



CYSTIC FIBROSIS:

Your guide to transitioning from paediatric to adult care

This cover artwork by Jane Dunne and inside cover by Trinity Cooligan is dedicated in memory of Meaghan Addante, an adult with CF and member of the Adult Cystic Fibrosis Advisory Committee, who sadly passed away in 2021. Meaghan was a fierce fundraiser and advocate for people with cystic fibrosis, she had a creative spirit and was passionate about this project to better support those going through the challenging transition from paediatric to adult CF care.



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INTRODUCTION

This document was developed by Cystic Fibrosis Canada's Adult Cystic Fibrosis Advisory Committee after many young adults with CF in Canada identified that transitioning from Paediatric CF Clinic to Adult CF Clinic and stepping into adulthood can be a very challenging and overwhelming time.

The hope is that this guide can be used to help you transition to adult care in the easiest way possible. The guide is meant to be a go-to resource to help you keep track of your important CF clinic information in one place for quick and easy reference. The checklists and fill-in-the-blank sections are to help guide you to think about some of the important things that you will need to know as you take on your own care.

CYSTIC FIBROSIS CLINIC TEAM

Use this chart to keep track of clinician names and how they support you in the clinic:

MY CF TEAM	
CLINICIAN ROLE AND NAME	OVERVIEW OF THEIR ROLE IN THE CF CLINIC
CF Physician Name:	Doctor with expertise in CF
CF Nurse Name:	Nurse Clinician dedicated to providing support for all aspects of health care needs.
Dietitian Name:	Specialized to provide support for optimal nutrition for people with CF and diabetic needs.
Physiotherapist Name:	Expertise in exercise and airway clearance.
Pharmacist Name:	Dedicate to facilitating access to the best possible individualized drug and antibiotic therapy.
Social Worker Name:	Knowledgeable about financial and community resources, can provide support through life challenges.
Respiratory Therapist/Technician Name:	Facilitate pulmonary function testing.
Psychiatrist/Psychologist Name:	Expertise in mental health, chronic disease and sleep.
Administration Support Name:	Schedules CF clinics and helps coordinate tests.
Genetic Counselor Name:	Available to answer questions regarding genetic testing, family history and family planning.

Use this chart to keep track of your other healthcare providers and important people in your healthcare. Examples: Homecare, Drug Access Navigator, Endocrinologist, ENT, Metabolic Team, etc.

OTHER HEALTHCARE PROVIDERS

HEALTHCARE PROVIDER	OVERVIEW
Specialty: Name: Contact Information:	How they support me: Frequency of appointments: How are appointments booked:
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Specialty: Name: Contact Information:	How they support me: Frequency of appointments: How are appointments booked:
Specialty: Name: Contact Information:	How they support me: Frequency of appointments: How are appointments booked:

IMPORTANT CONTACT INFORMATION

CF CLINIC CONTACT INFORMATION

OFFICE HOURS

Monday – Friday:
Days that CF Clinic runs:

PHONE NUMBERS

CF Clinic Phone Number (during office hours):
Hospital Phone Number:
Phone number for after-hours/emergency:
Any other important phone numbers:

CLINIC LOCATION

CF Clinic Address:
Closest Parking Lot:

CLINIC EMAIL

WEBSITES

CF Clinic Website:
Hospital Website:

OTHER IMPORTANT CONTACT INFORMATION

THINGS TO THINK ABOUT BEFORE AND DURING YOUR FIRST ADULT CF CLINIC APPOINTMENT

THINGS TO THINK ABOUT BEFORE YOUR FIRST CLINIC VISIT:

- How am I going to get to my appointment?
- How long can I anticipate being there?
- Do I need to take time off school or work? Do I need a letter for my absence to attend this appointment?
- Do I have any specific questions or concerns?
- Do I have any barriers that may make attending clinic appointments challenging (transportation, expenses, other)?
- Do I have any thoughts or ideas for what kind of clinic support I would benefit from the most?
- Do I need support to help explain CF to others around me (school life, work life, personal life)?
- Are there any specific policies on mask wearing or infection prevention and control that I need to know before going to my first appointment?

