



Taking charge of your health



A guide for teens with Cystic Fibrosis
to plan the transition to adult care

Taking charge of your health

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Taking charge of your health

Your guide to a smooth transition from pediatric to adult care

When you think about transition what comes to mind? 'Change' is likely the first word that you think of.

Your teenage years are filled with change. As you grow up, you learn how to do new things and get better at what you have already learned. You make more of your own decisions as you take on more responsibility. Learning life skills and becoming independent happens slowly, over time.

Your health care needs change too. Gradually, you will say goodbye to your health care team at McMaster Children's Hospital and start to see the team that takes care of adults.

You, your family and your health care team share the responsibility for making your transition to adult care as smooth as possible. We will work together.

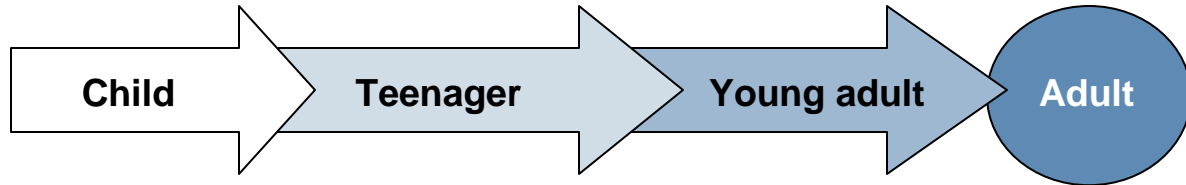
Your health care team will help by:

- ✓ telling you what to expect
- ✓ helping you make plans, set goals and learn what you need to do
- ✓ making the change gradual, not sudden
- ✓ supporting you along the way

This book can guide you through this process. We hope you find it helpful as you prepare for adult life with cystic fibrosis.

Growing up with Cystic Fibrosis

As you grow up, you become independent by gradually taking on more responsibility for your actions and choices in life. This includes the things that you do for your health.



As a child, your parents and the health care team took care of you.

During your teenage years, parents and the health care team help you learn what you need to know and do to take care of yourself.

You gradually take on more responsibility for your care.

As a young adult, you will transfer from McMaster Children's Hospital to the adult CF Clinic.

As an adult, you are responsible for yourself, including the care you need for cystic fibrosis.

Becoming an adult means learning to:

- ✓ take responsibility for yourself and your actions
- ✓ be as healthy and fit and as possible
- ✓ manage your own health care

This is more challenging when you have Cystic Fibrosis. There is a lot to learn about managing your health care. For example, learning to do physiotherapy and take enzymes.

It's best to take it one step at a time. Turn to the next page to see how you can get started.

How do I get started?

1. Put a checkmark beside the things that your family does to help you stay healthy.
 - remind me to do my physiotherapy
 - remind me to take my enzymes
 - schedule appointments with my doctors
 - take me to my doctors' appointments
 - come into the clinic examination room with me
 - answer the questions the doctor asks
 - tell the doctor how am I feeling
 - order my medications
2. Now, review the list again and think of at least ONE thing that YOU could take responsibility for before your next clinic visit.
3. Let your parents know that you would like to take responsibility for this.
4. Follow through!



Staff will review this list with you at your clinic visits. We will encourage you and your family to have you assume more responsibility for your medical care.

The goal is for you to be able to do ALL these tasks by the time you have your first appointment in the adult CF clinic.

Meeting with the CF Team on your own

One step towards adult care is spending part of each clinic visit meeting with the CF team on your own.

- ✓ This gives you the chance to ask questions that you may feel too uncomfortable to ask in front of your parents. It's OK to write down questions for the doctor if you are too embarrassed to ask.
- ✓ This shows your parents that you are maturing and taking more responsibility for your health.



Want to do things on your own or with friends?
Like going to the mall, a school trip or a sleepover?

Your parents are more likely to give you more privileges when you demonstrate that you are more responsible.

One way to do this is to show your parents that you are willing and capable of managing your health needs on your own.

Tools for transition

As you grow and get ready for adult care, you may find out checklists helpful. Use them as often as you like. You can get more copies from the CF team.

Information about Cystic Fibrosis

- Fill out the checklist on page 31 to let us know what topics you would like more information about.

Learning to live with Cystic Fibrosis

- Fill out the checklist on page 33 to see how ready you are to take charge of your health.

Talking about CF

You may find it hard to talk about having cystic fibrosis. You may worry that others will think you aren't normal or will treat you differently.

