



Patient & Family Guide
2020

The Adult Cystic Fibrosis (CF) Program at the QEII



www.nshealth.ca

Prepared by the QEII's CF Team.

This guide will help you learn about the services that the Adult Cystic Fibrosis Program offers and how you can access them.

Contents

Your health care team	1
Clinic doctors	1
Nurse coordinator	2
Dietitian	3
Physiotherapist	4
Psychologist	4
Social worker	5
The CF Clinic	5
Common tests	7
Chest X-ray	7
Pulmonary function test (spirometry)	7
Blood tests	8
Bone mineral density test.....	8
Medications	9
Taking care of your equipment	10
Respiratory equipment and supplies	10
Home IV antibiotics	11
Hospital stay	12
Admission	12
Your role in hospital	13
Keeping yourself updated	15
Research and you	15

The Adult Cystic Fibrosis (CF) Program

Your health care team

Clinic doctors

In the clinic, you will see Dr. Nancy Morrison and Dr. Meredith Chiasson. They work with other members of the health care team as needed.

Dr. Morrison and Dr. Chiasson will:

- › diagnose and treat you.
- › help you if you have a change in your symptoms, or other medical problems.
- › help you if you have a change in your condition and are not sure if you should go to the Emergency Department.

If you need help, you can:

- › call the nurse coordinator at 902-473-4147.
- › email sarah.sutherland@nshealth.ca (if you have signed a consent form to communicate with the CF Clinic via email).
- › call Dr. Morrison at 902-473-6611.
- › call Dr. Chiasson at 902-473-3698.

Nurse coordinator

The nurse coordinator is your first contact person for all problems. The nurse coordinator can help you by:

- › arranging clinic appointments.
- › arranging followup treatment after being in the hospital.
- › arranging followup treatment after a Clinic visit.
- › coordinating your CF health care team.
- › involving you in decisions about your treatment.
- › acting as your contact between Clinic visits, if you have any medical concerns.
- › helping you learn more about CF.

Phone: 902-473-4147

If there is no answer, you can leave a message. You can expect to have your call returned by the end of the same day, unless the voicemail says “out of office”.

Dietitian

The dietitian can help you reach and keep good nutrition, both in the Clinic and in the hospital. Some of the ways the dietitian can help include:

- › checking your weight, diet history, and vitamin and enzyme use.
- › counselling you about: nutrition problems, such as weight loss, poor appetite, heartburn, nausea (feeling sick to your stomach), diarrhea (loose, watery poop), constipation (not being able to poop), enzymes, and diabetes.
- › teaching you about planning and preparing meals, and grocery shopping on a budget.
- › issues related to bone health (such as support with calcium and vitamin D intake).
- › teaching you about G-tubes (gastric feeding tubes), figuring out your nutrition requirements, and deciding on feeding products and schedules.

Phone: 902-473-2300

You can also tell the nurse coordinator if you would like to talk with the dietitian.

Physiotherapist

The physiotherapist can help you while you are in the Clinic or in hospital. The physiotherapist can:

- › help you keep your airways clear using breathing techniques, special masks, or other physiotherapy devices.
- › help you to stay active through exercise.
- › teach you exercise programs for back and joint pain, muscle strengthening, and relaxation.

Tell the nurse coordinator if you would like to talk with the physiotherapist.

Psychologist

The psychologist can help you deal with emotional or stress-related concerns, such as:

- › Stress management
- › Coping with CF
- › Referral to community resources

A full range of psychological services are available. Please ask about these services during your Clinic visit, or call 902-473-2525.

Social worker

The social worker is your link to getting and staying independent. The social worker can help you with:

- › Support in a role or lifestyle change
- › Changes in work and income level
- › Finding programs and services in the community
- › Working with community services to support special needs

Tell the nurse coordinator if you would like to talk with the social worker.

The CF Clinic

- The CF Clinic is usually held once or twice a week (but less often in August). It is located on level 400 of the Halifax Infirmary. Use the Robie Street entrance and register at the kiosk, then go directly to the Respirology Clinic. **Do not wait in the large waiting room.**
- A mask will be mailed to you with your clinic appointment letter. Please wear the mask when you enter the hospital.

- A Clinic aide will direct you to a room and measure your height and weight. The respiratory therapist will check your temperature, pulse, breathing rate, blood pressure, and oxygen saturation, and do spirometry (measure the air going in and out of your lungs). They will also review your medications with you.
- Next, you will see the doctor, the nurse coordinator, and other team members. The team members will talk with you about treatment options. You will have the chance to express any of your concerns. Together, you and your health care team will develop your individual plan of care.
- The nurse coordinator will mail a followup appointment letter to you. This will remind you of your next Clinic visit and any scheduled tests.