THINGS TO ASK MY CF CLINIC DURING THE APPOINTMENT:

CF clinic logistics in general:

1. How will all clinic appointments be completed? All in person? Telehealth/phone options?
2. Are lab tests performed as a part of clinic days or can they be done at home or locally (i.e. lung function tests, bloodwork, diagnostic imaging)?
3. How and when will your next appointment be scheduled? What frequency can I anticipate being seen?
4. What do I do if I need to be seen before my next scheduled appointment?
5. What else does my Clinic do for infection prevention and control?
6. What do I do if I am feeling sick between clinic visits?
7. What are the reasons that I should call the CF Clinic between clinic visits?
8. What happens if I have to go to the Emergency Department and what should I bring with me?

Questions specific to me:

1. How do I access medical equipment or devices that I might need?
2. How does the clinic address pulmonary exacerbations? When would I need home IVs vs. hospitalization?
3. What do I need to know about my medical insurance and prescription coverage?

THINGS TO BRING TO YOUR CF CLINIC APPOINTMENT:

1. Drug coverage cards
2. Healthcare card and photo ID
3. List of questions/concerns to share with your team
4. Chest physiotherapy device
5. A support person, should you wish to bring a family member or friend
6. Pen/paper/electronic device to take notes
7. Detailed medication list with start dates for each medication
 1. What needs to be refilled
 2. What medications were added/changed recently
 3. Any known drug allergies
8. Glucometer and/or blood sugar log (if diabetic)
9. Water or snacks
10. Enzymes, insulin or other medications that will be needed during the clinic time
11. Book or other entertainment
12. Anything else _____

INFECTION PREVENTION AND CONTROL - BASICS

DID YOU KNOW?

People with cystic fibrosis (CF) should not be around other people with CF. This is to prevent the spread of lung infections from one person to another. Simply put, there are bacteria in the environment that don't affect people without CF, but that can have serious, potentially fatal, effects on those who do have CF – and these bacteria can spread between people with CF.

WHY DO PEOPLE WITH CF HAVE LUNG INFECTIONS?

CF causes thick, sticky mucus in the lungs, which encourages bacterial growth. People with CF have chronic lung infections with different types of bacteria. Once a person with CF becomes infected with a particular type of bacteria, it can be difficult or impossible to get rid of, due to their compromised immune system. Lung infection flare-ups are a leading cause of illness and death in people with CF.

HOW COULD INFECTIONS SPREAD AMONG PEOPLE WITH CF?

When people with CF get too close to each other, bacteria from one person's lungs can spread through droplet transmission (from things such as coughing, sneezing, etc) to another person. This can cause the spread of infections, which can lead to lung damage and death.

HOW MUCH DISTANCE SHOULD PEOPLE WITH CF KEEP FROM OTHERS WITH CF?

People with CF should stay at least 6 feet away from other people with CF at all times. This reduces the chances that harmful bacteria will spread from one person with CF to another.

HOW MANY PEOPLE WITH CF CAN BE AT AN EVENT?

Infection Prevention and Control Guidelines for CF state that only one person with CF shall attend indoor events. For outdoor events – where air circulation is assumed to be better – the recommendation is that people with CF maintain a distance of at least 6 feet from other people with CF at all times.

DO THESE GUIDELINES APPLY TO SOMEONE WHO HAS HAD A LUNG TRANSPLANT?

Yes. Individuals with CF may continue to carry potentially dangerous bacteria within their upper airways following transplantation and can pass these infections on to other people with CF. In addition, transplant recipients have a suppressed immune system, which puts them at risk of becoming infected from others with CF. Therefore, to reduce person-to-person spread of infections, Cystic Fibrosis Canada recommends that all individuals with CF follow the infection prevention and control guidelines.

WHERE CAN I FIND MORE INFORMATION?

For a copy of the full Infection Prevention and Control Guideline for Cystic Fibrosis and further information, please visit: <https://www.cysticfibrosis.ca/about-cf/living-with-cystic-fibrosis/infection-prevention-and-control>

MY PHARMACY INFORMATION

MY PHARMACY INFORMATION

SPECIALTY PHARMACY INFORMATION

List of medications that need to be filled here:

Phone Number:

Address:

Hours:

How to order and receive:

How much notice do they need?

Do they offer delivery?

Anything else important to know?

REGULAR/LOCAL PHARMACY INFORMATION

List of medications that need to be filled here:

Phone Number:

Address:

Hours:

How to order and receive:

How much notice do they need?

Do they offer delivery?

Anything else important to know?

MEDICATION COVERAGE

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 their parents, spouse, or through their work. Many parental plans cover people up until the age of 25 or when they are finished school. The coverage of medications may be complete or there may be a deductible (e.g., 80 % of the cost of the medication is covered).

