

A TEEN'S GUIDE TO NAVIGATING CYSTIC FIBROSIS

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Resources
& Tools



for
physical,
emotional

&
mental
wellbeing



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Editor's Note:

Navigating one's teen years can be fraught with challenges under the best of circumstances. For those living with cystic fibrosis (CF), navigating the physical, social and emotional changes can be even more difficult. This first edition of "A Teen's Guide to Navigating Cystic Fibrosis: Resources & Tools for Physical, Emotional, and Mental Wellbeing," aims to address the multifaceted and intersectional experiences faced by teens with CF. It is our hope that this booklet is a resource to teens, as well as to their families and professional support networks.

As the landscape of CF therapies evolves, so too do the experiences and needs of people with CF. CFTR modulators, which address the underlying issue with specific CF-causing genetic mutations, have expanded life expectancy and improved the quality of life of many people with CF. Yet not all people with CF—and most notably a greater proportion of people of color—are able to benefit from these novel treatments. This resource recognizes this reality; it has been created for all members of our diverse community of teens with CF.

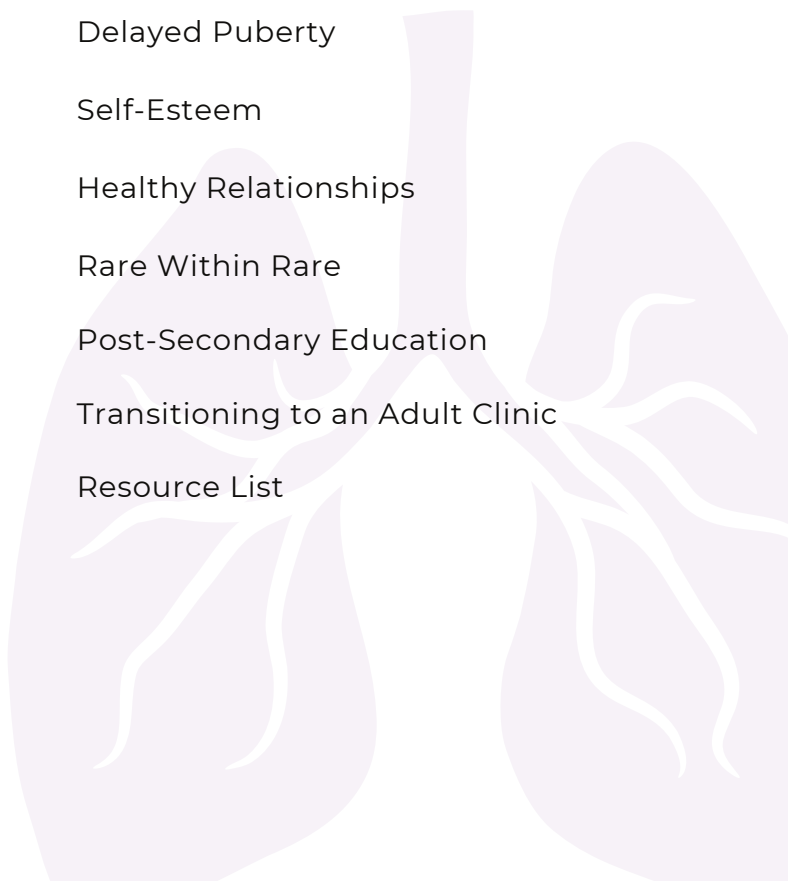
In health and hope,

—Siri Vaeth, MSW

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WHAT IS CYSTIC FIBROSIS



Cystic fibrosis (CF) is an inherited (genetic) disease that impacts the glands that produce sweat and mucus. CF is not contagious. Due to improved treatments, the median age of survival for those with CF has increased dramatically. In the 1970s, children were not expected to reach adulthood. Today, there are more adults than children with CF, and many are expected to reach middle age.

Approximately 40,000 people in the U.S. have been diagnosed with CF. **CF impacts people of every race and ethnicity.** While it occurs more often in people of northern European ancestry, CF impacts the Hispanic/Latinx, African American/Black, South Asian, East Asian, and Native American communities. There are many mutations of the CFTR gene, and people of color are more likely to have rare mutations that are not responsive to the newest modulator therapies. There are many therapies in the pipeline, with hopes that new therapies – and a cure – will be found for all people with CF.

IN 2022, TEENS MADE
UP APPROXIMATELY
19% OF PEOPLE WITH
CF IN THE UNITED
STATES.

Teens with cystic fibrosis face unique and sometimes challenging experiences as they balance coming of age with a progressive disease. This booklet is intended to be a resource for teens with CF, as well as for those who have teens with CF in their life who they wish to best support. The content was created with the input of teens with CF, their family members, and care team providers.



DISCLOSING ONE'S CF STATUS



Talking about having CF can be a bit complicated depending on where you are, who you're with, and what's going on. As you grow up, especially when you become a teenager, you might find yourself being the one to tell others about your CF status instead of your parents doing it for you. This can make you wonder when and how to talk about it.

Figuring out how to tell people about your CF status might take some trial and error. You might find that using humor, giving educational facts, or just keeping it short and simple works best for you. For example, you might casually mention taking enzymes during dinner on a first date, which could lead to talking about CF naturally. Whatever you gravitate towards, disclosing your CF status is a personal choice. There is no right or wrong way to decide when, where, or how to bring it up. Giving yourself permission to try on different communication styles and change your mind about delivery is most important.

AT THE END OF THE DAY, ESTABLISHING COMFORTABILITY AND KNOWING THAT NO ONE IS ENTITLED TO YOUR CF STATUS IS MOST IMPORTANT.



As you meet new friends, classmates, romantic partners, teachers, or bosses, you'll constantly be faced with the decision of whether or not to tell them about your CF. Take a moment to reflect on the people in your life who do not know your CF status, and consider each question in relation to that person.