Talking about CF may help your friends understand you better. It is likely that most of them will be supportive. A few may not know how to deal with it at first, but it is up to you to educate them. Remember that this is not a reflection on you, but on their ability to handle a new situation.

You don't need to explain CF to everyone. It would be helpful for your close friends to know. This will help them understand why you need to spend time doing physiotherapy, taking pills and eating snacks etc.

When and how?



When and how you tell others about your CF is up to you. However, it's a good idea to have an honest answer ready for when a friend asks about your health.

For example, you could say: "I inherited a disease called cystic fibrosis. It can cause some problems with my lungs and digestive system. Don't worry, you can't catch it."

If you wish, briefly explain your treatments and how they help. Be prepared for questions, as most people know very little about CF.

If you cough a lot, you may want to reassure others that you are not spreading an infection. You could say: "I'm coughing because I have a chronic lung problem [or a medical condition]. You can't catch it." Don't feel that you need to tell them you have CF unless you feel comfortable doing so.

Sexuality

Sexuality is a normal, healthy part of your life. Your sexuality includes:

- how you feel about yourself and your body
- wanting to be intimate with someone
- sexual feelings
- sexual activity
- protecting yourself and your partner during sexual activity
- your desire and ability to have children in the future

Many teens are uncomfortable bringing up the topic of sexuality. But it is important to learn about sexuality and CF, and get your questions answered.

This section of your binder provides general information. If you have any questions, please feel free to ask us. You can have a private talk with a CF team member at any time.

Telling someone special that you have CF



It is up to you if and when you discuss your CF with someone you are dating.

Talking about it will become more important as you become more committed to a relationship.

Your partner may be understanding and supportive. This can bring you closer together.

It is also possible that your partner may find it hard to cope with your illness, perhaps because he or she is afraid of losing you one day.

Deciding when to have sex

Deciding on the right time to have sex is difficult for all teenagers. Some teens feel pressured to have sex before they are ready. Deciding when you are ready to have sex is a mature choice to make.



It is important to decide when sex is right for YOU.

Having CF does not affect your desire to have sex. If you are thinking about having sex, consider how you are going to:

- be responsible for your sexual feelings
- do what is right for you and your partner

Here are things to talk about with your partner:



Safe sex

- Infections can be passed from person to person during any type of sexual activity. These are called sexually transmitted infections or STIs.
- Examples of STIs are HPV, Herpes, Chlamydia and HIV (AIDS).
- To reduce the risk, use a male or female condom every time you have sex. Use a condom or dental dam for protection during oral sex.

Birth control

- Heterosexual couples who don't wish to get pregnant need to decide on a method of birth control – and have it ready before they have sex.

How does CF affect fertility?

It's important to be aware of how CF can affect reproduction. CF affects guys and girls differently.

Information for guys



CF doesn't affect your sex drive or your ability to have sex, but it does affect your ability to make a baby. As many as 95% of men with CF are infertile.

Your testicles make sperm, but the tube that carries sperm from your testicles to your penis may be blocked or missing. So there may be no sperm in your semen when you ejaculate.

A simple test of your semen can tell if you are infertile (no sperm are found). Until you know for sure, use birth control to prevent an unwanted pregnancy. Condoms are a good choice as they also protect you from STIs.

When you wish to start a family, talk with your CF doctor. Becoming a dad may be possible by:

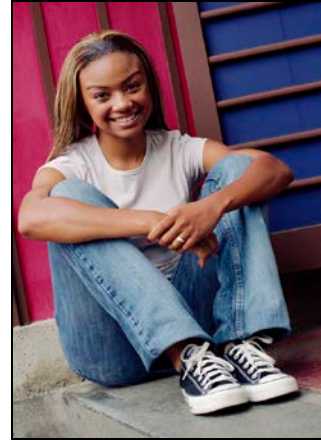
- adopting a child
- having a procedure to take sperm from your testicles (which can be used to fertilize an egg)

Information for girls

If you are generally healthy, having CF may not affect your fertility.

If you do not wish to become pregnant, talk with your family doctor about birth control. Choose a method that is right for you.

- Condoms are a good choice to protect you from STIs, but aren't the most effective way to prevent pregnancy.
- Birth control pills (oral contraceptives) are very effective in preventing pregnancy. 'The pill' is safe to take with enzymes for CF.