IMPORTANT INSURANCE COVERAGE TO CONSIDER

- Do you currently have coverage? If so:
 - Is this provided through:
 - Your parent(s)/guardian(s) plan?
 - What age does your coverage go to if you are still covered under your parents'/guardians' insurance plan?
 - Are you still covered by your parents' insurance plan if you are in post-secondary education?
 - What happens if my address changes?
 - A Post-Secondary Education plan?
 - Both?
 - Does your current plan(s) provide 100% coverage of medications, or is there a deductible and/or co-pay?
 - What happens if I change jobs or get married?
 - Does my insurance plan have a lifetime max?
- Does the province I live in have special medication coverage?
 - What are the eligibility requirements for provincial insurance?
 - How and when should I apply for coverage under the provincial insurance plan?
- If I switch insurance plans, is there a wait period before medication coverage commences? If so, how do I ensure that I have no break in coverage between my current plan and the plan I am switching to (i.e. do I need to stock up on medications)?
- Do some of my prescriptions need special authorization? How long will approvals typically take?

***Please see the next page for a sheet to keep track of your health insurance information.**

MY MEDICATION COVERAGE

MY HEALTH INSURANCE INFORMATION

PRIMARY HEALTH INSURANCE COVERAGE

Company:

Plan number:

Through my parents/post-secondary/other:

Prescription drug coverage:

Medical device coverage:

Copays/deductible:

Lifetime maximum:

Other coverage important information:

SECONDARY HEALTH INSURANCE COVERAGE

Company:

Plan number:

Through my parents/post-secondary/other:

Prescription drug coverage:

Medical device coverage:

Copays/deductible:

Lifetime maximum:

Other coverage important information:

POST-SECONDARY EDUCATION CONSIDERATIONS

SCHOOL ACCOMMODATIONS/SUPPORTS

Most post-secondary institutions will have services for students in order to make education accessible for a variety of needs. These services may be available to you as either a prospective student or as an enrolled student.

Student Success Department: (*may go by an alternative name depending on the post-secondary school*). Advisors can review your medically-documented needs and provide guidance and support the implementation of accommodations to support you. Consider having documentation from your CF clinic ready to present to your Advisor.

It is best to meet with an advisor prior to the beginning of your program to allow time to arrange for and implement any necessary accommodations.

COMMON CF CONCERNS AT POST-SECONDARY EDUCATION:

- Needing time off classes for CF clinics or other specialist appointments
- Unplanned absences for hospitalization
- Need to access food/medications/IV pumps/etc during classes and/or exams
 - Depending on the exam, you may need to have your doctor complete a specific accommodations form prior to the exam
- Private space for treatments while on campus
- Avoidance of specific tasks or environments (i.e. microbiology labs)
- Deferment if you cannot finish your semester

COUNSELING SERVICES AND HEALTH INSURANCE

Most post-secondary institutions offer counseling services when you are a student. Connect with your Student Services to find out more.

Most post-secondary institutions offer the choice of student insurance packages, included in tuition fees, with the option to opt-out if you already have existing coverage (ie. under parents'/guardians' insurance). Proof of insurance is required to opt out of the plan. You may wish to contact the Student Union or Association as they usually oversee the insurance plans.

Please refer to the [Cystic Fibrosis Resource Guide](#) for more details.

PLANNING FOR POST-SECONDARY EDUCATION IN A CITY OUTSIDE YOUR NORMAL CLINIC

Below are important considerations when you are going to be attending school outside of where you live now:

- Connect with the CF Clinic closest to where you will be attending post-secondary school to see about becoming a patient
- Ensure you have your medications required for your semester at school and that you know where/how to get refills of your medications if required
- Evaluate whether you will need to change your provincial and/or private health insurance, particularly if you are moving out of province

POST SECONDARY SCHOOL SCHOLARSHIPS

There are many educational scholarships available to people with CF. The link below highlights financial support opportunities for Canadians in the CF community seeking higher education:

<https://www.cysticfibrosis.ca/blog/higher-education-financial-support-opportunities-for-the-cf-community-3/>

FOR MORE QUESTIONS OR SUPPORT

Please reach out to your CF team or Social Worker for more information or for support.

CF AND EMPLOYMENT

DISCLOSING YOUR CF TO YOUR EMPLOYER

Disclosing your CF to your current or prospective employer is a complex and personal decision.