- **DOES THIS PERSON NEED TO KNOW MY CF STATUS?**
Example, does a gym teacher need to know that I may have different physical needs than my peers?
- **WILL DISCLOSING MY CF STATUS HELP ME PHYSICALLY, EMOTIONALLY, AND/OR MENTALLY?**
Example, will telling people at a sleepover make me feel less anxious about coughing?
- **DO I TRUST THIS PERSON TO RESPECT MY PRIVACY?**
Example, do they understand that just because I shared my CF status does not mean I gave them consent to tell other people?
- **DOES DISCLOSING MY CF STATUS AFFIRM MY IDENTITY?**
Example, is living with CF an important, empowering and integral part of how I describe myself and want others to know about?
- **DO I NEED HELP SHARING MY CF STATUS WITH THIS PERSON?**
Example, would I feel more comfortable telling my employer about accessibility measures with the assistance of a letter from my doctor?



MEDICAL DISCLOSURE & CONSENT



Just as many teens become the primary person to share their CF diagnosis instead of their parents as they get older, many begin to speak to their doctors independently too. If the topic of medical disclosure and confidentiality is confusing to you, you are not alone. With 50 states, age of medical consent depending on geographic location varies. For example, in California consent to general medical care begins at age 15. However, people as young as 12 are legally allowed to make decisions and consent to mental health care, substance abuse, and birth control treatments without parental sign-off. Other states might have different laws that make the age of medical consent older.

As a teen with CF, it's important to know what the age of doctor-patient consent and confidentiality is where you live. Take a look at this [article \(https://tinyurl.com/yxwstwy9\)](https://tinyurl.com/yxwstwy9) for information about when patient consent and privacy begins in your state. From there, talk with the parental figures in your life about any concerns, desires, and needs you have on the topic.



TREATMENT FRUSTRATIONS



Treatment for people with CF is different for everyone. Some might need to do moderate physical activity and special breathing exercises, which can take up a lot of time. Others might need more intense treatment, like surgery, and then time to recover.

Regardless of what one's treatment looks like, having to spend hours every week to improve one's health can be frustrating, especially while trying to keep up with school work, extracurricular activities, and social relationships. Additionally, there may be the added frustration when friends without CF don't understand one's limitations when it comes to making plans or interrupting activities to perform your treatment regimen.

When you feel frustrated, having honest talks can help. People often crack jokes or make snide comments when they don't understand the 'why' behind what someone else is doing. If it's important to you, you can try including your friends in your treatment routine. For example, you could ask them to watch a movie or do a project with you while you do your respiratory therapy. This can help them understand and support you better.

If you're not comfortable talking about certain parts of your CF routine, but you don't want people asking questions, you can ask your parents to talk to their parents about it. This can help avoid awkward situations and keep things respectful.

“

"SOMETIMES I BUTT HEADS WITH MY PARENTS IF IT FEELS LIKE THEY'RE NAGGING ME TO DO MY TREATMENTS. I HAVE TO ALWAYS TRY AND REMEMBER THAT THEY JUST WANT THE BEST FOR ME."

- TEEN WITH CF

”

TREATMENT IN THE AGE OF MODULATORS

With the introduction of modulators, like Trikafta®, some teens might feel frustrated about still needing to follow certain treatment routines, even if their health has improved a lot. On the other hand, those who can't take modulators might feel frustrated because they have to stick to older treatment routines while other people with CF don't. Being aware of everyone's situation can help keep our CF community supportive and caring.

MAINTAINING ROUTINES



As a teen you may be the one starting to take more control of your personal schedule, which includes treatment adherence. Though sometimes a hassle, staying consistent with your personalized treatment plan can help reduce hospitalizations and exacerbations. Keeping a schedule can be a useful way to keep track of and balance everything you have going on. Take a look at the example schedule below and try writing out your own. Who knows, it may be more helpful than you think! If you're unsure of where to start, ask your care team and parents to help you.

Example Schedule

LEGEND	MON	TUES	WED	THUR	FRI	SAT	SUN
M & E = medication & enzymes	M & E (8am)	M & E (8am)	M & E (8am)	M & E (8am)	M & E (8am)	M & E (8am)	M & E (8am)
A = airway clearance	A (8:30am) (3:30pm)	A (8:30am) (3:30pm)	A (8:30am) (2pm)	A (8:30am) (3:30pm)	A (8:30am) (3:30pm)	A (8:30am) (2pm)	A (8:30am) (3:30pm)
D = doctor's visit					D (11am)		
Ex = extracurriculars	EX: Dance (7pm)		EX: Soccer (3:30pm)			EX: Soccer (3:30pm)	
S = social Activity					S: Movies (5pm)	S: sleepover (8pm)	
P = projects				P: history report			

TIP: SET REMINDERS ON YOUR PHONE, OR SAVE YOUR SCHEDULE AS YOUR PHONE'S LOCKSCREEN.

"TELEMEDICINE OFFERS SEVERAL BENEFITS THAT MAKE HEALTHCARE MORE ACCESSIBLE, CONVENIENT, AND EFFICIENT FOR BOTH PATIENTS AND HEALTHCARE PROVIDERS."

- ALICIA, A PARENT OF A YOUNG ADULT WITH CF



GEOGRAPHIC TREATMENT CHALLENGES

For some people, getting CF care can be hard because they live far away from their CF center. Most people with CF are advised to go to their CF center four times a year, but for people with greater health issues, it might be more often. When one has to commute long distances to clinic appointments, taking time out of school or missing social engagements can pose challenges.

As a community we should always be advocating for changes to make clinical care easier for everyone to access. As we work toward this, take a look at some tips, which might make receiving treatment easier.

- Your care team should be aware of any barriers you face to access a CF care center. However, practice reminding and updating them of this at each visit. You never know if untapped resources have become available.
- Ask about setting up a secondary healthcare team at a more local medical facility. Your CF care team will be able to provide the necessary medical information to them.
- Use telemedicine where appropriate. According to a recent study, online video chats with members of one's healthcare team are effective in improving treatment adherence and as a result physical wellbeing (<https://tinyurl.com/2p6hfncu>).

PEER PRESSURE



During adolescence, there is often more pressure to take part in activities that someone might be afraid of or disagree with. In middle and high school, more teens become exposed to things like alcohol, cigarettes, vaping, and sexual activity. For teens with CF, there may be the added appeal of participating in activities that normalize coming of age and put one on an 'equal playing field' as their peers. This is especially true of people who haven't disclosed their CF status. Educating oneself on the risks associated with these activities is the most important way to make safe and healthy choices. Especially as a teen with CF, there are added layers to consider before being influenced to do something a friend or peer does.

