CFRI Cystic Fibrosis Research Institute
RESEARCH · EDUCATION · ADVOCACY · SUPPORT

SELF-ADVOCACY TOOLKIT:

EMPOWERMENT TIPS FOR YOUR CF JOURNEY

About the Cystic Fibrosis Research Institute & Advocacy

The Cystic Fibrosis Research Institute (CFRI) is a 501(c)(3) dedicated to enhancing quality of life for the cystic fibrosis (CF) community. CFRI's mission is to be a global resource for the CF community while pursuing a cure through research, education, advocacy, and support.

CFRI's advocacy efforts focus on educating and engaging those impacted by CF, care providers, the general public, and lawmakers. We aim to broaden understanding of the challenges faced by the CF community and identify solutions to promote equity, access to therapies and care, and enhanced quality of life for all.

CFRI's advocacy and awareness programs aim to:

- Build and strengthen coalitions of regional, state, and national CF and rare disease agencies and community members
- Educate the CF community, care providers, the general public, and lawmakers
- Track national and state legislation important to those with CF and CFRI as an organization
- Serve as a trusted resource to decision makers throughout the nation's federal and state legislative, executive, and administrative bodies

About This Resource

CFRI believes that everyone can be an advocate. This self-advocacy toolkit is designed to empower individuals with CF by supporting informed decision-making and providing tools to confidently speak up for your needs, or advocate for others. This toolkit was reviewed with input by CFRI's CF Adult Advisory Committee and Diversity and Inclusion Advisory Committee.

For more information about CFRI's advocacy efforts, visit www.cfri.org/advocacy. For more information about how to engage in legislative advocacy efforts impacting the CF and rare disease communities, explore CFRI's Advocacy Toolkit located at www.cfri.org/resources-reports.

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Patient Rights

KNOW WHAT YOU ARE ENTITLED TO AS A PATIENT

As a patient, you have rights when it comes to your medical treatment and protection of personal health information. The Patients' Bill of Rights, created in 1997, is federally mandated legislation, which guides healthcare treatment in the United States.

I. INFORMATION DISCLOSURE: You have the right to receive accurate, easily understood information to help you make informed decisions about your health plans, professionals, and facilities.

II. CHOICE OF PROVIDERS & PLANS: You have the right to a choice of healthcare providers that is sufficient to ensure access to appropriate high-quality healthcare.

III. ACCESS TO EMERGENCY SERVICES: You have the right to access emergency healthcare services when and where the need arises. Coverage of emergency department services are available without authorization if you have reason to believe your life is in danger or you would be seriously injured or disabled without immediate care.

IV. PARTICIPATION IN TREATMENT DECISIONS: You have the right and responsibility to fully participate in all decisions related to your healthcare. People who are unable to fully participate in treatment decisions have the right to be represented by parents, guardians, family members, or other conservators.

V. RESPECT & NONDISCRIMINATION: You have the right to considerate, respectful care from all members of the healthcare system at all times and under all circumstances. You are not allowed to be discriminated against in the delivery of healthcare services.

VI. CONFIDENTIALITY OF HEALTH INFORMATION: You have the right to communicate with healthcare providers in confidence and to have the confidentiality of your individually identifiable health care information protected.

VII. COMPLAINTS & APPEALS: You have the right to a fair and efficient process for resolving differences with your health plans, healthcare providers, and the institutions that serve them, including a rigorous system of internal review and an independent system of external review.

Read more about the Patients' Bill of Rights at: https://cfri.tiny.us/wdy8jpzb

Effective Dialogue

Healthcare treatment goes beyond medical procedures and treatment plans. A positive relationship with your care team also promotes wellbeing and improved health outcomes by reducing stress in the clinical setting, fostering opportunities for collaboration or clarification, and the creation of holistic treatment goals that speak to you as a multifaceted person. Explore the tips below to improve communication with members of your care team.

DON'T BE AFRAID TO OVERSHARE

Doctors appointments can be short and your list of concerns or questions can be long. Be descriptive with your words, consider showing your care team photos or physically demonstrating particular concerns. Be honest and don't let embarrassment get in the way of having your healthcare needs addressed.

MAKE REQUESTS IF THEY AREN'T OFFERED

If a provider does not offer a referral that you deem necessary to your physical or mental wellbeing, ask again or seek a second opinion. As a patient, you are entitled to treatment options. Just make sure you consider your insurance coverage in the process.