If you decide to take birth control pills, your family doctor can give you a prescription. Some antibiotics make birth control pills less effective. When you need to take antibiotics, discuss this with your doctor. You may need to use another method of birth control as well as the pill.

When you wish to start a family, talk with your CF doctor. It is best to plan ahead. Pregnancy can seriously affect your health even if your lung disease is mild. Your doctor will discuss what this means for you.

Smoking, drinking and taking drugs

What are the risks?

All teens have heard the warnings about smoking, drinking and taking drugs. So why do some teens do this?

- To have fun?
- To be like their friends?
- To cope with stress?

Each person decides what's best for himself or herself, by weighing the pros (benefits) and cons (risks).

Give this important decision a lot of thought.



To make your decision:

- Learn how smoke, alcohol and drugs can affect your health. The risks are greater for someone with CF. This part of your binder gives you basic information about this.
- Consider how you can have fun, stay positive and cope with stress without harming your health.

As part of your care, we will ask you about your choices. We hope you will feel free to talk openly with us. We will respect your privacy if you don't want to share this information with anyone else.

Smoking

Cigarette, cigar and marijuana smoke is harmful to your lungs. It doesn't matter whether you are smoking or breathing in someone else's smoke.

Some teens may think smoking isn't that harmful. Perhaps because the damage happens slowly, over time. They don't get sick right away. But you could. Lung damage from smoke appears sooner and more often in people with CF.

You can do your body a big favour by not smoking.

If you smoke



Do you tell people that you don't smoke and hide when you do? You're not alone. Many teens secretly smoke.

Please be honest with us about your smoking. We won't give you a lecture. We just want to know so that we can give you the best possible care.

Do you want to quit? It can be hard to break the habit, but you can get help. Talk to your family doctor or a member of your CF team. To learn more go to the 'Quit 4 Life' website. <http://www.quit4life.com/>

Drinking

You will probably be offered alcohol long before you're legally old enough to drink it. What will your decision be? Are you going to drink, how often and how much?

Becoming an adult means learning to drink responsibly, meaning:

- drinking alcohol in moderation
- never driving if you've been drinking

Moderation means drinking a reasonable amount, not too much. What is reasonable when you have CF?

We recommend little or no alcohol.

Even a small amount of alcohol can stop antibiotics and other medications from working properly. Alcohol also hurts your liver, which is already damaged by CF.



If you drink alcohol

Consider where and why you drink. In those situations, could you drink something other than alcohol? Could you drink less, less often?

If you can't seem to control or stop drinking, you may need some help. Talk with your family doctor or a member of your CF team.

Taking drugs

You may have spent a lot of time in school learning about “drugs” and the harmful effects they have on your body and mind.

When people talk about drugs they usually refer to illegal substances like marijuana or cocaine. But they aren't the only drugs that can make you high. Some teens inhale chemicals or misuse prescription medications like painkillers. These are just as harmful.

Taking drugs is risky for everyone, but the risks to someone with CF could be more serious. Drugs also change the way you think, feel and behave. If you're high, you may not take care of yourself or your CF.

If you are using drugs

Do your own research. What's in the drugs you use? Are they safe? How are drugs affecting your life? What would happen if you were caught?

If you are concerned about your use of drugs or medications, talk with your family doctor or a member of the CF team. Please don't feel defensive or embarrassed. We can connect you to effective treatment programs and helpful resources.

Smoking, drinking and taking drugs are risky behaviours.

They can affect:

- your breathing
- your appetite and weight
- how well your liver works
- your moods
- the effectiveness of your medications

Becoming dependent can spin your life out of control and affect your family and other relationships.

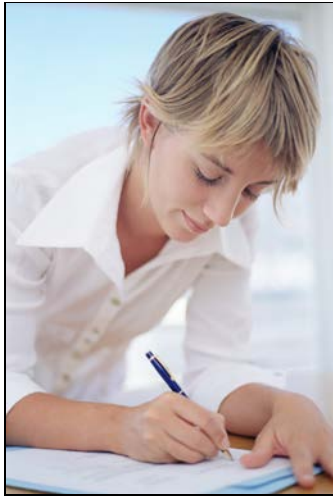
Can you afford the risk?



Going to college or university

If you are planning to go to college or university, you will be asked to select schools early in your last year of high school. Your decision will be based on your choice of program and what each school has to offer. Having CF means you will also have to consider how easily you can get to classes.

Scholarships



Check the websites of your chosen schools for their scholarships and bursaries.