While many people, especially those with CF, know the risks associated with activities like smoking, alcohol consumption, and sexual activity, there is a lot of conflicting information online that can make it hard to make informed choices. Take a look at the facts below to see how these activities can affect the body and mind.



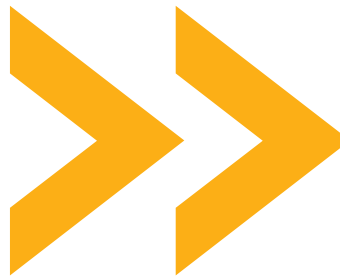


SMOKING, VAPING, & MARIJUANA:

- Nicotine is the primary agent in regular cigarettes and e-cigarettes, and it is highly addictive.
- Nicotine is a toxic substance that raises your blood pressure and spikes adrenaline (stress hormone), which increases your heart rate and the likelihood of having a heart attack.
- Both traditional and e-cigarettes contain nicotine, but many e-cigarettes offer more nicotine than a combustible tobacco product would.
- Many people use e-cigarettes to try and quit smoking. However, a recent study found that most people who intend to use e-cigarettes to kick the nicotine habit end up continuing to use traditional and e-cigarettes.
- Nicotine can harm adolescent brain development.
- Smoke and water vapour are irritants when inhaled that can cause inflammation to one's lungs. This is especially true for people with CF.
- There is still not enough long-term research on the effects of vaping to conclude that it is a relatively safe activity.
- A recent study indicated that tobacco smoke exposure may reduce the clinical efficacy of CF drug Kalydeco.
- The risk of developing marijuana use disorder (unable to stop using) is greater in people who start using marijuana during youth or adolescence and who use marijuana more frequently.

SEXUAL ACTIVITY:

- 97%-98% of males with CF are infertile. This does not mean they are sterile; most males with CF produce sperm but the vas deferens is absent. While the risk of pregnancy may be lowered, one must still protect themselves against sexually transmitted infections (see next page).
- Especially since the introduction of highly effective modulators, the majority of females with CF are able to get pregnant.
- The most effective kind of contraception is abstinence. However, there are lots of other forms of birth control including condoms, the pill, the patch, or IUD. Each one comes with various benefits and drawbacks depending on the person.



FOR EXAMPLE:

- o Although the pill can be a good option for some people with CF, Orkambi and certain antibiotics have been known to decrease its effectiveness.
 - o Similarly, the hormonal injection method is generally not recommended for people with CF as it may cause loss of bone density and increase the risk of osteoporosis in women with CF.
 - o Take a look at this table for more information about birth control & CF: <https://tinyurl.com/2p9c7bz2>
- Visit the Cystic Fibrosis Reproductive and Sexual Health Collaborative for resources. Visit <https://cfreshc.org/>

Sexually Transmitted Infections, commonly referred to as STIs, can be transmitted through kissing, oral sex, and penetration. Consider the following regarding STIs:

- Getting tested and asking your romantic partner to get tested is the best way to avoid STIs if you are sexually active.
- Even though the majority of males with CF are infertile, they are just as likely to give or get a STI as those in the general population.
- STIs can cause a range of health concerns for anyone, and especially for those with CF who may have compromised immune systems from antibiotic use; therefore, the risks of STIs are greater.

Depending on where you live you may not have easy access to healthcare that supports your right to sexual health and autonomy. Planned Parenthood has a presence in all 50 states and may be an appropriate resource if you need to talk to someone.



ALCOHOL & DRUG USE:

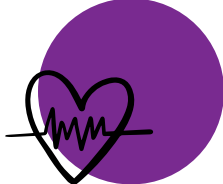
- In people with CF, the liver can be 'sluggish,' which means it has to work harder to rid the body of alcohol. This puts more strain on it, and puts you at greater risk of liver damage than the general population.
- Trikafta® can cause issues for the liver – another reason to avoid alcohol.
- As alcohol is a depressant, it can cause short and long-term effects like anxiety or mood swings.
- People with CF-related diabetes should be extra cautious when drinking. When drinking alcohol is combined with the medications most often used to treat diabetes, low blood glucose can occur.

**BOTTOM LINE? ALWAYS TALK TO YOUR DOCTOR ABOUT WHAT IS SAFE AND HEALTHY.
YOUR CF CARE TEAM IS THERE TO PROVIDE GUIDANCE AND SUPPORT, WHETHER
ABOUT SUBSTANCE USE, SEX, OR ANOTHER TOPIC.**

When faced with activities like drinking, using drugs, or having sex, the pressure to fit in might make it hard to make the best decision for yourself. But remember, true friends will respect your choices. If you ever feel pressured to do something and want to say no, try these strategies:

- Say no with confidence and ask that they respect your boundaries. Don't be afraid to repeat yourself.
- Remind people of your CF diagnosis (if you feel comfortable) and use it as a reason why you don't want to engage in their activity.
- Avoid situations where you know you will be pressured to do something you don't want to do.
- Find likeminded individuals and make friends with new groups of people. If you do find yourself in an environment where you might be asked to do something you don't want to, you will have friends who support your choices with you.
- Seek support and talk to a trusted adult who will respect your privacy and keep conversations confidential (e.g., doctor, social worker, guidance counselor, etc.).

MENTAL HEALTH



For everyone, taking care of one's mental health is a full-time job. For teens with CF, that full-time job can often feel like working overtime every day of the week. Whether it's the effects of how you feel physically bringing you down, side effects of medications, the stress of treatments on top of being a normal teenager, family conflicts, or guilt for 'taking up too much space,' the mental and emotional toll felt by people with CF is huge.

COMMON SIGNS OF DEPRESSION:

- ☐ Withdrawal & loss of interest in social activities
- ☐ Intense sadness or irritability
- ☐ Change in appetite (more or less hungry than usual)
- ☐ Change in sleep patterns (sleeping more or facing insomnia)
- ☐ Drug or alcohol abuse
- ☐ Self harm



Scientific studies and stories from people with CF show that people with CF often have higher rates of depression and anxiety compared to others (about 2-3 times more). Now, with treatments like Trikafta®, there are reports that some users are experiencing more anxiety, depression, trouble sleeping, and brain fog. Given the health benefits of Trikafta® and other modulators, this can come as a frustrating and scary realization.