REMAIN RESPECTFUL

Respect lies at the center of comfort and care. While appointments can be filled with anxiety, frustration or anger, remaining considerate can help foster positive outcomes. If a provider isn't taking your feelings seriously, it's okay to say 'I'm not sure you heard how concerned I am about this.'

ASK QUESTIONS

If you don't understand something a provider has told you, do not remain silent out of embarrassment or fear of seeking clarification. It's okay to say, 'I'm not following what you said,' or 'Can you explain that again?' It's better to ask questions in person than try to follow-up later with different providers.

ASK FOR ACCOMODATIONS

If you require a translator, interpreter, or advocate do not hesitate to request one. If you know this is something you will need, consider calling ahead to have one arranged prior to your arrival. Don't let providers rush or force you into completing an appointment without the supports you need.

Clinic Visit Checklist ✓

CONSIDERATIONS FOR
AN EMPOWERED VISIT

DATE: **PROVIDER:**

BEFORE YOUR VISIT

☐ Ensure you have the most up-to-date list of your medications, noting any current side effects or changes since your last clinic visit.

☐ Consider any questions you have for your provider, and ideally write them down; sometimes the pace of activities at clinic appointments can distract you from asking for needed information.

☐ Contact your provider's office to confirm the appointment, making sure to ask about specific requirements or needed preparations (i.e. ensuring the medical team has received the latest lab results).

☐ ____________________

DURING YOUR VISIT

☐ Request appropriate resources and supports, such as a translator, printed materials, or an advocate, to ensure comfort and accessibility.

☐ Keep track of information shared during the appointment through a medium that works best for you; consider taking notes or audio recording.

☐ Discuss recommendations with your provider, asking follow-up questions and expressing any concerns you have about your healthcare regimen.

☐ ____________________

AFTER YOUR VISIT

☐ Follow-up on referrals made by your care team. Do not feel like you are nagging them if you repeatedly have to ask for timely follow-up.

☐ Keep a log tracking your health if any changes were made to your treatment regimen. Take a look at the next page for an example.

☐ If you receive a medical bill that doesn't seem to match your insurance policy, contact your care team's social worker and request assistance.

☐ ____________________

Accomodations

A SUCCESSFUL VISIT STARTS BY HAVING YOUR NEEDS MET

The Americans with Disabilities Act (ADA) is federal legislation that requires healthcare organizations to provide full and equal access to people with disabilities.

Under the ADA, healthcare providers must offer accommodations through:

- Reasonable modifications of policies, practices & procedures
- Effective communication
- Accessible facilities

EXAMPLE OF ACCOMMODATIONS

- Language interpreters, including ASL
- Wheelchair access
- Written explanations/instructions
- Large print materials or braille
- Appointment reminders
- Service animals
- Longer appointment times
- Accessible exam tables
- Sensory requests (light, sound, etc.)
- Breaks
- Telephone calls instead of emails (or vice versa)
- Requesting forms prior to your visit
- Verbal descriptions of visual aids

STEPS TO TAKE

✓ Contact your provider’s office or speak with a clinic social worker. If possible, make the request before the appointment and in writing so you have a record of the interaction.

✓ If your request is denied, ask for clarification of the denial in writing. Seek support from your clinic’s social worker in appealing the denial.

✓ If the issue remains unresolved, reach out to your healthcare system’s Patient Experience Department or Patient Advocate. You can also contact state or local agencies, such as your State Department of Health.

✓ If all other avenues are exhausted, you may file a formal complaint with the US Department of Justice Civil Rights Division, either online or by mail.
Visit: https://www.ada.gov/file-a-complaint/

Symptoms Log

KEEPING TRACK OF YOUR SYMPTOMS BETWEEN VISITS

A symptom tracker can be a useful tool when speaking with your provider, as it offers an organized overview of your health. A log of symptoms can also reduce the likelihood of medical gaslighting—a practice where providers dismiss a patient's concerns and symptoms, making the patient question their own experiences.

Always consult with a healthcare provider as symptoms occur; this tracker is meant to be a tool or example, and not to be used in place of seeking medical care.