As a student with CF, you may also be eligible for additional financial support, scholarships or bursaries. Here are some websites to check:

- Canadian Cystic Fibrosis Foundation:
www.cysticfibrosis.ca
- KIN Canada Bursaries
<https://www.kinCanada.ca/bursaries>
or call 1-800-742-5546
- yconic www.studentawards.com

Living away from home

To gain more independence, you may want to move away from home and try living on your own. This is an exciting time of life, but you can also expect some struggles and uncertainty.

It is important to be prepared, should you become ill. Make sure your roommate and close friends:

- ✓ are aware that you have CF
- ✓ know what to do if you get sick
- ✓ know how to get emergency medical help

Wanting some distance from parents and siblings is a normal part of growing up. As you become more independent of your family, you start to rely more on your friends for emotional support.



Good health is vital for someone with CF.

When you are away at school you will start to be responsible for your own health.

Here are some things you can do:

- Prepare your own medications and do your physiotherapy without being reminded by others.
- Make your own appointments at the CF Clinic.
- Have at least some of your clinic visit by yourself or go to your appointments on your own.
- If you feel unwell between visits, call the CF Clinic to discuss your condition and decide whether you need to see the doctor.

These are important steps in your transition to adult care.



**Helpful
tips!**

Tell your parents what you are doing to manage your health at school.

This is reassuring and helps them accept that you are a responsible and independent young adult.

Transition isn't always easy

Life at your new school can be fun as well as a lot of work. Your life may be so busy that you become distracted from your CF treatment and care. And when you meet new friends, you may be reluctant to talk about your CF.



This may be why some teens with CF go through a period where they stop going to the clinic, taking medication and doing treatments. It seems like they are pretending that they don't have CF.

But this does not stop the damaging effects of CF and many of them become ill. They return to the clinic expecting that the damage can be undone. Unfortunately for many teens, the damage cannot be reversed.

The only way to slow the effects of CF is by taking care of your health.

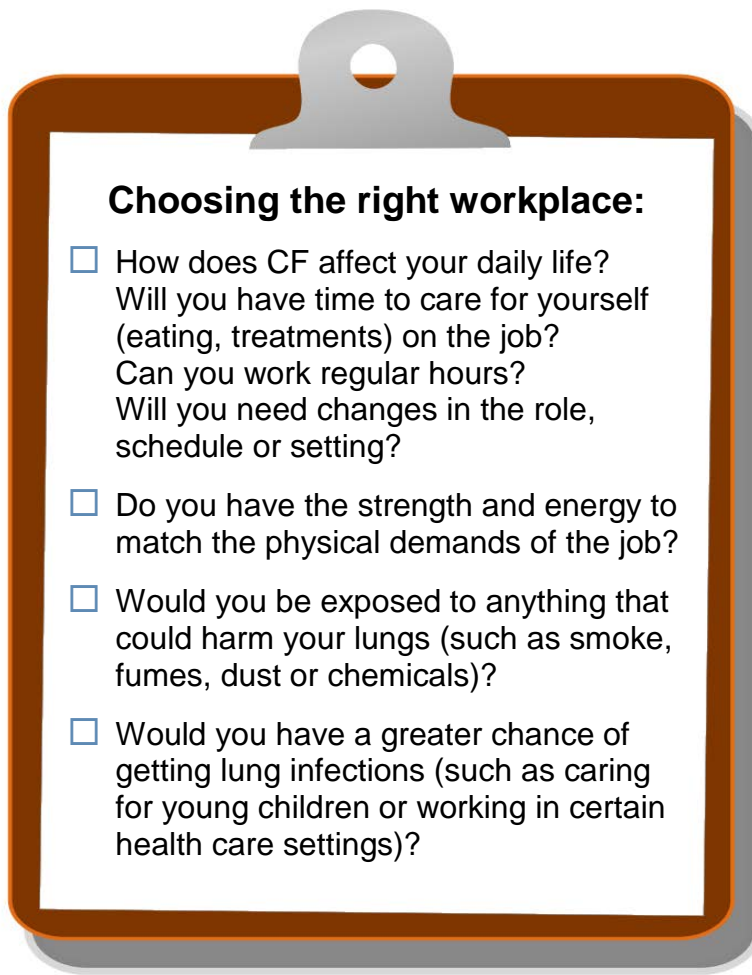
Planning a job or career

Working for a living may seem a long way off, but you can think about what you might like to do.

