



# Managing Your Life with Cystic Fibrosis

A TEEN'S GUIDE

Foundation Care<sup>™</sup>

An **AcariaHealth** Solution

*Transforming Lives With Compassionate Care*

## **LIFE AS A CF TEEN**

This is a fun and exciting time in your life. It can also be busy and challenging. You're juggling school, friends, activities, and planning for your future while growing into yourself. You will become more independent and take on more responsibility.

With the support of your parents and your Cystic Fibrosis (CF) care team, you will take a more active role in managing your health and CF treatments. You'll notice more correlation between your eating habits, exercise, and treatment schedule with the way you feel.

Stick to your treatment schedule, follow healthy habits, and engage the support of your CF care team, family, and friends. Doing so can help you feel your best and allow you to enjoy many exciting things about this time in your life, such as:

- > ***Trying out a new club, sports team, or hobby***
- > ***Expanding your social life by making new friends***

- > ***Dating and going to school dances***
- > ***Earning good grades and attending college***
- > ***Discovering your passions and planning your career***

Teenage years are often marked by change. Maybe you have different friends, your taste in music has evolved, your style has changed, or you switched schools. Like others your age, you will start to notice changes with your body. You may experience that you have a deeper voice, hair growth, or that you are taller. Puberty brings with it many changes. As a teen with CF, you may experience these changes later than your peers. This can be due to issues with nutrition or frequent illness.

It's important that you stick to your regular treatment schedule. As you get older, new types of bacteria and fungus begin to develop. This can result in new inflammation and scarring in your lungs. As you age, respiratory complications can become more serious.



## Importance of Nutrition

Like all teens, you should eat a balanced diet that includes plenty of fruits and vegetables, grains and breads, dairy products, fat, and protein. With CF, you probably need to consume more calories than others in your age group. Your body may need as many as 3,000 to 5,000 calories each day, depending upon your specific dietary needs.

You should work with your parents or caregivers and meet with a CF dietician to determine exactly how many calories you need each day. The dietician will look at your growth and weight gain to create a specialized nutrition plan for you.

## Stick to Your Nutrition Plan, Even When its Hard

It can be difficult for you to eat enough each day to meet your dietary needs, especially when you aren't feeling well. While, for many, it may seem desirable to eat whatever you want, you know too well that people with CF find it difficult to do so. If you have CF, eating well and taking your enzymes and supplements will benefit you now and in the future.

## Importance of Exercise\*

In addition to the right diet, exercise can help give you energy and a mental boost. Talk to your doctor about the right kind of exercise and pay careful attention to how you feel while exercising. Don't forget to rest or stop if you get tired.

The more fun you're having, the more likely you'll want to stay involved in your chosen activities. If you're a teen who feels uneasy or unable to play on a sports team or league, think about a formal exercise program.

Formal exercise programs can include treadmills, stationary bikes, swimming, etc. Before starting any program, you should have an exercise test ordered by your doctor. This test will show if your heart and lungs can handle the exercise.

*\*Rarely, exercise makes the hearts of some people with CF beat abnormally. If this happens during the test, your heart rate should be watched during exercise and your exercise kept at a lower level. Exercise should also be kept at a lower level if it causes low blood oxygen levels. You should be monitored until you learn how to keep your exercise at a safe level.*

## THE MOVE TO ADULT SERVICES

### Transitioning to a New Clinic

Now that you are becoming a young adult, your needs as a CF patient are much different than when you were a child. It is a good idea to start talking with your parents or caregivers, as well as your doctors about the appropriate time to transition to an adult care center. There is no specific age for transitioning to an adult center, but most CF patients begin the move between the ages of 14-18.

Here are some things to think about for transition:

- > ***Start the discussion early with your parents/ caregivers and doctors. Give yourself plenty of time to talk about the transition and ask questions***
- > ***Make sure you are fully involved in the transfer plans***
  - > ***Meet the adult team***
  - > ***Visit the adult center***
- > ***Look for a 'Joint Transition Clinic' to help ease you into the change***
- > ***Find a key person you can contact when needed***
- > ***Have a facility informational booklet on hand***



## Advocating for Yourself

It's common for anyone to want to fit in. Pressurized social environments can make this especially hard for teens. There can be underlying expectations to go with the group, even when you don't want to. Stand up for yourself and learn to ask for what you need. If friends do things that aren't healthy for you, share the possible health issues with them and make other suggestions. Your friends may not always understand the severity of your disease. You need to learn to speak up for yourself and educate your friends. Be confident and know that you are doing the right thing for your body and your long-term health.

## OFF TO COLLEGE

Preparing for college is an exciting time in any teen's life. It's a time to make new friends, learn independence, and find personal satisfaction.