	SUN	MON	TUE	WED	THUR	FRI	SAT
FATIGUE/LOW ENERGY							
FEVER							
PAINFUL COUGHING							
SINUS PRESSURE/PAIN							
JOINT PAIN/STIFFNESS							
TROUBLE BREATHING							
BLURRY/DOUBLE VISION							
PAIN IN EYES							
SWELLING							
HEARING LOSS/RINGING							
POOR APPETITE							
DIZZINESS/FAINTING							
ABDOMINAL PAIN							
VOMITING							

Symptoms Log

KEEPING TRACK OF YOUR SYMPTOMS BETWEEN VISITS

	SUN	MON	TUE	WED	THUR	FRI	SAT
NAUSEA							
DIARRHEA							
CONSTIPATION							
BLOOD IN URINE/STOOL							
BLOATING							
INCONTINENCE							
HEADACHES/MIGRAINES							
INCREASED PHLEGM							
TINGLING IN LIMBS							
ITCHING							
INSOMNIA							
MOOD SWINGS							
ANXIETY							
DEPRESSION							
CONFUSION							
OTHER							

Building Your Network

THE POWER OF CONNECTION

Finding a community—people you trust and share common ground with—is a vital part of healing and wellness. Community offers a space where knowledge is shared and gained, leading to increased confidence when speaking with healthcare providers, better preparation for medical appointments, and more creative problem-solving around health concerns.

CFRI offers year-round opportunities to connect with others affected by CF—whether you're living with CF or supporting someone who is. You can also learn from leading experts in the field. Explore the CFRI-funded programs below and click on the headings to find ways to engage and learn more about living with CF.

⟶ **National CF Education Conference:** Attend lectures by CFRI-funded researchers, medical providers, social workers, people with CF, and family members. Meet fellow members of the CF community. Visit: https://cfri.tiny.us/CFRI-Conference-2023

⟶ **Retreats for Adults with CF:** Created to enhance education, positive coping skills, and social support for people who share the common experiences with CF. Spend time together in person or virtually for a weekend of educaiton, fund, and community. Visit: https://cfri.tiny.us/yckvwwrc

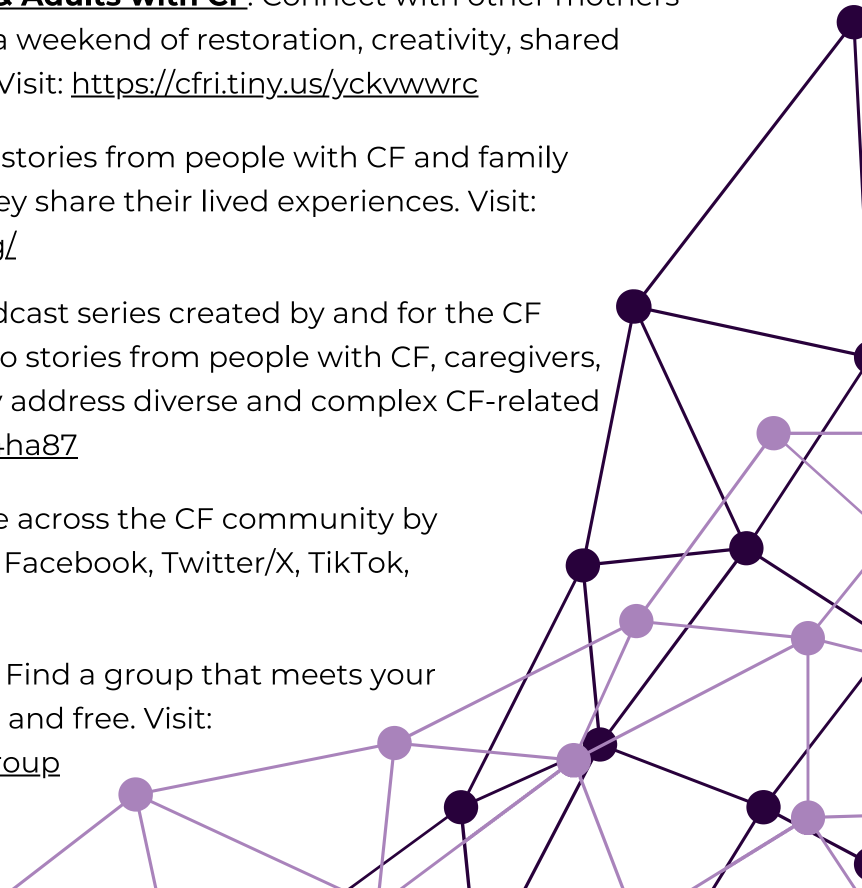
⟶ **Retreat for Mothers of Children & Adults with CF**: Connect with other mothers whose children have CF through a weekend of restoration, creativity, shared resources, and collective healing. Visit: https://cfri.tiny.us/yckvwwrc