You may want to start with a part-time job to earn extra money or save for college or university. Working helps you become more independent and may also help in making career choices.

Having CF does not limit your choices for employment. To decide on a job or career in the future, think about:

- your interests and talents
- your abilities and skills
- your life goals



Do I have to mention my CF at a job interview?

By law, an employer is not entitled to know the details of your medical history. In an interview, he or she cannot ask specific questions about your health.



An employer can only ask questions about the position you're applying for, such as:

- Are there any life circumstances that might prevent you from fulfilling the requirements of the job?
- Do you foresee any problems with attendance?

If you are reasonably sure that your CF won't prevent you from showing up and doing your job, there is no reason to mention CF when you answer these questions. The decision to hire you is based on your ability to do the job, not your diagnosis.

What about when I'm offered a job?

If CF will affect your work in any way, it is best to discuss this with your employer before you accept a job offer. Tell the employer about CF, your treatments and how they help. Talk about the physical tasks required in the job, the hours, and benefits (including sick time). Together you can decide if changes to the role, surroundings or schedule are needed and possible. The employer has a duty to accommodate your needs, unless this causes undue hardship.

If you don't expect CF will affect your job, you don't need to tell your employer that you have CF. Emphasize that you are the right person for the job!



Once you are working, you can decide if, how and when to tell your employer and coworkers about your CF. It may be easier to discuss CF once you have had a chance to prove yourself on the job and know your coworkers better.

Paying for your medications

Medications are necessary for you to live well with CF. As a child your medications may have been paid for by your parents' insurance plans or the Ontario Special Drug Program.

When you turn 18, coverage under your parents' plans may only continue if you are in school full-time. All coverage will likely end when you are 21 or 25.

You are responsible for having insurance coverage for your medications when your parents' plans run out.

Explore your options

Start early, long before your parents' coverage ends. Finding, applying and getting approval for insurance coverage can take several months.

Questions to guide your search:

- Am I eligible?
- Will all my medications be covered?
- Is there a deductible or co-payment?

Many drug plans require a deductible or co-payment. This means you will pay a small part of the costs.

Here are some options for drug coverage:

Special Drug Program

- Offered by the Ontario Ministry of Health and Long-Term Care.
- Covers the full costs of certain CF medications.
- Call: 416-212-4724
- E-mail: PublicDrugPrgrms.moh@ontario.ca
- Web: www.health.gov.on.ca/en/public/programs/drugs/programs/sdp.aspx

Trillium Drug Program

- Helps people who cannot afford their medications.
- May cover newer medications not covered by the Special Drugs Program.
- Call: 1-800-575-5386
- E-mail: trillium@resolve.com
- Web: www.health.gov.on.ca/en/public/programs/drugs/programs/odb/opdp_trillium.aspx

Ontario Drug Benefit (ODB) Program

- Offered to people on social assistance, those registered in the Trillium Drug Program and receiving professional home care services, and others.
- Covers most of the cost of the prescription medications listed in its Formulary.
- Web: www.health.gov.on.ca/en/public/programs/drugs/programs/odb/odb.aspx
- For medications not in the Formulary, the Exceptional Access Program may help: www.health.gov.on.ca/en/pro/programs/drugs/eap_mn.aspx

Employee benefits

- If you are working, your employee health plan may include prescription drug benefits.

Private insurance

- If you are not covered by a company plan, you may buy prescription drug benefits from a private insurance company such as Ontario Blue Cross or Green Shield Canada.

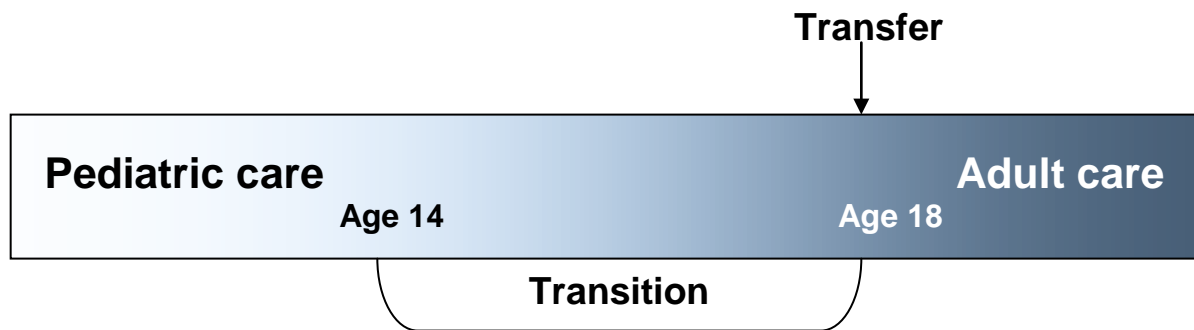
What if I have questions or need help?

