



Patient & Family Guide
2017

The Adult Cystic Fibrosis (CF) Program



www.nshealth.ca

Prepared by QEII CF Team:

Nancy J. Morrison, MD, FRCPC, FCCP

Meredith Chiasson, MD, FRCPC

G. Butler, PhD, R.Psych.

Jane Cowie, MSW

Fran Gosse, RN, BN

Janey Hughes, Pdt, CDE

Krista Almond, BSc, PT

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

Contents

The health care team	1
Clinic doctors	1
Nurse coordinator	2
Nutritionist	3
Physiotherapist	4
Psychologist	5
Social worker	5
The CF Clinic	6
Common tests	7
Chest X-ray	7
Pulmonary function test	7
Blood tests	8
Medications	9
Taking care of your equipment	10
Respiratory equipment and supplies	10
Home IV antibiotics	11
Hospital stay	12
Admission	12
Emergencies	13
Other health care team members	14
Your role	15
Keeping yourself updated	16
Research and you	17
The future	17
QEII map	18

The Adult Cystic Fibrosis (CF) Program

The health care team

Clinic doctors

Dr. Nancy Morrison and Dr. Meredith Chiasson are the doctors who will diagnose and treat you. They work with other members of the health care team as needed and are your main contacts for medical care.

Dr. Chiasson and Dr. Morrison can help you when:

- You need a prescription reordered.
- You have a sudden 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. You can also call Dr. Morrison and Dr. Chiasson at 902-473-4024. When they are not available, the doctor who is on call will help you. You can call 902-473-2220 and ask to speak with the respirologist (lung doctor) on call.

Nurse coordinator

The nurse coordinator is your first contact person for all problems. If they are not available, call the doctors' office directly. The nurse coordinator can help you by:

- Arranging follow-up treatment after acute medical care.
- Arranging follow-up treatment after a Clinic visit.
- Coordinating your CF team.
- Involving you in decisions about your treatment.
- Acting as your point of contact between the inpatient and outpatient setting.
- Helping you learn more about CF.
- Promoting public awareness of CF issues.

You can call the nurse coordinator at 902-473-4147. If there is no answer, you can leave a message or call 902-473-2220 and ask to have 2129 paged.

Nutritionist

The nutritionist can help you achieve and maintain good nutrition both in the Clinic and in the hospital. Some of the ways the nutritionist can help are:

- Checking your weight, diet history and vitamin, mineral and enzyme use.
- Counselling you about:
 - › Nutrition problems such as weight loss, poor appetite, heartburn, nausea (feeling sick to your stomach), diarrhea, constipation, enzymes, diabetes
 - › Planning and preparing meals, grocery shopping on a budget
 - › Bone health
 - › G-tubes (gastric feeding tubes)
- Planning and monitoring your nutritional care while you are in the hospital.
- Helping you choose the right nutritional supplements, and finding where to buy them and how to take them.

The nutritionist can be reached at 902-473-2300 or through the nurse coordinator.

Physiotherapist

The physiotherapist can help you keep your airways clear and stay active through exercise. In addition to in-hospital care, the physiotherapist can also help you in the clinic setting:

- To learn how to keep your airways clear using breathing techniques, a PEP mask and Flutter (a device to help you clear your airways yourself).
- By teaching you exercise programs for back and joint pain, muscle strengthening, and relaxation techniques.

The physiotherapist can be reached at 902-473-3578 or through the nurse coordinator.

**What are your questions?
Please ask. We are here to help you.**

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 talk about these services during your Clinic visit with Dr. Chiasson or Dr. Morrison.

Social worker

The social worker is your link to getting and staying independent in society. 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.
- Education services and advocacy of special needs.

The social worker may be reached through the nurse coordinator or by calling 902-473-4074.

The CF Clinic

The CF Clinic is held every week (except during the month of 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.

There is information about CF in the Clinic waiting area. Please take a copy and ask any questions you have when you see the CF team.