⟶ **Community Blog:** Read personal stories from people with CF and family members of people with CF as they share their lived experiences. Visit: https://www.cfri.org/about-cf/blog/

⟶ **CF Community Voices:** Video podcast series created by and for the CF community. Watch and/or listen to stories from people with CF, caregivers, researchers, and providers as they address diverse and complex CF-related topic. Visit: https://cfri.tiny.us/2p84ha87

⟶ **Social Media:** Engage with people across the CF community by following CFRI's many Instagram, Facebook, Twitter/X, TikTok, LinkedIn, or Bluesky accounts.

⟶ **Support and Discussion Groups:** Find a group that meets your needs; monthly groups are virtual and free. Visit: https://cfri.tiny.us/CFRI-SupportGroup



Medical Records

ACCESS TO YOUR PERSONAL INFORMATION

As a patient, you have the right to request access to your medical records. Under the Health Insurance Portability and Accountability Act (HIPAA)—federal standards dictating how a patient's health information is protected—individuals have the right to the information found in their personal 'designated record set.' This information includes:

- Medical records and billing records;
- Enrollment, payment, claims adjudication, and case or medical management record systems; and/or
- Other records that are used by or for the covered entity to make decisions about individuals.

Learn more about your rights under HIPAA at https://cfri.tiny.us/mrxfu9ck

Individuals should note that while federal laws exist regarding a patient's right to their personal health information, state law regarding access, retention, and how providers handle medical record requests may vary. Laws regarding requests for medical records may also vary based on provider. For example, your primary care provider may have different obligations than a therapist.

For more information about variation by state, visit https://cfri.tiny.us/jzvhdeuy

Not sure where to start? Approach your provider directly. Likely, you will be directed towards someone in administration who will ask that you fill out paperwork documenting your request for medical records.

Under HIPAA you have the right to get a copy of your health information.

You cannot be refused access to your health information because you haven't paid your health care bill.

You have the right to have your health information sent to anyone you want.

Providers are no longer responsible for the security of your health information after it is sent to a third party.

Clinical Trial Participation

TRIAL

HOW TO GET INVOLVED

What is a clinical trial?

Clinical trials are research studies that bring together doctors, scientists, and patients. They help determine whether a treatment, drug, or device is safe and effective. People often join these studies in the later stages of research. For those with CF, clinical trials may test new treatments like modulators, antibiotics, anti-inflammatory drugs, or digestive supplements. By participating, you play a vital role in moving medical research forward!

Different ways to participate:

- Engaging as a trial participant
- Providing data to researchers post-trial by participating in follow-up studies
- Asking that samples or tissues that would normally be discarded (e.g., nasal polyps post-surgery) be saved
- Enter a study that uses any of your samples or tissues
- Volunteer to be an advisor during the design
- Participating in surveys and focus groups aimed at collecting patient perspectives
- Participating in a follow-up study (phase 4). Note, that people can join studies at any stage of research (phases 1-4)
- Advocating for the continued awareness, recruitment, and funding of trials
- Assisting a friend of family member through the clinical trials process (driving, checking in on them, being a translator, etc.)

Interested in participating in a clinical trial? Talk to your providers and explore online search engines like the ones below.

- ClinicalTrials.gov
- CFF Clinical Trials Finder (https://apps.cff.org/trials/finder/)

Clinical Trial Considerations

ASKING THE RIGHT QUESTIONS

Consider asking the following questions when determining clinical trial participation.

Trial & Participation Details:
- What is the purpose of the trial? Is it testing a new medicine, treatment, device, or therapy?
- How long will the trial last?
- Have many visits or tests are needed during the trial experience?
- Is travel involved?
- What will happen to my current treatment(s)?
- Who is running the trial? Is it a reputable hospital, university, or organization?
- Is the trial listed on a government website, such as ClinicalTrials.gov?
- For blinded trials (placebo controlled), will I be told which treatment group I was in?