If you have noticed a change in your mood since starting a new medication, don't write it off as something you have to deal with alone. Tell your parents and doctors so that the most appropriate course of action can be determined. Sometimes, options like lowering the dose of the medication and getting psychological support can be helpful. It's important to speak up so you can get the support you need.

For those who are unable to use the new modulators, the already higher risk of depression and anxiety may be increased with the sense that they have been left behind in the push for new therapies. The lack of relief from the daily treatment burden and fear about one's disease progressing can exacerbate one's mental health challenges.

There are lots of ways to improve one's mental health. Finding what helps you remain grounded can help you slow down, remain calm, and work through tough times. What do you do when you feel anxious or low? Do any of the domains below resonate for you?

 <p>PHYSICAL</p> <ul style="list-style-type: none">• Sleep• Stretching• Exercise• Nutrition• Rest	 <p>ENVIRONMENTAL</p> <ul style="list-style-type: none">• Organization• Clean space• Safety	 <p>SOCIAL</p> <ul style="list-style-type: none">• Support system• Boundaries• Clubs• Asking for help• Acts of kindness	 <p>INTELLECTUAL</p> <ul style="list-style-type: none">• Journaling• Hobbies• Learning/education• Therapy	 <p>SPIRITUAL</p> <ul style="list-style-type: none">• Meditation• Prayer• Nature
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Can you think of any other ways to reduce anxiety, depression, stress, or a low mood? Write or draw them out below, and remember, you can do any of these activities whether or not you feel good or bad. Prevention is always better than reaction.

CFRI'S WELLNESS CLASSES



To support teens with CF, CFRI offers multiple support groups and wellness classes free of charge. Visit www.cfri.org/education-support and explore the options below to see if any are a good fit for you!

ONLINE SUPPORT GROUP FOR TEENS WITH CF

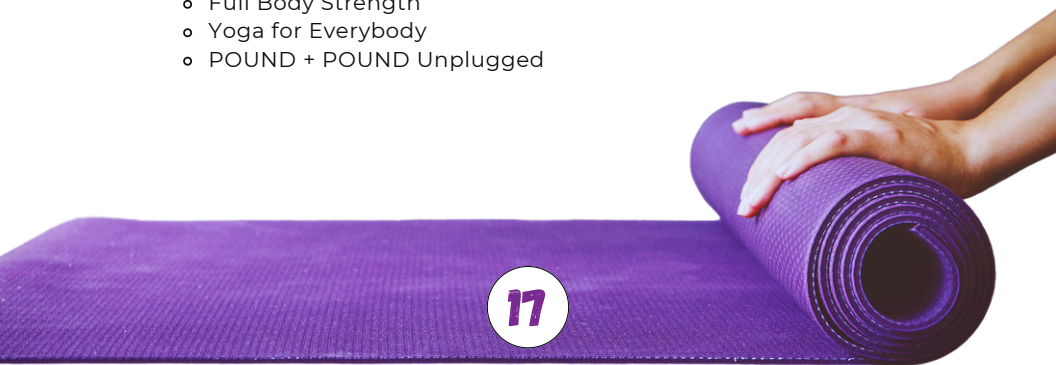
- Peer-to-peer support group, facilitated by a social worker, that addresses the unique issues faced by teenagers between the ages of 13 and 18 growing up with CF.
- Meets the third Wednesday of every month
- For more information and to register, please email Sabine Brants (sbrants@cfri.org)

COUNSELING SUPPORT PROGRAM

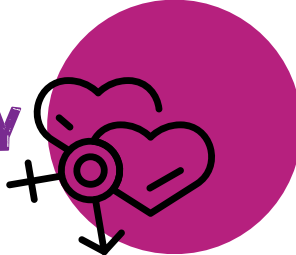
- Financial support to receive up to six individual therapy sessions per year with the licensed provider of one's choice. CFRI will cover the cost of one's insurance co-pay for six sessions, or pay up to \$125 per session if one has no insurance, or your provider does not accept insurance or is out of network.
- For more information on how to participate, please email Sabine Brants (sbrants@cfri.org)

WELLNESS CLASSES

- CFRI's Wellness Classes for individuals with CF, as well as their loved ones, provide opportunities to improve one's physical and emotional health. No experience is required for any class, all abilities and mobilities are welcome.
- Classes include:
 - U-Jam
 - Mat Pilates
 - Full Body Strength
 - Yoga for Everybody
 - POUND + POUND Unplugged



DELAYED PUBERTY



Puberty is a stage when your body goes through big hormonal changes. Females typically experience puberty between the ages of 10-14, while males typically experience puberty between the ages of 12-16. Growth in one's height, changes to one's voice, the development of breasts and body hair, as well as menstruation, are all part of the puberty process.

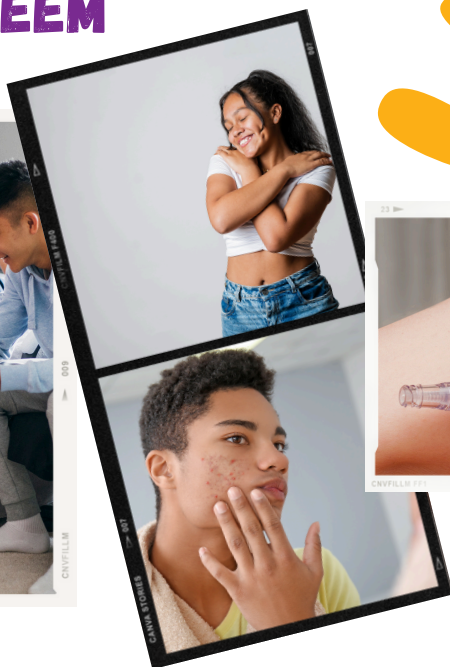
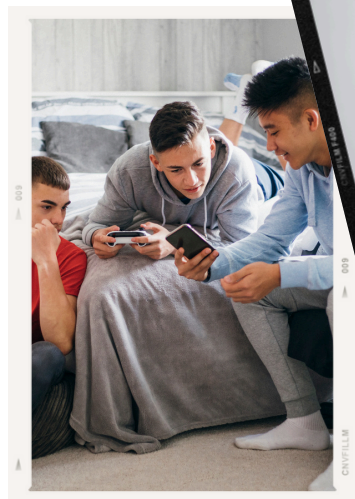
While puberty happens at different times for everyone, people with CF might experience a delay in puberty. This delay is usually because of things like nutrition problems, trouble absorbing nutrients, or having diabetes.