If you cannot keep your Clinic appointment, please call the nurse coordinator at 902-473-4147 as soon as possible to set up another time.

Common tests

Chest X-ray

An X-ray helps your doctor see your lungs. This helps them to make a more accurate assessment of the disease. They can then use this information to help them make treatment decisions.

If you need an X-ray:

1. Pick up the requisition form in the Clinic.
2. Go to level 300 (X-ray Department) of the Halifax Infirmary.

Hours: 8:30 a.m. to 5 p.m., Monday to Friday
(closed on holidays)

Pulmonary function test (spirometry)

This test measures:

- › How much air your lungs can hold
- › How much air your lungs can breathe out
- › How fast you breathe out

This information gives an indirect measure of the amount of narrowing in your bronchial tubes. This test helps to show changes in your lungs and helps us make decisions about treatment.

Blood tests

Blood tests give information that helps to find and treat problems. These tests may show:

- › Your general health
- › How well your blood carries oxygen to tissues
- › How well your liver and pancreas work
- › The amount of salt and minerals in your blood
- › The amount of nutrients such as protein, carbohydrate, fat, vitamins, and minerals in your body
- › Blood sugar levels (an oral (by mouth) glucose tolerance test may be used to check for diabetes)

If you need blood tests:

1. Pick up the requisition forms in the Clinic.
2. Go to Blood Collection on level 400 of the Halifax Infirmary.

Bone mineral density test

A bone mineral density test is done to check the strength of your bones. CF patients often have low bone mineral density.

Medications

- For Nova Scotia residents, the medications that you take at home are free of charge. They are available from the Metropolitan Dispensary at the IWK Health Centre.
- The Dispensary is open from 8:30 a.m. to 4:30 p.m. Monday to Friday (except on holidays). You may pick up your medications at the Metropolitan Dispensary on level 100 of the IWK Health Centre (use the South Street entrance) or they can be sent to you by courier for a fee.
- **Be sure to check the refill information on the bottle.**
- If your prescription has a refill, or you need more enzymes or vitamins, you can call the Metropolitan Dispensary directly at 902-470-8135.
- Call the nurse coordinator if you need a new prescription or a prescription reordered (for example, when the label reads: ‘This is the last refill for this prescription, please contact your physician’). Long-term CF medication prescriptions require refills once per year, this can be arranged at Clinic appointments.

- For patients in New Brunswick and PEI, medications are dispensed from local pharmacies. In PEI, you can get some medications from the Provincial Pharmacy that are covered by your drug plan (not all medications are covered by the provincial plan).

Taking care of your equipment

- You are responsible for keeping your home care equipment clean. Equipment that is not properly cleaned and maintained can lead to more respiratory infections.
- When you are at the Clinic, ask the nurse coordinator and respiratory therapist for tips on how to care for your equipment.

Respiratory equipment and supplies

- For Nova Scotia residents, your respiratory equipment and supplies are dispensed and serviced by the CF Clinic at the IWK Health Centre.
- Call the nurse coordinator at 902-473-4147 to arrange for your equipment.

Home IV antibiotics

- Some people with CF are a good fit for self-administering (giving to yourself) intravenous (IV) antibiotics at home.
- There is no cost for equipment, supplies, or medications (Nova Scotia residents only). Equipment and supplies are arranged through Home Care Services and the nurse coordinator.
- In Nova Scotia, home IV antibiotics are provided through the Metropolitan Dispensary. It may take 2 full weekdays for the Metropolitan Dispensary to fill your IV antibiotic prescription. In PEI home IV antibiotics are provided through PEI Home Care.
- In New Brunswick, home IV antibiotics are arranged through the Extra-Mural Program.
- Some people with CF need a permanent IV access device. This device is called an implanted infusion port or Port-a-Cath®. It is available for those who meet the criteria. If you would like more information, please ask your doctor and the nurse coordinator when you are at the Clinic.

Hospital stay

Admission

- Your doctor may recommend that you be admitted to the hospital if:
 - › Your lung infection makes you quite sick. The doctor may decide to admit you right away through the Clinic or Emergency Department.
 - › You have ongoing problems which show that your infection is getting worse, and antibiotics are not helping. Your doctor may decide to admit you for treatment with IV antibiotics.
- You will be admitted to a single room on one of the medical units.
- You will be cared for by the CF team and other health care providers. These include an intern or resident doctor, and may include other doctors.
- The nurse coordinator will visit you to talk about any concerns you may have about your treatment and to plan your Clinic followup.

Your role in hospital

You play an important role in your CF therapy while in the hospital. You can get the most out of your hospital stay by:

- › eating well-balanced meals at regular times.
- › getting enough rest. Try to go to sleep early and have a nap during the day.
- › taking part in physiotherapy. Since most hospital stays are because of lung infections, it is important for you to plan time for physiotherapy in your day. You will work with the physiotherapist to make a physio plan.
- › communicating clearly with hospital staff. Sometimes it is hard to tell hospital staff about your needs. The nurse coordinator can help you with this.