- Your CF team can give you more information and help you find options for drug coverage. If you have questions, please speak with the Social Worker.
- Your local pharmacist can give you information about provincial drug plans.
- Visit the Cystic Fibrosis Canada website: www.cysticfibrosis.ca

Your transfer to adult care

In your early teen years, you started to learn how to take care of yourself. Over the next few years you gradually took more responsibility for your health. This process is called **transition**. It is part of growing up – just like going to a new school or starting a job.

At around 18, most teens are ready to say goodbye to McMaster Children's Hospital. They **transfer** to the adult CF clinic where they begin taking charge of their health. The exact time of the transfer varies from person to person.



It is normal to feel uneasy about going to the adult CF Clinic. You may have come to our clinic and seen the same health care team for a long time. We know each other well and you're used to our routines.

Please let us reassure you. We will work with you, your family and the adult CF team to make this move as smooth as possible.



Fill out the “Learning to live with Cystic Fibrosis” checklist to reassure yourself that you are ready for adult care.

Your care at the Adult CF Clinic

The Adult Cystic Fibrosis Clinic is in the Boris Clinic (4th floor, yellow section) at McMaster University Medical Centre.

This is in the same building as McMaster Children's Hospital.

Patient and family centred care

- Care in the adult CF clinic is patient and family centred. This means that the health care providers will work closely with you to determine your health needs, and plan care to meet your needs.
- You and your family are important members of the health care team. You can decide who is important to you and should be included in your care.
- The health care team will give you information and support to help you make your own healthcare decisions and take part in your care.
- Your personal information will be kept private and confidential. Without your permission, we will not discuss your health with anyone else, including your parents.
- Please feel free to ask questions and discuss your concerns at any time. If you have trouble adjusting or following your adult treatment plan, please talk with your doctor.

At the Adult CF Clinic, you are in charge of your health

You are responsible for:

- ✓ sharing information about your health
- ✓ taking part in planning your care
- ✓ asking questions
- ✓ expressing your needs, preferences and concerns
- ✓ booking and keeping your appointments
- ✓ calling the clinic to cancel or change an appointment

Your health care team

You will meet new health care providers at the adult clinic. They are specially trained to care for adults with CF.

At your first appointment, you will meet each member of the team. At follow-up visits you will see the clinic doctor and nurse. Please ask if you would like to speak with other team members.

The health care providers on your team	
Dr. Andreas Freitag Clinic Director	<ul style="list-style-type: none">• Dr. Freitag is responsible for your medical care. You will see him at every appointment.
Kelly Campbell Registered Nurse	<ul style="list-style-type: none">• Kelly is the clinic nurse. You will see her at every appointment.• To reach Kelly, call 905-521-2100, ext 75711.
Suzanne Hansen Registered Dietitian	<ul style="list-style-type: none">• Suzanne is available when you need information or help with your diet, enzymes and supplements.• To reach Suzanne, call 905-521-2100, ext 75476.
Barb Pollock Physiotherapist	<ul style="list-style-type: none">• Barb is available if you have questions or concerns about chest physio or your equipment.• To reach Barb, call 905-521-2100, ext. 76549
Social Worker	<ul style="list-style-type: none">• A social worker can help you cope with managing CF, and connect you with community resources or financial help.• The clinic does not have a social worker, but we can arrange an appointment for you.

Your appointments



Please come to the clinic 30 to 45 minutes before your scheduled appointment and check in at the desk.

Arrive early to have time for Spirometry before your appointment. Your spirometry appointment will take 15 to 30 minutes.

- Appointments are on Wednesday afternoons from 1 to 4 p.m. If you have MRSA or cepacia, you will be given one of the last appointments of the day.
- Regular appointments, about every 3 months, are an important part your CF care. You are welcome to bring someone with you to your appointments.
- If you need to cancel or change an appointment, call 905-521-5051.

Your medications

To reorder medications, please call 905-521-2100 ext 75019 at least 1 week before your clinic visit. This gives the pharmacy time to prepare the medications and have them ready for you at your clinic visit.