New therapies like CFTR modulators, have reduced the rates of delayed puberty among people with CF. However, teens who are unable to take modulators may experience delayed puberty at higher rates. As many people of racial and ethnic minorities are unable to take current modulators, delayed puberty might be more common among people of color. Among teens of color this might feel like another hurdle they have to deal with as a minority within the larger CF community.

Feeling insecure, anxious, or scared is normal if you're experiencing delayed puberty. If you're worried about your physical development, the best thing to do is ask for help. Talking to friends, adults you trust, or your healthcare team can help ease your worries. You might find relief by sharing your feelings, or you might get some advice on what to do next.



SELF-ESTEEM



Though self-esteem is characterized by one's personal view of oneself, that view is often shaped by a number of external factors. Social media, pop culture, familial beliefs, or politics are just a few examples of how what one is exposed to affects how we think about and view ourselves.

For teens with CF, self-esteem may be negatively impacted by delayed puberty, redirected or postponed life plans, as well as treatments—like PICC lines or nasal cannulas—that cause discomfort and changes to one's physical appearance. People with CF might also struggle with how society views disability, which often focuses on physical limitations rather than the barriers created by our surroundings. Some people with CF may not see themselves as disabled, but have to deal with other people seeing them that way. On the other hand, some people with CF have hidden disabilities and face judgements from those who don't understand the impact of CF. Giving oneself the grace to feel a range of emotions when it comes to self-esteem is vital, as it affirms that what one is experiencing is understandable.

Take a look at the tips and tricks on the next page and consider which might work best for you. Remember, building strong self-esteem can be a lifelong process, and living with CF often means embracing new or unforeseen circumstances. Despite this, there are things you can develop now that might help you feel more confident moving forward in the future.

BOOSTING SELF-ESTEEM



1

GET TO KNOW YOURSELF

Take a moment to drown out other people's perceptions, and think about who you truly are. What type of music do you listen to? Where do you see yourself in a year? How would you describe yourself to a stranger?

2

PRACTICE POSITIVE SELF-TALK

Try switching the narrative. For example, instead of saying "What's the point? There's nothing I can do about it," try saying, "I may not be able to control the situation, but others can help me find ways to manage it better."

3

DO THINGS THAT BUILD CONFIDENCE & SET GOALS

Are you interested in acting, robotics, dance, or business? Exploring different activities and developing skills can help build confidence.

4

EMBRACE VULNERABILITY

Remind yourself that vulnerability is a human experience that makes us more compassionate and empathetic towards others. It's a superpower!

5

GROUND YOURSELF BY FOCUSING ON CORE BELIEFS

What do you live by? Is it the power of kindness, curiosity, or friendship? Now practice putting the words 'I am' in front of those beliefs. Reminding yourself of what you believe in can help us feel empowered and energized.

6

CREATE AFFIRMATIONS AND MANTRAS

Sometimes, it's as simple as telling yourself 'I add something special to the world.' Think about what phrase gives you comfort; practice saying it to yourself or write it down where you will see it often.

7

CHALLENGE DISCRIMINATION (RACISM, ABLEISM, SEXISM, ETC.)

Practicing advocacy and standing up for yourself and others builds confidence and can help you make new friends. Remember that discrimination literally means 'unjust or prejudiced treatment' and should not be tolerated.

HEALTHY RELATIONSHIPS




When discussing self-esteem, it's important to address the topic of healthy relationships and the higher presence of intimate partner violence (IPV) among people with chronic illnesses. IPV happens when current or former romantic partners engage in abusive, aggressive, or manipulative behavior, which can include emotional, psychological, physical, financial, or sexual abuse.



Despite the fact that IPV typically refers to romantic relationships, it's important to understand that abusive behaviors such as these can happen in friendships and family relationships too. Additionally, they can occur between people of any gender, race, or age. The stereotype that IPV only happens to women, particularly White women, is a misconception that can cause harm and spread false information.

For people with a chronic disease, like CF, one may stay in unhealthy relationships longer than they want to because they are made to feel that no one else will want to be in a relationship with them due to their CF. Of course, this is not true and is a form of psychological abuse and manipulation. Others may be financially dependent on their partner or live with them. Or perhaps one depends on their partner for caretaking. There are lots of reasons people might stay in unhealthy relationships, and often there are many barriers to being able to leave.



"LETTING A PERSON YOU'RE IN A RELATIONSHIP WITH KNOW ABOUT CF CAN BE SO SCARY, BUT IN THE END, IF IT'S THE RIGHT PERSON, BEING OPEN WILL ONLY HELP THEM LOVE AND UNDERSTAND YOU MORE. THE RIGHT PERSON WILL ACCEPT EVERY PART OF YOU AND BE THERE WITH YOU THROUGH THE UPS AND THE DOWNS OF LIFE AND THIS DISEASE. "

- HANNAH, YOUNG PERSON WITH CF

As teens who may be entering into new relationships, consider what healthy partnership means to you. If you are currently in an unhealthy relationship, know that there is no shame and there are people who can help you. Confide in friends, family, or a trusted adult like a teacher, therapist, or social worker. You can also call the **National Domestic Violence Hotline for confidential support at 1-800-799-7233.**

Without a doubt, relationships can be confusing—especially if you have limited dating experience to draw from. Take a look at the image below. Think about and then write down what qualities comprise a healthy relationship to you.

