



Patient & Family Guide

2024

Adult Cystic Fibrosis Program

Halifax Infirmary



www.nshealth.ca

Adult Cystic Fibrosis Program

What is the Adult Cystic Fibrosis (CF) Program?

- The Adult Cystic Fibrosis Program helps people with CF by:
 - › Providing CF information and support
 - › Helping you create an action plan
 - › Suggesting programs and services that may help

Your health care team

Doctors

- Dr. Nancy Morrison and Dr. Meredith Chiasson will:
 - › diagnose and treat you.
 - › help with any changes in your symptoms or condition.
 - › help you decide if you should go to the Emergency Department if there has been a change in your condition.

Dr. Morrison

- › Phone: 902-473-3698

Dr. Chiasson

- › Phone: 902-473-6611

Nurse coordinator

- The nurse coordinator is your first contact person for the Program. They can:
 - › help you learn more about CF.
 - › book your clinic appointments.
 - › plan follow-up treatment after a Clinic visit or a hospital stay.
 - › help you make decisions about your treatment options.
 - › act as your contact between Clinic visits, if you have any concerns.
 - › coordinate your care with the CF health care team.

Sarah Sutherland

- › Phone: 902-473-4147
- › Phone (cell): 902-233-3514
- › Email: sarah.sutherland@nshealth.ca
(if you have signed a consent form to communicate with the Clinic by email)
- **Hours:** 9 a.m. to 5 p.m., Monday to Friday
(closed on holidays)
 - › If there is no answer, please leave a message. We will contact you the same day, unless we are out of the office.

Dietitian

- The dietitian can help you learn how to eat healthy, in the Clinic and in the hospital. They can:
 - › check your weight, eating habits, and vitamin and enzyme use.
 - › help you manage poor appetite, weight loss, heartburn, nausea (feeling sick to your stomach), diarrhea (loose, watery poop), constipation (not being able to poop), enzymes, and diabetes.
 - › help you learn how to plan and prepare meals, and buy groceries on a budget.
 - › help you manage problems related to bone health (like getting enough calcium and vitamin D).
 - › help you learn about G-tubes (gastric feeding tubes), including figuring out your nutrition needs, choosing feeding products, and making a schedule.
- If you have diabetes, your CF team will work with other members of your health care team to monitor your blood sugars and recommend changes to your insulin, as needed.

Carly Nichols

- › Phone: 902-266-5274
- › Email: carly.nichols@nshealth.ca
- Ask the nurse coordinator if you would like to talk with the dietitian.

Physiotherapist (PT)

- The PT can help you in the Clinic or in the hospital. They can:
 - › help you keep your airways clear using breathing techniques, special masks, or other physiotherapy devices.
 - › help you to stay active by teaching you exercises relax, ease back and joint pain, and strengthen your muscles.
- Ask the nurse coordinator if you would like to talk with the PT.

Psychologist

- The psychologist can help you:
 - › Cope with stress
 - › Manage your condition
 - › Find community resources
- Ask the nurse coordinator or call 902-473-2525 to book an appointment with the psychologist.

Social worker

- The social worker can help you become and stay more independent. They can support you if you have:
 - › Changes in your role or lifestyle
 - › Changes in your work or income
 - › Finding programs and services in the community
 - › Finding community services to support special needs
- Ask the nurse coordinator if you would like to talk with a social worker.

CF Clinic

- The CF Clinic is held 1 or 2 times a week (usually on Tuesdays and Fridays).
- The Clinic is on level 4 of the H.I.
 - › Use the Summer Street entrance.
 - › Register at the kiosk, then go directly to the Respirology Clinic.
 - › **Do not wait in the large waiting room.**
- A clinic aide will show you to a room and measure your height and weight.

- The respiratory therapist will check your:
 - › Temperature
 - › Blood pressure
 - › Pulse (heart rate)
 - › Oxygen levels
 - › Breathing rate

They will also get you to do a spirometry test (see page 7) and review your medications.

- You will then see the doctor, the nurse coordinator, and other team members. They will talk with you about your treatment options. Please tell a member of your health care team if you have any questions or concerns. Your health care team will help you make your plan of care.
- All health care team members must wear masks, gloves, and gowns to prevent infection.
- The nurse coordinator will mail you a letter with your follow-up appointment date and any tests you may need.

If you cannot keep your appointment, please call the nurse coordinator as soon as possible to rebook. This allows us to book another patient in your time slot.