Managing your CF health needs

To help you manage your CF health needs, you will have regular visits with the CF health care team. You will also need tests each year such as:

- blood tests
- chest x-ray
- exercise test
- bone density test
- oral glucose tolerance test
- other tests as needed



For questions or appointments, call the Adult CF Clinic at 905-521-2100, ext 75711.

Information

Here's what I want to know more about:

Health information about:

- CF websites
 - Nutrition
 - Sexuality
 - Fertility
 - Preventing infections
 - Genetic counseling and testing
 - Lung transplantation
 - Adult CF clinic and routines
 - Financial help
 - Insurance
 - Disclosing CF
 - Disability Rights
 - Employment
 - Education
 - Advanced directives
 - Mental health and services that are available
 - Medication coverage
 - Other:
-

**Give your completed checklist to a member of the clinic.
We will help you get the information you have requested.**

Learning to live with cystic fibrosis

A checklist for teens, 14 to 18 yrs

Please fill out this checklist

- We will review it together during your clinic visits.
- Your responses will help us know how we can help you take charge of your own health.

Use this scale to rate each statement:

0 = Does not apply
1 = Never
2 = Sometimes
3 = Often
4 = Always

Knowledge of Cystic Fibrosis	0	1	2	3	4	Comments
I can describe what cystic fibrosis is.						
I can describe the symptoms of cystic fibrosis.						
I know the 'warning signs' that indicate I should call the doctor.						
I know how enzymes work.						
I know how to prevent lung infections.						
I know how CF and diabetes are related.						
I know how BMI and FEV1 are related.						
I know some basic facts about lung transplants.						
I know where and how to get more information about CF, when needed.						

Taking care of my health	0	1	2	3	4	Comments
I can describe my daily care routine.						
I take charge of my daily health care without reminders.						
I help my parents remember my daily care routine.						
I get my own prescriptions filled.						
I know the names of my medications.						
I know what each medication is for.						
I know how to take my medications (how much to take, when to take).						
I take my medications as directed, without reminders.						

Use this scale to rate each statement:

0 = Does not apply, 1 = Never, 2 = Sometimes, 3 = Often, 4 = Always

Managing my health care	0	1	2	3	4	Comments
I know my health care providers and how to contact them, if needed.						
I can answer my health care providers' questions myself.						
I can ask questions of my health care providers and tell them what I need.						
I spent some time alone with my health care providers at each appointment.						
I schedule my own appointments.						
I keep a record of my appointments, tests and medications.						
I call the clinic to report symptoms or changes in my health.						
I know the phone numbers to call for emergency medical help.						

Healthy living	0	1	2	3	4	Comments
I know what and how much to eat and drink to be healthy.						
I get regular physical activity.						
I get enough sleep.						
I know how smoking, alcohol and drug use can harm my health.						
I have friends that support me and I see them regularly.						
I am realistic about my health.						

Use this scale to rate each statement:

0 = Does not apply, 1 = Never, 2 = Sometimes, 3 = Often, 4 = Always

My mental health	0	1	2	3	4	Comments
I enjoy my life and generally have a positive outlook.						
I know when I feel stressed out, nervous, angry or down.						
I talk over my problems with people I trust, when needed.						
I know when and how to ask for help from health professionals.						
I have considered the risks and benefits of discussing my health with others.						

My sexual health	0	1	2	3	4	Comments
I know about sex and reproduction.						
I know how to prevent an unplanned pregnancy.						
I know how to prevent sexually transmitted infections.						
I know how cystic fibrosis may affect my fertility.						

My financial health	0	1	2	3	4	Comments
I know the length of my insurance coverage under my family's plan.						
I know where and how to access programs for financial help (ODSP, Trillium).						
I have a bank account and manage my own money.						

Use this scale to rate each statement:

0 = Does not apply, 1 = Never, 2 = Sometimes, 3 = Often, 4 = Always

Planning for the future	0	1	2	3	4	Comments
I have ideas of what I'd like to do after high school.						
I have plans for college, university or getting a job.						
I know how to look for a job.						
I know how to apply for college or university.						
I know who to ask for help with career planning.						

My health care as an adult	0	1	2	3	4	Comments
I know the kinds of health care providers I will need as an adult.						
I understand what genetic counseling is.						
I know where the adult CF Clinic is.						
I know where adults with CF stay in the hospital.						