There are several factors you should consider when deciding on a school:

- > **Location**
- > **Courses offered**
- > **Social life**

As a student with cystic fibrosis, you will also need to consider other factors, such as:

- > **How far a CF Center is from campus**
- > **A university's Disability Statement for accommodations of your needs\***
- > **Buildings with a "no smoking" policy**
- > **Ground floor room**
- > **Self-catering or a catered hall**
- > **Facilities for intravenous equipment**
- > **Sufficient electrical outlets**
- > **Security among all university buildings and accommodations**
- > **Windows that open**
- > **Refrigerator for medications**

*\*According to the Disability Discrimination Act of 1995, all higher education institutions must have a Disability Statement*

When searching for accommodations, make things as easy as possible for yourself. If you have concerns, contact the school and ask questions.

During your college search, you should find the closest CF center and plan a visit to see the services it can provide. Colleges in areas with extreme weather may exacerbate your symptoms. You may want to avoid certain climates, or make sure a CF center is close so you can get help quickly if you become ill.

### Preparing for College

Once you've chosen your college, verify that you have the support of the school and staff before you arrive on campus. Check with the college to make sure it offers support in the following areas:

- > ***A college nurse who communicates with you often***
- > ***Resident Hall Coordinators/Advisors who are aware of your condition (subject to your personal wishes)***
- > ***Help with tasks such as laundry, when needed***
- > ***Daily contact during times you may be hospitalized/bedridden***
- > ***Referrals for professional services the college doesn't provide, such as counseling, housing, and financial help***



You will need to check with the college about the other students with CF. You should try to avoid being in the same classes or dorm room due to the possible spread of infection.

It is also important to consider your course work and your workload. Will you be a full-time or part-time student? Going part-time means it will take longer, but it is something to consider when adjusting to a new environment. Be sure to check with your professors if you miss classes due to hospitalization. Ask your professors how you can make up course work and/or tests.

## Financial Considerations

There are several scholarships offered specifically to college students with CF. Your college has a financial aid office to contact for more information. Ask about other programs for which you may be eligible.

## How to Handle Life Away from Your Parents

As you grow up you will learn to be more independent. Even those without cystic fibrosis find growing up challenging and exciting. As someone with CF, you will have to ensure that your health is being taken care of properly.

To start this transition, think about taking these steps:

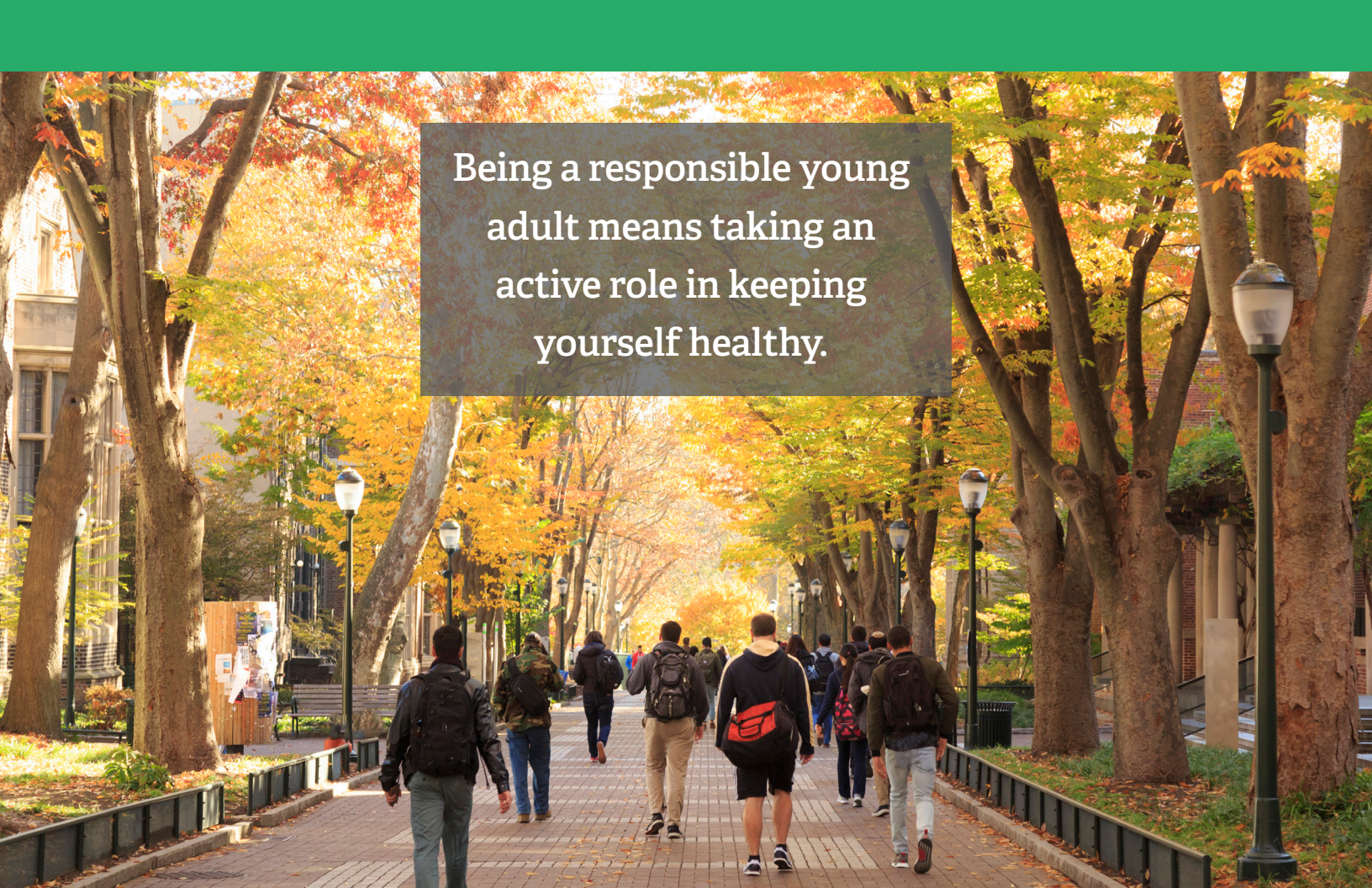
- > ***Call your doctor and schedule your next appointment***
- > ***Learn your medication names, doses, times, and side effects***
- > ***Be able to correctly recognize your symptoms if you notice any changes in your daily life (such as coughing more, feeling more tired during the day, etc.)***