UNHEALTHY

You are codependent on this person

They make you feel insecure

You don't trust each other

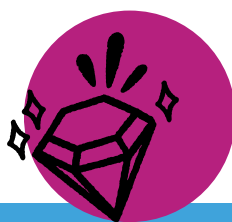
They ignore your boundaries

They don't encourage you to grow as an individual

You can't tell them how you really feel

HEALTHY

RARE WITHIN RARE



DEAR BIPOC CF TEENS,

According to my mother, I was extremely sick as a baby. She recounted to me how scared she was. Thankfully, my mother had extreme strength and determination. She fought for my life by not taking no for an answer, and advocated for me until she found that answer—that I had CF. Unfortunately, it took a lot for her to get a second opinion from another doctor to find out what was wrong with me. In this pursuit, it appeared to us that I was tested for everything except CF, because it has historically been accepted in the medical community that CF is a Caucasian disease. I am the literal example of never judge a book by its cover. To know that I was overlooked for this illness because of my skin color is overwhelmingly disheartening. The thought that I could have had more serious health issues or even may not have lived due to this incorrect thinking is frightening.

My hope is that by sharing my story, I can let other BIPOC teens with CF know that they are not alone. I hope this letter encourages you to advocate for yourselves, and lean on others for support. What we go through is far from easy, but we are in this together!

It can be overwhelming and discouraging being “the only one” within any given scenario. As a BIPOC teen with CF, there are times that you may feel self-conscious. Know that your feelings are valid and completely normal. It is 100% natural to desire connection with others who look like you. However, also remember that it is possible for connection to go far beyond skin color. Connection is not confined to skin color; it is founded upon identity and shared experiences. Therefore, fight the instinct to isolate yourself from others and push yourself outside of your comfort zone. Make an effort to connect with other people who have CF no matter what color they are. There is comfort and reassurance in talking to someone who knows what you are going through as a teen with CF, and in knowing that there are also spaces of connection for teens with CF of color. Knowing that you are not alone, and creating a support system grounded in both types of connection is required for your wellbeing and survival.

“AS A BIPOC TEEN WITH CF, THERE ARE TIMES THAT YOU MAY FEEL SELF-CONSCIOUS. KNOW THAT YOUR FEELINGS ARE VALID AND COMPLETELY NORMAL.”

DEALING WITH IGNORANCE:

When I was hospitalized as a teen, I can remember feeling scared and upset. It is not a comforting feeling having 4-6 doctors in a room while experiencing a health crisis. I felt as if I was a spectacle, and I felt disrespected by their fascination and disbelief that I was a black person with CF.

Remember that ignorance is never about you. Set boundaries in order to protect your peace. There are many times where you will feel vulnerable, and you should not tolerate disrespect or inconsideration from anyone. Simply ask them to stop or limit their time with you as much as possible. Your health goes beyond just your physical body. It also includes your emotional, psychological, and spiritual states. When you are dealing with ignorant comments, if possible, try to ignore it or educate that person. Avoid responding in a way that makes you angry. When you respond in a way outside of your character, then you relinquish your power.

EMBRACING YOUR POWER:

Remember that it is all in your head. You must be careful of the words that you say to yourself. Do not say anything to tear yourself down. Find ways to connect to yourself and fuel your identity and be confident in it. There have likely been times where white people are heard - including in the CF clinic - and you are not. Don't shy away from having your voice be heard. Find someone who supports you and is on your team.



BUILDING CONFIDENCE:

Confidence stems from the inside. Build it by doing things that make you feel good.

- Reading self-development books
- Reading books by or about other people with diseases or disabilities
- Listening to sermons or motivational speakers
- Wearing clothes that make you feel amazing
- Finding new or perfecting your hobbies
- Journaling
- Talking to a therapist or life coach
- Exercising within your abilities
 - Lifting weights, walking, skating, bike riding, yoga, dance, etc.

THE POWER OF SELF-ADVOCACY:

Self-advocacy is one of the greatest ways to show yourself love and respect. Decide in your mind that you will not be silenced or talked over. Trust your intuition; it serves as a proactive measure to protect you. If something does not feel right then acknowledge it and seek an answer. Consult with a parent, physician, therapist, or even a friend. It is always better to be safe than sorry. You are the master of yourself and your body. Ask every question no matter how minuscule it may feel. It is part of learning how to take care of yourself.

Most importantly, **NEVER GIVE UP! NEVER!** It's easy to give up and harder to keep going. Remember the goal at the end. You are worth fighting for. Of course, there are many hard days as a person living with CF. Just take everything one day at a time, one hour at a time, or even one minute at a time. Choosing to continue on is what gives hope that things will be better. Honor yourself and do everything in your ability to experience what life has to offer.

From,
JAELYN, A FELLOW BIPOC PERSON WITH CF

***"DECIDE IN YOUR MIND THAT YOU WILL NOT BE
SILENCED OR TALKED OVER. TRUST YOUR INTUITION; IT
SERVES AS A PROACTIVE MEASURE TO PROTECT
YOU."***



POST-SECONDARY EDUCATION



Whether you are a senior in high school applying to colleges, or you decided to take a break to explore a different path after high school and are now curious about post-secondary education, it is a very exciting time. Perhaps going to college was never something you considered due to compromised health, or maybe you've been anticipating this next step for a long time. In both circumstances, the mental, emotional, and physical logistics of preparing for post-secondary education can feel uncertain—especially as friends and peers simultaneously discuss the transition without the understanding of what factors someone with CF has to consider.

I didn't plan for college.
Now what do I do?

I don't feel ready to
make the same
transition as my peers.

If I want this, I can
do this.



For students attending college away from home, the transition will be made much easier with some proactive planning. While you may not feel that you need the support of the campus disability office, it is better to register in advance should the need for additional support arise.

Many people opt to maintain care at their CF center close to home, and plan their clinic visits around school breaks. Nonetheless, it is important to research in advance where you would go should you have a health emergency or a CF exacerbation. Your CF team can help you with this information. They can also help you with some of the items from the list below.

Taken from CFRI's resource, titled *CF In the Classroom*, below are some tips that one can use to help ease the transition into post-secondary education.