The Clinic aide will take you into a room. The respiratory therapist will take your temperature, pulse, breathing rate, height and weight, as well as spirometry (measuring the air going in and out of your lungs). Your medications will be checked over with you at this time.

Next, you will see the doctor, the nurse coordinator, and other team members. After your exam, staff will talk about treatment options with you. You will have the chance to express any of your concerns. Your individual plan of care will be developed by you and your health care team.

You will be mailed a return appointment card by the nurse coordinator. This will remind you of your next Clinic visit and any scheduled tests.

If you cannot keep your Clinic appointment, please call the booking clerk at 902-473-4194 as soon as possible to set up another time.

Common tests

Chest X-ray

With the help of an X-ray, the doctor can visually check your lungs. The X-ray allows for a more accurate assessment of the disease. More information will help to make treatment decisions. If you need an X-ray, you can pick up the requisition form in the Clinic and go to level 300 of the Halifax Infirmary. The department hours for X-rays are 8:30 a.m.–4:30 p.m. (weekdays). They are closed on holidays.

Pulmonary function test

This test measures how much air your lungs can hold and breathe out. It also measures how fast you breathe out. This information gives an indirect measure of the amount of narrowing in the bronchial tubes. This test helps to show changes in the lungs and helps us make decisions about treatment.

Blood tests

Blood tests give information that helps pinpoint and treat problems before they get really bad. Some things that these tests show include:

- Your general health and natural ability to fight off infection.
- How well your blood can carry oxygen to tissues.
- How well your liver and pancreas work.
- Salt and mineral amounts in your blood.
- Nutrition levels.
- Blood sugar levels. An oral glucose tolerance test may be used to screen for diabetes.

If you need blood tests, you can pick up the requisition forms in the Clinic, then go to Blood Collection on the 4th floor of the Halifax Infirmary.

A bone mineral density test may be needed to check the strength of your bones. CF patients often have low bone mineral density, so it is important to do this test.

Medications

The medications that you take at home are free of charge. They are available from the Metropolitan Dispensary, IWK Health Centre.

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’).

The Dispensary is open from 8:30 a.m.–4:30 p.m. on weekdays, except holidays. You may pick up your medications on the 1st floor of the IWK Health Centre, Outpatients Department, or they can be sent by courier to you for a fee.

Medications will not be left for pick up at the IWK Health Centre’s Emergency Department.

Taking care of your equipment

As an adult, you are responsible for keeping your home care equipment clean.

Improperly cleaned and maintained equipment can lead to more respiratory infections.

For tips on how to take care of your equipment, please speak with the nurse coordinator and respiratory therapist when you are at the Clinic.

Respiratory equipment and supplies

Your respiratory equipment and supplies are dispensed and serviced from the IWK Health Centre, CF Clinic.

Contact your 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 or supplies or medications. The equipment or supplies are arranged through Home Care Services and the nurse coordinator. The medications are provided through the Metropolitan Dispensary. It may take 2 full weekdays for the Metropolitan Dispensary to fill your IV antibiotic prescription.

Home visit follow-up arrangements are usually made through VON. Please note that there may be a fee for this service.

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

The doctor may recommend that you be admitted to the hospital when:

- Your lung infection makes you sick and you can't do your usual activities. The doctor may decide to admit you right away through the Clinic or Emergency Department.
- You have had ongoing problems which show that your chronic infection is getting worse. 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 (8.2, 8.3 or 8.4).

Emergencies

Go to the Emergency Department if you have:

- Pneumothorax (air leaking from the lung into the chest cavity). This happens in about 20% of adult CF patients. Symptoms may include a sudden sharp pain in the side, rapid breathing with shortness of breath, feelings of restlessness and anxiety, or muscular strain in the chest and neck when breathing.
- Large amounts (more than a few streaks) of blood in the 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 do go to the Emergency Department, please call and leave a message with the nurse coordinator.

Other health care team members

When in the hospital, you will get care from the CF team and other health care providers. These include the respirologist, infectious disease doctor, intern or resident doctor, and other consult services.

The nurse coordinator will visit you to talk about any concerns you may have about treatment and to plan your Clinic follow up.