› Phone: 902-473-4147

Common tests

Chest X-ray

- An X-ray helps your doctor check how CF is affecting your lungs. This helps them to decide on your treatment. If you need an X-ray:
 1. Pick up the form (called a requisition) at the CF Clinic.
 2. Go to the X-ray Department on level 3 of the H.I.
 - › Hours: 8:30 a.m. to 5 p.m., Monday to Friday (closed on holidays)

Spirometry (pulmonary function) test

- This test measures:
 - › How much air your lungs can breathe out
 - › How fast you can breathe out
- This helps us to check the amount of narrowing in your bronchial tubes (tubes that carry air from your windpipe to your lungs) and other changes in your lungs.

Blood work

- These tests may show:
 - › Your overall health
 - › How well your blood carries oxygen to your tissues
 - › How well your liver and pancreas are working
 - › The amount of salt and minerals in your blood
 - › The amount of nutrients (like protein, carbohydrates, fat, vitamins, and minerals) in your body
 - › Your blood sugar levels:
Depending on the results, you may also need an oral (by mouth) glucose (sugar) tolerance test to check for diabetes.
- The nurse coordinator can do your yearly CF blood work in the Clinic. **If the CF Clinic recommends other blood work:**
 1. Pick up the form at the CF Clinic.
 2. Go to Blood Collection on level 4 of the H.I.

Bone mineral density test

- This test checks the strength of your bones. People with CF often have low bone mineral density.

Medications

If you live in Nova Scotia:

To get your medications at the Metropolitan Dispensary, you can:

- › Pick them up at:
- › IWK Health Centre (South Street entrance), level 1
- › **Hours:** 8:30 a.m. to 4:30 p.m., Monday to Friday (closed on holidays)

or

- › Have them sent to you by courier for a fee.
- There is no fee for your CF medications.
- **Make sure you check the refill information on the bottles.**

Contact the Metropolitan Dispensary if:

- › your prescription has a refill.
- › you need more enzymes or vitamins.
- › Phone: 902-470-8135
- › Email: metro.dispensary@ns.aliantzinc.ca

Call the nurse coordinator if:

- › you need a new prescription.
- › you need a prescription reordered (for example, when the label reads: ‘This is the last refill for this prescription. Please contact your physician.’).
- › Phone: 902-473-4147

- You must reorder your long-term CF medication prescriptions once a year. This can be done when you visit the Clinic.

If you live in New Brunswick or Prince Edward Island (PEI):

- Your medications will be available at your local pharmacy.
- In New Brunswick, you can apply for the Cystic Fibrosis Plan.
- In PEI, you can get some medications from the Provincial Pharmacy for free. **Not all medications are covered by the provincial drug plan.**

Respiratory equipment and supplies

If you live in Nova Scotia:

- Your respiratory equipment and supplies are provided and serviced by the CF Clinic at the IWK Health Centre.
- Call the nurse coordinator to pick up your equipment:
 - › Phone: 902-473-4147

Taking care of your equipment

- You are responsible for keeping your home care equipment clean. Equipment that is not cleaned well and cared for can lead to more respiratory infections.
- Ask the nurse coordinator and respiratory therapist for tips on taking care of your equipment.

Intravenous (I.V.) antibiotics

- You may need a permanent (long-lasting) I.V. access device (called an implanted infusion port or Port-a-Cath®). Ask your doctor and the nurse coordinator for more information.
- You may be able to give yourself I.V. antibiotics at home.

If you live in Nova Scotia:

- There is no cost for the equipment, supplies, or medications.
- You can order equipment and supplies through the nurse coordinator and Home Care Services.
- You can pick up your medications at the Metropolitan Dispensary (see page 9). It may take 2 full weekdays (Monday to Friday) to fill your prescription.

If you live in New Brunswick:

- Your medications are ordered through the Extra-Mural Program. To learn more about the program, visit:
 - › <https://extramuralnb.ca/>
- or**
 - › Scan the QR code on your smartphone (open the camera on your smartphone, point the camera at the code, and tap the banner or border that appears):



If you live in PEI:

- Your medications are available through the Home Care Program. To learn more about the program, visit:
 - › www.princeedwardisland.ca/en/information/health-pe/home-care-program



Hospital stays

- Your doctor may recommend that you stay in the hospital if:
 - › your lung infection makes you very sick. They may send (admit) you right away through the Clinic or the Emergency Department.
 - › you have ongoing problems that mean your infection is getting worse, and antibiotics are not helping. They may admit you for treatment with I.V. antibiotics.
- You will be admitted to a single room at your local hospital.
- You will be cared for by your CF team and other health care providers.
- All health care team members will wear masks, gowns, and gloves to prevent infection.
- The nurse coordinator will visit you to:
 - › talk about any concerns you may have about your treatment.
 - › plan your Clinic follow-up care.