Trial Concerns:
- What are the risks and benefits? Could there be side effects or problems?
- Could it have an impact on my reproductive health?
- If I am admitted to the hospital or become ill, can I continue using the treatment?
- Can I change my mind about participating in the study?
- Can I return to my usual care if I stop participating in the trial?

Eligibility Requirements:
- What is the eligibility criteria for participating in the study?
- Are there certain health conditions that would prevent me from participating?
- Is there a lung function requirement to qualify? If my lung function drops during the trial, can I continue to participate in the study?

Compensation & Support:
- Is the treatment free?
- Will travel and other miscellaneous expenses be covered?
- Is there compensation for participating in the trial? I am on SSDI; am I eligible for compensation?
- Can my spouse/partner/parent travel with me? How are expenses handled for the caregiver?

Post-trial Considerations:
- Will I be told what was learned from the trial?
- How will the data from the trial be used and shared?
- If the treatment works for me, can I continue to receive it? Is there any compassionate care to continue use?

Co-Pay Accumulators

Copay accumulator policies, enacted by insurance companies, prohibit financial assistance—whether from a private foundation, pharmaceutical manufacturer, or individual—from counting toward one's deductible or out-of-pocket maximum.

This means that although patients can use their copay assistance for initial cost savings, once the funds are expended they must still pay their annual deductible or out-of-pocket maximum.

Copay accumulator policies allow insurers and pharmacy benefit managers (PBMs) to receive two payments per prescription—first with the funds from patients' copay cards, and again with patients' funds—once the copay card has been maximized.

Note that insurance companies may try to disguise an accumulator as a benefit: CVS Caremark/CVS Health calls it "True Accumulation"' Express Scripts/Cigna calls it "Out of Pocket Protect"; United Healthcare calls it "Copay Card Solutions: Accumulator Benefit."

Worried about whether your insurance plan has a co-pay accumulator policy? Here's what you should know.

1. Your insurance plan may use a different term to refer to a co-pay accumulator policy, such as:
    a. Accumulator adjustments policies
    b. Out-of-pocket protection programs
    c. Coupon adjustment: Benefit plan protection programs

2. If your insurance plan has such a policy, you should receive a separate, written letter notifying you of changes to your coverage.

3. Co-pay accumulator policies are most common in employer-based, high deductible insurance plans.

4. Consult with your insurance company and/or your employer to see if you are enrolled in a co-pay accumulator program.

Co-pay accumulator policy example adapted from the Crohn's & Colitis Foundation.

① Alex goes to the pharmacy to pick up her monthly CF specialty medication prescription. Alex uses her savings card, which allows her to pay $0 for each 28-day refill up to a $14,000 maximum per year. Her insurance plan has a $5,000 deductible before they start paying for 100% of the medication.

② Alex's savings card allows her to pick-up her prescription for the majority of the year at no cost. Alex thinks that she's already reached her insurance plan's deductible for the medication.

③ However, in October the pharmacist tells her she owes $1,500 for the medication.

④ Alex speaks to her insurance company and finds out that her insurance plan has a co-pay accumulator policy, meaning her patient assistance savings card hasn't counted towards her $5,000 deductible this entire year. Alex must now find a way to pay $1,500 for the medication until the next calendar year begins.

Insurance Denials

CLAIM
DENIED

WHAT TO DO WHEN YOUR CARE IS DENIED

Facing an insurance denial can be frustrating, disheartening, and pose threats to a person's health. While no one should be refused a medical treatment or service they need, denials—particularly for pharmacy claims—are growing increasingly common. Though it may take time and repeated attempts, the majority of appealed insurance denials are overturned. Use the tips below when contesting a denial.

- Take your time when reviewing notifications from your insurer regarding a claim. Denials should always specify the reason(s) why as well as the steps to take to file an appeal.
- If the notification is unclear, always request information in writing in addition to speaking with someone verbally. Best practice is to keep a paper trail of all outreach attempts and conversations with your insurer.
- Always record the name, employee identification number (if applicable), date, time, contents of your phone calls, and direct call back numbers or emails with insurance and medical providers.
- Urge your doctor and their staff to assist you in fighting the denial by advocating for the necessity of the treatment or service.
- Ask what codes were used in the claim—sometimes codes are recorded incorrectly leading to a denial.
- Don't wait to submit an appeal and be mindful of your timely reporting requirements.
- Engage patient advocate networks for free or low-cost legal counsel and information.
- Contact your state's Department of Insurance or Department of Managed Health care to file an unresolved complaint and make an appeal.
- Even after a successful appeal, keep your records; they may be helpful for future claims.