In Canada, you are not legally required to disclose your health to your employer as long as you are able to perform the essential duties of your job without accommodations and your health does not pose a safety concern to yourself or others. However, if you require work accommodations in order to do your job, you will need to tell your employer that you have a health condition and name your work restrictions. An employer does not have the right to ask or know your specific diagnosis or treatments, just what the functional implications are for your ability to perform your job.

There are many different times you may consider disclosing your CF, including:

- On your cover letter or resume
- In an interview
- Upon a job offer
- Any time while you are hired and working

Regardless of when you choose to disclose (or if you choose to disclose at all), it can be helpful to rehearse what you plan to say to your employer. Your CF Team can help you with this.

Some helpful resources about disclosure:

Tips about Disclosure:

<https://discoverability.network/wp-content/uploads/2020/07/DCOI-handout-Tips-about-Disclosure-General.pdf>

Disclosing Your Disability:

<https://disabilityalliancebc.org/wp-content/uploads/2017/06/DisclosureGuide.pdf>

DUTY TO ACCOMMODATE

You have the right to ask for accommodations in the workplace to help you do your job the best you can. It is your responsibility to tell your employer if you need an accommodation.

It is always helpful to come to your employer with specific accommodations that would help you and to work with your employer to make sure that the accommodations are reasonable and possible within your job and work environment.

All Canadian employers are legally required to accommodate the needs of employees with disabilities, up to the point of “undue hardship.” This is called “duty to accommodate” and comes from the Canadian Human Rights Act. See here for more details: http://publications.gc.ca/collections/collection_2013/ccdp-chrc/HR21-80-2006-eng.pdf

Some examples of work accommodations that might enable you to stay at work while also keeping on top of your CF may include:

- Flexible work hours. For example:
 - A later start time to give you extra time in the morning to complete your medication routine)
 - An extended lunch break to give you time to complete midday medications if needed
- Access to a private room to complete treatments during the working day
- Time off for CF Clinic, home-IVs, or hospitalization
- The ability to work from home (some of the time or all of the time)
- Not being required to complete work tasks that are higher-risk for infection
 - For example, if you work in healthcare, avoiding working with patients with acute respiratory illnesses
- Having somewhere to safely store your medications
- Back-up plan to manage unexpected extended absences

LEAVING THE WORKPLACE

Sometimes your CF may cause you to stop working either for a while or forever. This is a very complex decision to make. If you do decide that you need to stop working, please reach out to your CF Team **before** you discuss this with your employer. They can help you understand benefits and funding options (such as sick leave, short-term disability, long-term disability, Employment Insurance (EI) sickness benefits, Canada Pension Plan – Disability, etc).

RETURNING TO EMPLOYMENT AFTER A MEDICAL LEAVE

Sometimes after taking a leave from work, your CF symptoms will stabilize, which can let permit you to go back to work. Returning to work can be gradual and may include new accommodations to your job duties or work schedule. Please reach out to your CF Team for

guidance on returning to work to make sure your return to work is successful, lasts, and does not make your CF symptoms worse.

SELF-MANAGEMENT TOOLS

STRATEGIES TO KEEP TRACK OF YOUR APPOINTMENTS

- Use the “Calendar” app on your smartphone to keep track of appointments.
 - Set multiple alerts to remind you of upcoming appointments (example: one week prior to appointment and the day before the appointment)
 - Share your calendar with a support person to help you keep track
- Use a monthly calendar to write down all of your appointments, hang it in a central location
- Ask your CF Clinic whether they can offer you reminder phone calls or emails for upcoming appointments

STRATEGIES TO KEEP TRACK OF YOUR HEALTH CARE PROVIDERS

- Use our template to create a list of CF Clinic contact numbers and hang in a central location (example: on your fridge)
- Keep a list of who each healthcare provider is within your CF Clinic and how to contact them if needed
- Create a bookmark for your CF Clinic’s website on your phone or computer
- Program CF Clinic phone numbers directly in your phone
- Ensure that others close to you are aware of where to find the CF Clinic contact information should they need to call for you

STRATEGIES TO KEEP TRACK OF AND REMEMBER TO DO YOUR MEDICATIONS

- Keep your own list of medications, doses and special instructions
 - Paper list (ask your CF Clinic for a copy of your medication list or use the template in this guide)
 - List on your smartphone
 - List saved in your email
- Use reminders to help cue you to remember to take medications or complete chest physiotherapy
 - Daily alarms in your smartphone
 - Medication management apps (there are many to choose from!)