This pamphlet is just a guide. If you have questions, please talk to your health care provider. We are here to help you.

Your role

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

- Eating healthy, especially when you are sick. Eating well-balanced meals at regular times is very important.
- Getting enough rest. Try to get a good night's sleep, as well as 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 with hospital staff. Sometimes it is hard to tell hospital staff about your needs. The nurse coordinator can help you with this.

Keeping yourself updated

New therapies for cystic fibrosis 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.

Keeping yourself updated can be done during your Clinic visits or while you are a patient in the hospital.

A free adult CF newsletter is available to all adults with CF. It is published twice a year by Cystic Fibrosis Canada.

You can get on the mailing list by writing to:

Circle of Friends

c/o Cystic Fibrosis Canada
2323 Young Street, Suite #800
Toronto, Ontario M4P 2C9

Phone: 416-485-9149

Toll-free: 1-800-378-2233

Fax: 416-485-0960 or 416-485-5707

www.cysticfibrosis.ca

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 your decision.

The future

Ongoing research increases the possibility of new options in CF care.

These options may include:

- › New medications to treat infections
- › Improved nutritional therapies
- › New methods of physiotherapy
- › New medications to treat the underlying basic defect of CF

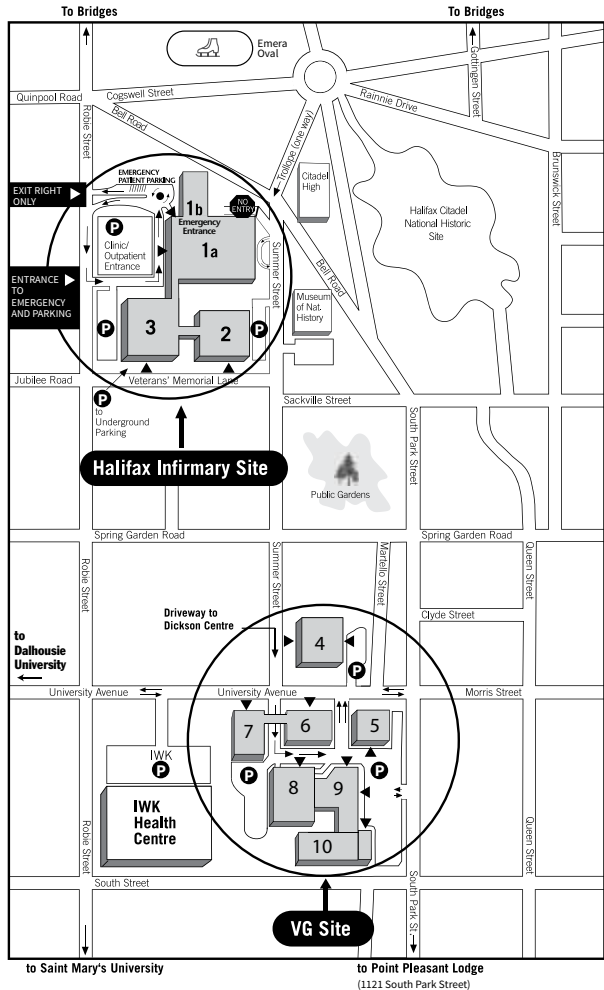
QEII Health Sciences Centre

is made up of 10 buildings located on two sites

- | Halifax Infirmary Site |
|--|
| <ol style="list-style-type: none"> 1a. Halifax Infirmary 1b. Emergency Dept. 2. Abbie J. Lane Memorial Building 3. Camp Hill Veterans' Memorial Building |
| VG Site |
| <ol style="list-style-type: none"> 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.



Prin A504 Rev. 02/2016

Looking for more health information?

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

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

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

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

Please do not use perfumed products. Thank you!

Nova Scotia Health Authority

www.nshealth.ca

Prepared by: The Adult Cystic Fibrosis Program at the QEII ©

Designed by: NSHA Library Services

The information in this brochure is for informational and educational purposes only.

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.

WF85-0611 Updated May 2017

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