Each year, 850 million claims are denied by insurance companies.

https://cfri.tiny.us/mr24uvbm

75% of physicians reported that prior authorization denials have increased over the last 5 years.

https://cfri.tiny.us/y92e8vde

83.2% of insurance denials are overturned when patients, caregivers, and providers appeal.

https://cfri.tiny.us/ry4st69m

However, only 18% of doctors appeal, due to competing demands, medical urgency, and administrative labor.

https://cfri.tiny.us/ry4st69m

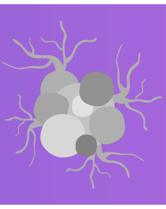
AI has been recorded to deny care at a rate of 16 times greater than what is typical.

https://cfri.tiny.us/y657wzy7

31% of doctors reported feelings that payers rarely use evidence-based criteria to determine coverage.

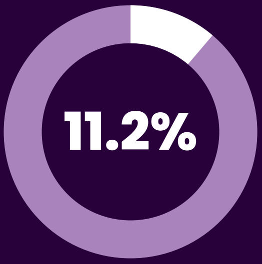
https://cfri.tiny.us/y92e8vde

CF & Cancer Awareness



INCREASED RISK IN THE CF COMMUNITY

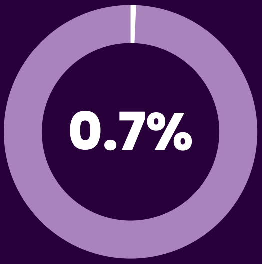
AS LIFE EXPECTANCY FOR THOSE WITH CYSTIC FIBROSIS (CF) INCREASES—LARGELY DUE TO HIGHLY EFFECTIVE MODULATOR THERAPIES—CANCER DIAGNOSES ARE BECOMING MORE COMMON. LEARN MORE ABOUT THE CONNECTION BETWEEN CF & VARIOUS CANCERS AT WWW.CFRI.ORG/CANCER-AND-CF



Cancer as the primary cause of CF-related deaths in 2023

3.9 yrs

Median time between transplant & the first incidence of cancer



Increase of cancer among non-transplanted people with CF between 2006-2017

RISK FACTORS

- Undergoing a transplant, which increases immunosuppression
- Mutations to the CFTR gene, which is known to be a tumor suppressor. Note: this includes CF carriers
- CF-related diabetes, which causes metabolic abnormalities
- Chronic inflammation, which can increase tumor cell survival and proliferation

CANCERS THAT MAY BE MORE PREVALENT AMONG PEOPLE WITH CF

GASTROINTENSTINAL

Colorectal, pancreatic & liver cancers are particularly common.

People with CF are 5-10 times more likely to develop colon cancer than the general population.

PANCREATIC

Studies show that people with CF have a five to ten times higher risk of developing pancreatic cancer than the general population.

RESPIRATORY

Bronchial gland carcinoma is a lung cancer subtype more common among people with CF. Frequent infections from pseudomonas aeruginosa may contribute to this increase.

CERVICAL

Individuals post-transplant are at a higher risk of developing HPV, which can progress into cervical cancer. A 10-fold higher risk in people post-transplant has been documented.

Spotlight: Colon Cancer

SCREENING & DETECTION TIPS

COLON CANCER IS PREVENTABLE THROUGH SCREENING

People with CF are 5-10 times more likely to develop colon cancer

Individuals with CF post-lung transplant have 25-30 times the risk

CF carriers are more likely to develop colon cancer

COLON CANCER IS PREVENTABLE THROUGH SCREENING

Polyps form in the large intestine. While generally not cancerous, these polyps can turn into colon cancer over time. Early detection and removal of polyps can prevent cancer.

GET SCREENED EARLY

Early detection is key. CFRI believes the current recommended age of 40 for people with CF for one's first colonoscopy (30 post-transplant) is too late. Don't be afraid to advocate for an early screening.