- Once accepted to a college, and after sending in the acceptance letter, students should meet with the campus disability office to register and inquire about accommodations and/or services they offer.
- Inquire about housekeeping services and request increased attention if necessary, including vacuums with HEPA filters, and extra care of shared bathrooms.
- Sign up at the campus recreation center to use the exercise facilities.
- Meet with the director of the student center to find a primary care doctor (preferably one who knows about CF), and schedule an initial meeting.
- Meet the campus pharmacist, as there may be times when medication must be ordered on short notice and the campus pharmacy is the most convenient location.
- Confirm local pharmacy locations in advance.
- If using a mail-order pharmacy, coordinate orders regarding the time of delivery and mailing address where medications are to be shipped, especially chilled medications that are sent overnight.
- Check on the college's health insurance program and see how it interfaces with any existing coverage.
- At 18, the Health Insurance Portability and Accountability Act (HIPAA) affects parents' ability to have access to their young adults' medical records and participate in their medical decisions. Consider signing a release form for each health care provider, pharmacy, and insurance carrier, etc. in advance.
- Ask the CF doctor from home to send standing orders for routine procedures such as sputum cultures, spirometry, and blood work, etc. to the primary doctor at school in case a change in health requires an immediate diagnosis.
- Get a recommendation from specialty doctors at home (i.e. endocrinologist, ENT, gastroenterologist, etc.) for an equivalent care provider near the college campus.

- Create a binder or electronic file with copies of the following: 1) a complete list of medications including their dose and frequency, 2) insurance contact information and copies of health insurance cards; 3) names and contact information of all CF-related doctors and nurse practitioners (for local doctors to fax or email test results).
- CF-related diabetes requires special attention: alert the dorm's resident assistant and possibly a neighboring student, and provide them with necessary information in case of an emergency.
- Consider assembling a 'med cart' with drawers and trays for the storage of medications, nebulizers and sterilization equipment.
- Make sure the sterilization process for nebulizers, etc. will work easily in a dorm setting.
- Get a small refrigerator for medications that need to stay cold.
- Stock an ample supply of paper towels, hand sanitizer, antibacterial wipes, tissue, etc.
- Consider a reduced course load when scheduling classes. Many students with CF need to devote the time equivalent to one or two class periods per day to respiratory treatments, cleaning equipment, exercise, etc. This way treatment times are built into the course load and are less likely to be sacrificed due to academic and social pressures.
- Schedule classes around treatment times, if possible.



"RESILIENCE, SELF-CARE, ADVOCACY, AND PERSEVERANCE, ARE ALL IMPORTANT QUALITIES FOR INDIVIDUALS WITH CHRONIC CONDITIONS TO CULTIVATE AS THEY NAVIGATE THE CHALLENGES OF MANAGING THEIR HEALTH WHILE PURSUING THEIR EDUCATIONAL GOALS:"
- ALICIA, A PARENT OF A YOUNG ADULT WITH CF

SCHOLARSHIPS

For those ready to take that next step in their education journey, it can be helpful to know what scholarships are out there to lessen financial pressure. Look through the list below to see which scholarships you may be eligible for.

ABBVIE— CF SCHOLARSHIP PROGRAM

- An annual offering of \$3,000 to 40 scholars, with one undergraduate and one graduate student selected to receive an additional \$22,000 each
- Contact: 1-855-227-3493 / info@AbbVieCFScholarship.com

BONNELL FOUNDATION — EDUCATION SCHOLARSHIPS

- An academic scholarship of up to \$2,500 (maximum of two years during an undergraduate degree)
- Contact: (248) 520-2329 / info@thebonnellfoundation.org

BOOMER ESIASON FOUNDATION — SCHOLARSHIP PROGRAM

- Financial assistance to students in the cystic fibrosis community who are pursuing higher education opportunities
- Contact: 1-516-746-0077 / info@esiason.org

LIVING BREATH FOUNDATION — SCHOLARSHIP PROGRAM

- Grants ranging from \$1,000 to \$5,000 for individuals with CF who are graduating from high school or continuing their higher education at a two-year, four-year, or trade school
- Academic scholarships may be used for any of the following: tuition, books, or any extra expenses which are directly correlated to attending school while having CF
- Contact: 1-831-392-5283 / LivingBreathFoundation@gmail.com

PATIENT ADVOCATE FOUNDATION — SCHOLARSHIP PROGRAM

- National undergraduate, Virginia undergraduate, and graduate scholarships for students who have experienced, or are currently experiencing, cancer or chronic illness
- Contact: 1-800-532-5274 / scholarship@patientadvocate.org

ROCK CF FOUNDATION — BOWMAN BROTHERS TRADE SCHOLARSHIP

- Financial assistance of up to \$5,000 will be awarded to five individuals with CF who have received entrance into a trade program
- Contact: emily@letsrockcf.org

VERTEX— VERTEX FOUNDATION SCHOLARSHIP

- Helps eligible students affected by CF, and their immediate family members or caregivers, afford college
- Scholarships of \$5,000 each are awarded to students pursuing two-year, four-year, or graduate degrees across the US or Canada
- Contact: 1-617-341-6100 / [online message platform](#)

UNITED STATES ADULT CYSTIC FIBROSIS ASSOCIATION INC. — EDUCATION SCHOLARSHIPS

- Three academic scholarships for people with CF who are seeking artistic and/or educational degrees
- Financial assistance varies depending on scholarship, ranging from \$2,500-\$5,000
- Contact: Email a representative at cfroundtable@usacfa.org

TRANSITIONING TO AN ADULT CF CLINIC



Transitioning from a pediatric to adult CF clinic is a big step and can come with many questions.

WILL I LIKE MY NEW CARE TEAM?

WILL THEY BE AS NICE TO ME AS WHEN I WAS A KID?

WHAT WILL I DO WITHOUT MY PARENTS WITH ME ALL THE TIME?



AM I READY TO ADVOCATE FOR MYSELF?

These are all valid questions, and ones that hopefully we can help answer to put your mind at ease! Your pediatric CF care team will be there to help you through this transition. However, learning how to advocate for yourself and be confident amongst medical practitioners is one the best ways to make this move as seamless as possible.

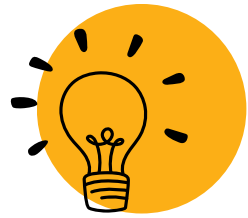
Advocacy means speaking up for yourself or others to make things fair and just. As someone with CF, you've probably been advocating for yourself with doctors and social workers for years, whether you know it or not. At a CF clinic, advocacy might look like asking for specific tests to be performed, being given equal access to quality care, having gender affirming care, making sure your privacy is respected, receiving multilingual support, or being connected to appropriate resources. Don't be afraid to voice your concerns and talk through anything that may be bothering you—odds are you're not alone.