Being a responsible young adult means taking an active role in keeping yourself healthy. Do not despair when it feels challenging. Your family, friends, doctors, and teachers are here to support you and help you navigate life with CF. Once you learn to handle your CF, you will become more confident in managing your health.

## FINDING A JOB

Your friends are finding jobs and making money and you want to do the same — and you can! But like most other things, living with CF means you have more to consider when looking for a job or career.





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You have to ask yourself: do you or do you not tell your potential employer you have CF? This is a very important decision. Talk to your family, friends, CF care team, and/or other CF patients who are currently employed. They may have advice that could help with your decision. Here are a few things to consider when deciding:

- > ***You do not legally have to share your diagnosis with your employer***
- > ***The severity of your illness could affect what jobs you can hold and how often you can work***
- > ***The company's decision to hire you should be based on your ability to do the job***
- > ***Disclosing your diagnosis during an interview can put the company in a tough spot***

## **Interviewing for a Job**

- > ***Prepare by doing research on best interview practices and details about the company***
- > ***Know your state and federal laws related to questions that can legally be asked [eeoc.gov](https://www.eeoc.gov)***
- > ***Use good judgment if you're not feeling well the day of the interview, and reschedule, if you need to***

As you grow up and become an adult, our team at Foundation Care is dedicated to helping you navigate your CF. Your future is bright and we want you to feel confident seizing the opportunities that will come your way. Our team of experts are always in your corner, ready to help when you need us.

## **PROFESSIONAL CARE DISCLAIMER**

Information in this booklet is not meant to replace professional care. Always seek professional care when making health-related decisions.

## **References**

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2. [www.everyday-cf.com/cf-health/divinginto-nutrition](https://www.everyday-cf.com/cf-health/divinginto-nutrition), Everyday CF. "Diving into Nutrition", May 2022.
3. [www.everyday-cf.com/cf-living/school-life](https://www.everyday-cf.com/cf-living/school-life), Everyday CF. "School Life", May 2022.
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## Also available from Foundation Care:

- > A Parent's Reference: Caring for an Infant or Child with Cystic Fibrosis
- > The Huxi Book Series
  - > The Amazing Story of Huxi: A Panda with Cystic Fibrosis
  - > Huxi Goes on Vacation!
  - > Huxi Meets Her Super Team

When creating this booklet, Foundation Care identified these websites as quality sources of information about CF.

[ReachingOutFoundation.org](https://reachingoutfoundation.org)

[CFLifestyleFoundation.org](https://cflifestylefoundation.org)

[CysticFibrosis.com](https://cysticfibrosis.com)

[CFResearchInstitute.org](https://cfresearchinstitute.org)

[Everyday-cf.com](https://everyday-cf.com)

[CFFoundation.org](https://cffoundation.org)

[Attainhealth.org/BloomingRoseFoundation](https://attainhealth.org/BloomingRoseFoundation)



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