COLON CANCER SYMPTOMS

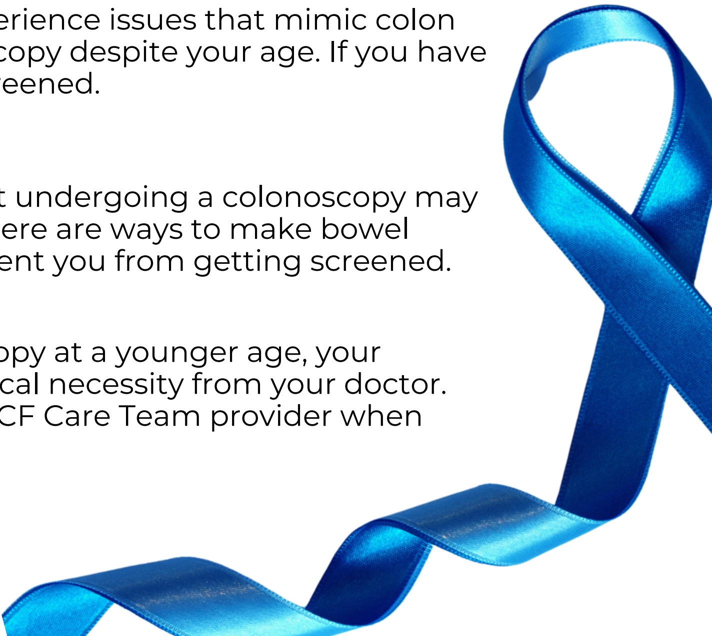
- More frequent diarrhea or constipation
- Rectal bleeding or blood in the stool
- Ongoing discomfort in the belly area
- A feeling that the bowel does not fully empty during a bowel movement
- Weakness or tiredness
- Losing weight without trying

TALKING TO YOUR DOCTOR ABOUT COLON CANCER SCREENING

☐ **SYMPTOMS:** Because people with CF often experience issues that mimic colon cancer symptoms, you are entitled to a colonoscopy despite your age. If you have symptoms, talk to your doctor about getting screened.

☐ **COLONOSCOPY PREP:** Physicians may cite that undergoing a colonoscopy may require additional prep for someone with CF. There are ways to make bowel cleansing easier; don't let a few extra steps prevent you from getting screened.

☐ **INSURANCE COVERAGE:** To receive a colonoscopy at a younger age, your insurance company may ask for a letter of medical necessity from your doctor. Print out this flyer to show your doctor or other CF Care Team provider when discussing colon cancer screening.



Social Security: SSI & SSDI

APPLY FOR & MAINTAIN BENEFITS

Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) are federal income and benefit programs intended to support people who are disabled and cannot work. A significant proportion of the CF community rely on SSI or SSDI for financial support and access to Medicaid or Medicare insurance. Recent legislation may have a dramatic impact on Medicaid funding and requirements. The following was current through June, 2025.

Supplemental Security Income (As of 2025)

Eligibility Criteria:

- Anyone who is:
  - Aged 65 years or older;
  - Blind (20/200 or less); or
  - Disabled
- And has limited income
  - Money earned from work, free food or shelter, and other money you receive from benefits such as workers compensation, unemployment benefits, or the Department of Veterans Affairs
- And has limited resources
  - Cash, bank accounts, stocks, land, vehicles, life insurance, etc.
- And is a US citizen or national*
- And is a resident of one of the 50 States, the District of Columbia, or the Northern Mariana Islands for a full calendar month
- And is not confined to an institution at the government's expense

What Does 'Disabled' Mean for a Child (Under 18)?

- You have a medically determinable physical or mental impairment that results in marked and severe functional limitations. The disability can be expected to result in death or has lasted or can be expected to last for a continuous period of not less that 12 month.

What Does 'Disabled' Mean for an Adult (18 or older)?

- You have a medically determinable physical or mental impairment that results in the inability to do any 'substantial gainful activitiy.' The disability can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 month.

Note: While CF is not a listed Compassionate Allowance condition, it is listed under respiratory disorders in the Social Security Blue Book (3.04) with specific lung function and pumonary infection criteria that one must meet.

Basic Payments Per Month:

- $967 for 1 person
- $1,450 for a couple

Note: You may get more if you live in a state that adds money to the federal SSI payment. You may receive less if your family has other income.

Other Benefits:

With SSI, recipients can typically gain access to the Supplemental Nutrition Assistance Program (SNAP) and Medicaid.

