the pharmacy can ensure that they can fill your order. This includes patients transitioning from the Hospital for Sick Children who are coming to the clinic at St. Michael's Hospital for the first time.

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

Call the CF office directly at (416) 864-5409 if you wish to have medication ordered at your local pharmacy. Please provide the phone and fax number for follow up and allow the office a few days to call your order in. Although the CF doctors and nurses are very busy they will do their best to accommodate your request in a timely manner.

## Medication delivery

Canada Post COD or Purolator can deliver medications. Delivery times depend on method and delivery address and can range from next day (GTA) to 7-10 business days.

## Nutritional Supplements

### Where do I get my nutritional supplements?

For people with CF who need nutritional supplements, such as Boost/Ensure, Scandishakes and G-tube feeds, they can be continue to be ordered and picked up through the [Specialty Food Shop](#) at the Hospital for Sick Children.

Please speak with one of the St. Michael's Hospital CF dietitians so that they can create a customer file for you at the Specialty Food Shop. Once this is done, you will not have to pay for the supplements you need because they are covered by the Ministry of Health CF



program. You will need your new St. Michael's Hospital ID number, which will be given to you at your first visit, when placing your order.

For those who find it difficult to pick up the supplements at the Specialty Food Shop, you may also order supplements to be delivered to your home. You will be responsible for the shipping costs.

### To place an order at the Specialty Food Shop:

**In person:** Hospital for Sick Children, Main Floor  
555 University Ave, Toronto, ON

**Phone:** 1 (800) 737-7976

**Website:** [www.specialtyfoodshop.com](http://www.specialtyfoodshop.com)

## Research

While you are a patient at St. Michael's Hospital you will be asked if you agree to have your records included in the Toronto CF database and the Canadian CF Data Registry.

- The Toronto CF database records your clinical information (e.g., weight and height, pulmonary test results, blood work results) and we use this database when we conduct research studies.
- The Canadian CF Data Registry collects similar information and uses this to calculate national statistics about CF including the median survival for people with CF in Canada. Please note that the information remains confidential and your name is not attached to your information.

St. Michael's Hospital has the largest adult CF centre in Canada. For this reason we are



asked to take part in many research studies looking at new treatments for CF.

You may be asked from time to time if you would like to take part in CF related research. This is purely voluntary and will in no way affect the quality of your clinical care. If you would like to get involved with CF research, please let the CF team know.

## **Telemedicine**

Telemedicine is a technology that allows people living outside of large cities to be seen more frequently and will help lead to improved care. It allows for interactive "face-to-face" communication through video conferencing equipment at a telemedicine studio that is closer to a patient's home. This program aligns with our goal to increase the care that we provide and ease the burden of travel for people living with CF.

We will continue to have satellite clinics take place in Sudbury and Thunder Bay twice a year. We hope to use telemedicine to bridge the gap between clinic visits 1-2 times per year as needed. We feel that it is very important to have annual visits in Toronto if possible as you will benefit from the direction and expertise of the entire multidisciplinary CF team at St. Michael's Hospital, which is the gold standard of care. If you live greater than 100km north (one way) there is funding support through the Northern Health Travel Grant program, a travel reimbursement program funded by the Ontario government.

In addition to doctor visits, other opportunities exist via telemedicine to take part in educational sessions plus telebehavioural support with other members of the CF team. Areas such as diabetes management, nutrition, physiotherapy, exercise, reproduction and fertility, and psychosocial concerns could be addressed.

If you have any questions regarding the telemedicine program or wish to take part please contact the CF clinic in Toronto to arrange an appointment.

## **Toronto Adult Cystic Fibrosis Centre Mentorship Program**

Developed in response to an identified need, the Mentorship program was initiated to create peer support. Many individuals find it helpful to speak to others who have gone through similar experiences. Daily living with cystic fibrosis, transition to adult care,



pregnancy, fertility treatments, transplantation, and career goals are just a few of the possible areas of discussion for this program.

The CF Centre will pair up individuals on the basis of experiences and the type of support requested. After this, it is up to the two individuals to determine when and how to communicate. Due to the unique infection control practices in CF, patients are advised to avoid direct contact. We suggest mentors use communication outlets that do not involve direct contact, such as email, telephone, and video formats.

**To find out more, speak with a member of the CF team!**



## Patient/Family Advisory Board



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 a clinical staff member in an advisory capacity. PFAB conducts monthly meetings via audio or video conferencing, in addition to having regular ongoing email communication.

The aim of PFAB is to act as an advisory resource to the Adult CF Program Quality Improvement (QI) team. PFAB collaboratively works 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 experiences 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](mailto:cf.pfab.toronto@gmail.com).

## Resources

For more information about the Adult CF Clinic please see our website at [www.torontoadultcf.com](http://www.torontoadultcf.com)

The CF team can be reached through the following phone number and/or email address. The secretary will forward your request to the most appropriate person.

**Phone:** (416) 864-5409  
**Email:** [CFClinicBookings@smh.ca](mailto:CFClinicBookings@smh.ca)



## Public Transportation and Parking

### TTC

Exit the subway at the Queen Subway station. The Queen Subway station is on the Yonge-University-Spadina subway line. Walk one block east on Queen Street to the Queen entrance of St. Michael's Hospital.

### GO Train

GO train is a convenient way for some people to travel into downtown. It will bring you to Union Station and you can either take the subway (TTC) north to Queen Subway station, or walk 15 minutes to the hospital.

### Driving

#### From the Don Valley Parkway:

1. Exit at Richmond Street
2. Go west to Church Street
3. Go north to Queen Street
4. Go west to Bond Street

#### From the Gardiner Expressway:

1. Exit at Jarvis Street
2. Go north to Queen Street
3. Go west to Bond Street

### Parking

There is indoor parking directly across Queen Street and an outdoor parking lot directly across from the hospital on Bond Street. These lots are not operated or owned by St. Michael's Hospital and require payment for parking. Cost ranges from \$3/half hour to \$25/day.