Go to the nearest Emergency Department right away if you have:

- › Severe (very bad) symptoms that start suddenly, such as sudden sharp pain in your chest, rapid breathing with shortness of breath, or a lot of trouble breathing
- › A lot of blood (more than a few streaks) in your sputum (mix of saliva and mucus)
- › Bleeding from your rectum (bum)
- › Vomiting (throwing up) with blood
- › Really bad abdominal (belly) pain that doesn't go away

If you go to the Emergency Department, please call and leave a message with the nurse coordinator.

Keeping yourself updated

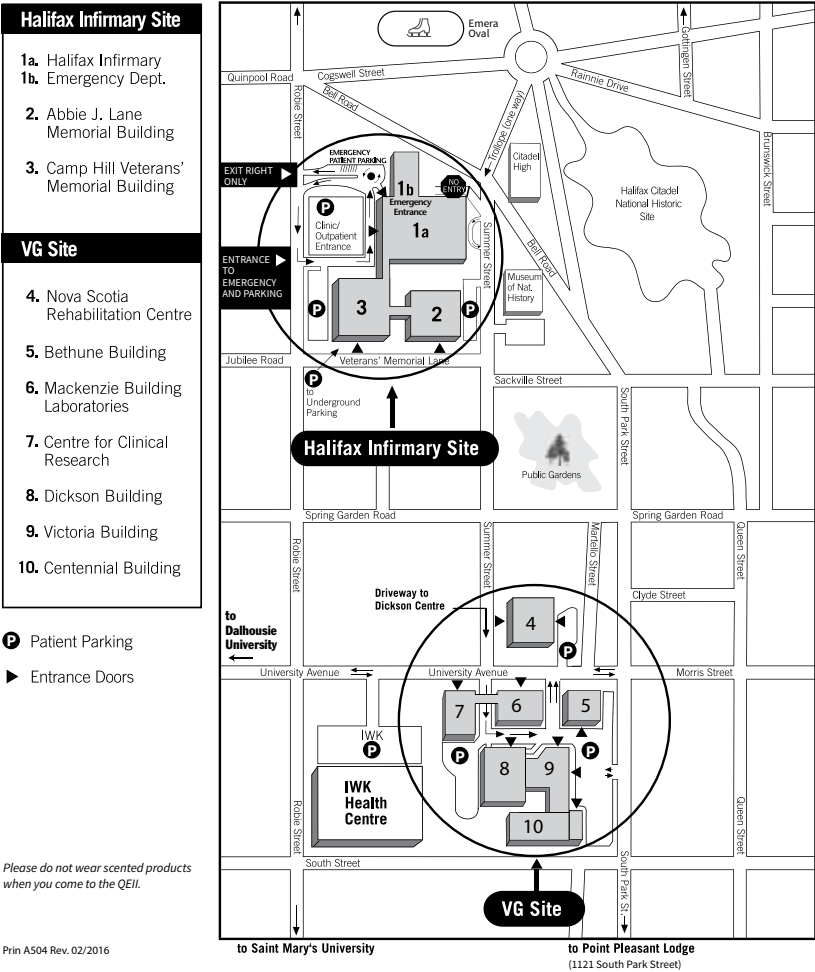
- New therapies for CF are being developed all the time. It is important for you to keep learning to make sure you are caring for yourself as well as possible.
- You can keep yourself updated during your Clinic visits or while you are a patient in the hospital.

Research and you

- CF research is key in improving the quality of patient care.
- From time to time, you may be asked to take part in a CF research project. Whether you take part or not is completely up to you. Your choice will not affect your care.
- Research increases the possibility of new options in CF care. These options may include:
 - › New medications to treat CF
 - › New medications to treat infections
 - › Improved nutritional therapies
 - › New methods of physiotherapy

QEII Health Sciences Centre

is made up of 10 buildings located on two sites



Notes:

Looking for more health information?

Find this pamphlet and all our patient resources here: <https://library.nshealth.ca/PatientEducation>

Contact your local public library for books, videos, magazines, and other resources.

For more information, go to <http://library.novascotia.ca>

Connect with a registered nurse in Nova Scotia any time: call 811 or visit <https://811.novascotia.ca>

Learn about other programs and services in your community: call 211 or visit <http://ns.211.ca>

Nova Scotia Health Authority promotes a smoke-free, vape-free, and scent-free environment.

Please do not use perfumed products. Thank you!

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The information is not intended to be and does not constitute health care or medical advice.

If you have any questions, please ask your health care provider.

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The information in this pamphlet is to be updated every 3 years or as needed.