Learn More & Apply:

- Review eligibility criteria here: https://cfri.tiny.us/2p87bxmt
- Documents needed for application: https://cfri.tiny.us/76ff9z2c
- Apply online here: https://cfri.tiny.us/y47nv93m or call 1-800-772-1213
- *Noncitizens in certain classifications can be granted SSI approval.

Social Security: SSI & SSDI

APPLY FOR & MAINTAIN BENEFITS

Supplemental Security Disability Insurance (As of 2025)

Eligibility Criteria:

- Have worked in jobs covered by Social Security
- Have a medical condition that meets Social Security's definition of disability
- Must have worked long enough based on the work credit system
    - Work credits are based on your total yearly wages or self-employment income.
    - You can earn up to 4 credits each year
    - Example: In 2025, you earn 1 credit for each $1,810 in wages. When you've earned $7,240, you've earned your four credits for the year.
    - The number of work credits you need depends on your age when disability begins.

Learn more about credits: https://cfri.tiny.us/2p88jx7y

What is the Definition of Disability for SSDI?

- The five questions used to determine disability are:

1. Are you working?
    a. In 2025, if your earnings average more than $1,620 ($2,700 if blind) per month, you generally cannot be considered to have a disability
2. Is your condition 'severe'?
    a. Your condition must significantly limit your ability to do basic work-related activities such as lifting, standing, walking, sitting, or remembering
3. Is your condition found in the list of disabling conditions?
    a. CF is listed under respiratory disorders in the Social Security Blue Book (3.04). However, you must meet specific lung function and pulmonary infection criteria.
4. Can you do the work you did previously?
5. Can you do any other type of work?

Payments Per Month:

The maximum benefit is $4,018.

Amounts vary according to each individual, as the amount depends on how long you have worked and your earnings over that time.

Other Benefits:

Medicare is available to SSDI recipients after 24 months. During the waiting period, you may be eligible for Medicaid.

Learn More & Apply:

- Review eligibility criteria here: https://cfri.tiny.us/4yekxeu2
- Read about disability criteria for CF: https://cfri.tiny.us/y54k2vtt
- Documents and information needed for application: https://cfri.tiny.us/y47nv93m
- Apply online here: https://cfri.tiny.us/y47nv93m or call 1-800-772-1231

Additional Resources

AVAILABLE
SUPPORTS

Patient Assistance Resources (CFRI - English & Spanish): Annually updated guide providing information about financial, educational, medical, and advocacy-related resources for people with CF. **https://cfri.tiny.us/5n8vcdtu**

Cystic Fibrosis In the Classroom (CFRI - English & Spanish): Resource for parents, caregivers, and educators supporting children with CF through their academic careers. **https://cfri.tiny.us/CF-in-the-Classroom**

A Teen's Guide to Navigating Cystic Fibrosis (CFRI - English & Spanish): Resource for teens with CF navigating the process of maturing with the disease. **https://cfri.tiny.us/2p8pmcsc**

YouTube & Podbean (CFRI): Audio and video recordings of conversations and testimonials from people with CF, family members, researchers, and clinicians. **https://cfri.tiny.us/2p84ha87**

Weekly eNewsletter & Biannual Newsletter (CFRI): CFRI publishes biannual newsletters and a weekly eNews column to bring updates and provide resources to members of the CF community. **https://cfri.tiny.us/bdctjp67**

My Patient Rights (External): Help for people who have been denied treatment, need medications, or have experienced delays. **1-916-531-3585.** **https://mypatientrights.org/**

Patient Advocate Foundation (External): Identification of insurance coverage options, and negotiations for payment plans, write-offs, and discounts with healthcare providers to resolve unpaid medical bills. **1-800-532-5274.** **https://www.patientadvocate.org/**

Disability Rights Legal Center (External): Free legal assistance to people with disabilities experiencing discrimination in violation of their civil rights. **1-213-736-1031 / DRLC@theDRLC.org.** **https://thedrlc.org/about/services/**

Compass (CFF): Personalized service that provides people living with CF and their families a partner in dealing with challenges related to life with CF. **1-844-266-7277 / compass@cff.org**. **https://www.cff.org/support/get-help-cf-foundation-compass**

Learn more about CFRI's advocacy efforts at
https://www.cfri.org/cystic-fibrosis-advocacy/

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