- Post-it notes in frequently viewed areas (example: on fridge, on bathroom mirror)
- Use a daily checklist to keep track of completed medications (use the template in this guide)
- Acquire accessories that can help you keep track of your medication usage. Most can be easily purchased online. For example:
 - Use medication dosettes/pill organization boxes to organize your oral medications for various times of the day and for each day of the week.
 - Ask your pharmacy about bubble packaging your medications (note: there is often a fee for this).
 - Use “pill timer caps” for pill bottles if you have a hard time remembering the last time you took a medication
 - Pill boxes with built-in alarms
 - If using insulin, acquire a timer that can clip to your insulin pen (there are several options) to easily remember the last time you took your dose so you don’t second-guess whether you took your last insulin shot or not
- Use reminders in your phone to refill pharmacy prescriptions

HELPFUL TOOLS FOR LEAVING THE HOUSE

- Travel pack and cooler for fridge medications
- Consider acquiring a medical alert bracelet
- Small pill containers or pill dosettes for easy transport of oral medications
- Create a “Take with you” checklist to help you remember all things you need to bring with you before leaving (example: enzymes, insulin, water, etc). Hang on your door in a visible place for a quick reminder as you leave.
 - Use the template in this guide
- Create a “Medication/Medical Devices Packing List” to help you when you are packing for overnight trips or vacations.
 - Use the template in this guide to get you started
 - Keep it on your computer and print out a copy for crossing off items as you pack them for each trip
 - For a reusable version, laminate and use a dry-erase marker
 - Create a list on your smartphone
- Travel Health Insurance that will cover you for travel outside of Canada
- Travel letter for medications and medical devices
- Health information kept with travel companion

PREPARING FOR CLINIC VISITS

- Bring a list of written questions that you may have.
- Use the “notes” feature on your smartphone
- Carry a small note pad that you can easily transport with you for questions that quickly come to mind and you want to remember

STRATEGIES FOR MANAGING DAY-TO-DAY LIFE WITH CF

- Become good at time management to fit everything in
 - Learn how long your morning and evening medication routines take so you can plan accordingly
 - Day timers or agendas can help to manage medications and other roles/responsibilities on a daily basis
 - Use weekly and monthly calendars to pace yourself through other responsibilities
 - Use the weekly planner and medication tracking template
- Track how you feel on a daily basis to identify trends (example: 1 - 10 scale completed every day)

PLANNING SHEETS TO MANAGE IT ALL

On the following pages you will find a variety of helpful tools and planning sheets that can help you to keep track of important medical details and can help to keep you organized so that you can best manage your CF.

IN CASE OF EMERGENCY

BASIC INFORMATION

Name:

Birthdate:

Healthcare number:

EMERGENCY CONTACT #1

Name:

Relationship:

Contact information:

EMERGENCY CONTACT #2

Name:

Relationship:

Contact information:

HEALTH CONDITIONS

MAIN DOCTOR INFORMATION

Name:

Hospital:

Contact information:

WEEKLY PLANNER

M	<p style="text-align: right;">MEDS DONE? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>DINNER:</p>	<p>TO-DO LIST & REMINDERS</p>
T	<p style="text-align: right;">MEDS DONE? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>DINNER:</p>	
W	<p style="text-align: right;">MEDS DONE? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>DINNER:</p>	
T	<p style="text-align: right;">MEDS DONE? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>DINNER:</p>	
F	<p style="text-align: right;">MEDS DONE? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>DINNER:</p>	
S	<p style="text-align: right;">MEDS DONE? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>DINNER:</p>	
S	<p style="text-align: right;">MEDS DONE? <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>DINNER:</p>	

THINGS TO BRING WITH ME WHEN I LEAVE THE HOUSE

Wallet	<input type="checkbox"/>
Keys	<input type="checkbox"/>
Enzymes	<input type="checkbox"/>
Other medications:	<input type="checkbox"/>
	<input type="checkbox"/>

PACKING LIST: MEDICATIONS AND DEVICES

Oral pills	<input type="checkbox"/>
Inhaled medications	<input type="checkbox"/>
Cooler for medications	<input type="checkbox"/>
Ice pack	<input type="checkbox"/>
Chest physio device	<input type="checkbox"/>
Nebulizer	<input type="checkbox"/>
Medication list	<input type="checkbox"/>
Travel letter from CF Clinic	<input type="checkbox"/>
	<input type="checkbox"/>