"WHEN YOU TRANSITION TO AN ADULT CLINIC, STAFF SPEAK MORE TO YOU AND LESS TO YOUR PARENTS. JUST BECAUSE YOU ARE NOW THE PRIMARY POINT OF CONTACT, DOES NOT MEAN YOUR SUPPORT SYSTEM HAS GONE AWAY; CONTINUE TO REACH OUT FOR SUPPORT."

- HANNAH, YOUNG PERSON WITH CF



PATIENT ADVOCACY - TIPS & CONSIDERATIONS



- Do not be afraid to ask questions.
- Bring a notebook to clinic to write down questions, terminology, and/or instructions.
- The American Medical Association has a Code of Ethics pertaining to patient rights. You can familiarize yourself with those here: <https://tinyurl.com/5h59bzc9>
- Ask for your preferences to be honored as much as possible. For example, if you know how to administer antibiotics at home and there is no clearly identifiable reason for you to stay in the hospital other than the IV antibiotics, discuss your options with your care team to explore whether you can be discharged to finish your IVs at home.
- Ask for your pronouns and preferred name to be respected at all times.
- Remember, your CF Care team wants the best for you, but no one cares more about you than you.
- Don't be afraid to state, and re-state your needs if they have not been met, to your care team.





FREQUENTLY ASKED QUESTIONS



WHAT IS THE AGE OF TRANSITION FROM PEDIATRIC TO ADULT CARE?

The age varies among CF centers, however the average age is between 18-21 years old. If you don't feel ready to transition as you approach your 18th birthday, ask your care team about options to delay or extend the process.



DOES THE ADULT MODEL DIFFER FROM THE PEDIATRIC MODEL OF CARE?

While there are no consistencies across the board, it is largely understood that pediatric CF centers focus on creating a nurturing environment with consistent team members. Parents are included in discussions and decision making. With the adult model of care, the focus is on the patient, and there is a greater expectation that the adult patient will have autonomy in working directly with the care team and making one's own care decisions. Depending on your center, members of your care team may vary from visit to visit based on availability.



WILL I MEET MY NEW ADULT CARE TEAM BEFORE I TRANSITION CLINICS?

Some adult CF clinics will coordinate with the nearby pediatric sites to offer a preliminary appointment to meet the adult CF team. However, despite best intentions from clinic staff, this is not always the norm. If getting to know your new care team and center environment is important to you, talk to your pediatric team about setting this up.



WILL I HAVE TO CHANGE LOCATIONS WHEN I MOVE FROM A PEDIATRIC TO ADULT CLINIC?

Whether one has to change locations when moving from the pediatric to adult clinic will vary from CF center to CF center. Ask your pediatric team for details.



WHO WILL BE PART OF MY NEW CARE TEAM?

- Patient Coordinator: Checks you in and provides you with relevant forms
- Medical Assistant: Checks your vital signs: height, weight, oxygen, etc.
- Respiratory Therapist: Checks your lung function
- Nurse Coordinator: Reviews your current medications and orients you to the clinic
- Pulmonary Fellow or Nurse Practitioner: Takes your detailed medical history, performs a physical examination, and discusses your care plan
- Dietician: Assesses your nutrition needs and meal plan
- Social Worker: Assesses your social supports and resources
- Pulmonologist: Oversees your plan of care

STAYING ON YOUR PARENT'S INSURANCE:

Preparing to transition from a pediatric to adult CF clinic might bring up questions about health insurance. In the United States, people can stay on their parent's health insurance plan until the age of 26. As young adults with CF approach their 26th birthday, anxiety regarding medical expenses can seep in. However, there are ways to prolong one's ability to remain covered under a group plan.

It's important to note that the policies listed below may use alternate names depending on the state. Always make sure to consult a health insurance expert before making any changes to your health insurance plan.

OPTION 1: DISABLED CHILD EXTENSIONS OF COVERAGE

- Most insurance providers have policies that allow for the extension of health insurance coverage for dependent children past the age of 26 if there is a demonstration that the dependent is:
 - Incapable of self-sustaining full-time employment because of mental or physical disability. This is typically demonstrated through a form that the insurance company will provide and your doctor has to confirm that you cannot self-sustain through employment because of your health. This means that you can work part-time, but not enough that would allow you to self-support.
 - Chiefly dependent on the parent for support and maintenance. For most states, this entails showing that at least 50% of your daily living expenses are paid for by your parents.
- Individuals must apply for the extension to the insurance carrier before reaching the limiting age of 26.
- Individuals 26 or older who are married are not eligible for this extension, though people under the age of 26 who are married typically are if they can demonstrate they meet the above stated requirements.



OPTION 2: COBRA

- If you are ineligible for the Disabled Child Extension of Coverage, you may still be able to extend your parent's health insurance for yourself under COBRA.
- Qualifying events under COBRA for extension include:
 - Termination of employment 18 months
 - Death of covered employee 36 months
 - Divorce or separation 39 months
 - Become eligible for SSDI 29 months
 - Reach limiting age of policy 36 months



RESOURCE LIST



- Cystic Fibrosis in the Classroom: <https://tinyurl.com/5946z9x5>
- Patient Assistance Resources: <https://tinyurl.com/3c3jydxr>
- Adolescent Privacy Laws by State: <https://tinyurl.com/yxwstw99>
- Telehealth Among People with CF: <https://tinyurl.com/2p6hfncu>
- Contraception & CF: <https://tinyurl.com/2p9c7bzb2>
- CF & Sexual Health: <https://cfreshc.org>
- Patient Rights: <https://tinyurl.com/5h59bzc9>
- CF Teen Resources - Stanford Center: <https://tinyurl.com/4v2xc7ad>
- Working with Doctors Toolkit: <https://tinyurl.com/y7x6yk4w>

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OUR MISSION

To be a global resource for the cystic fibrosis community while pursuing a cure through research, education, advocacy, and support.



OUR VISION

To find a cure for cystic fibrosis while enhancing quality of life for the CF community.