To get the most out of your hospital stay:

- Eat healthy meals at regular times.
- Get enough rest (go to sleep early and have a nap during the day).
- Take part in physiotherapy. The PT will work with you to make a plan.
- Tell a member of your health care if you need something. Ask the nurse coordinator for help, if needed.

What are your questions?

Please ask a member of your health care team. We are here to help you.

**Call 911 or go to the nearest
Emergency Department right away if
you have:**

- › Severe (very bad) symptoms that start suddenly (like a sudden, sharp pain in your chest, fast 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) blood
- › Severe belly pain that does not go away

If you go to the Emergency Department, call the nurse coordinator right away.

- › Phone: 902-473-4147

New treatments

- New treatments for CF are being created all the time. Your health care team will help you learn about these treatments during your Clinic visits or while you are in the hospital. Learning about your treatment options can help you make informed decisions about your care.

Research

- CF research is an important part of improving patient care.
- You may be asked to take part in a CF research project. Whether you take part or not is up to you. **Your choice will not affect your care.**
- Research raises the chance of finding:
 - › New CF medications
 - › New infection medications
 - › Better nutritional therapies
 - › New ways of doing physiotherapy

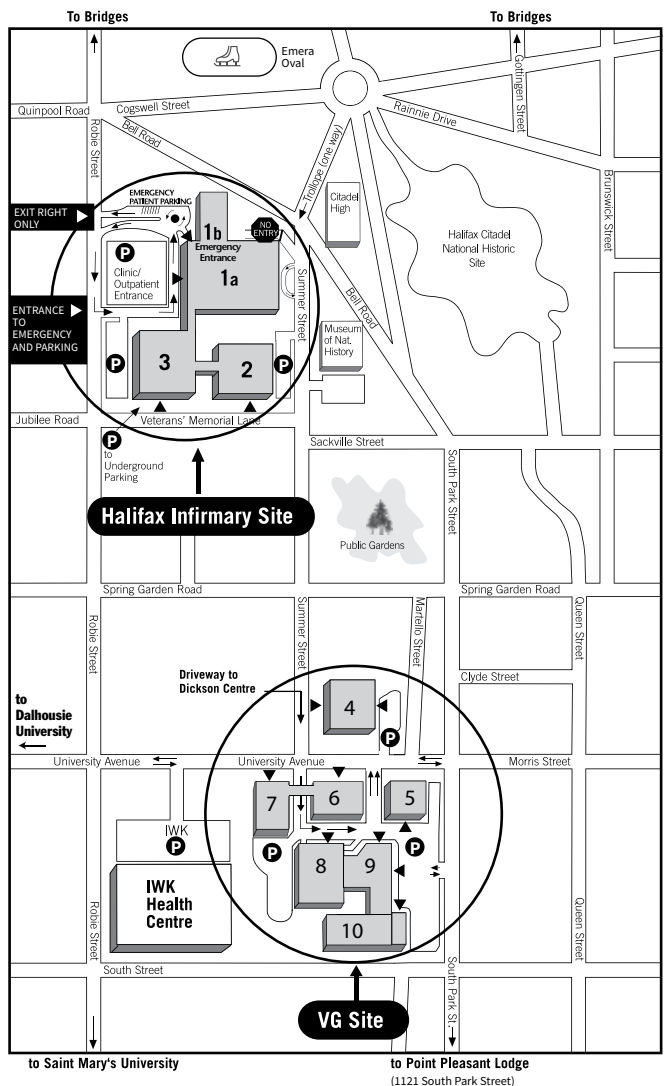
QEII Health Sciences Centre

is made up of 10 buildings located on two sites

- | Halifax Infirmiry Site | |
|------------------------|---------------------------------------|
| 1a. | Halifax Infirmiry |
| 1b. | Emergency Dept. |
| 2. | Abbie J. Lane Memorial Building |
| 3. | Camp Hill Veterans' Memorial Building |
| VG Site | |
| 4. | Nova Scotia Rehabilitation Centre |
| 5. | Bethune Building |
| 6. | Mackenzie Building Laboratories |
| 7. | Centre for Clinical Research |
| 8. | Dickson Building |
| 9. | Victoria Building |
| 10. | Centennial Building |

P Patient Parking
▶ Entrance Doors

Please do not wear scented products when you come to the QEII.



Notes:

This pamphlet is for educational purposes only. It is not intended to replace the advice or professional judgment of a health care provider. The information may not apply to all situations. If you have any questions, please ask your health care provider.

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

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

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