

Caring for an Infant or Child with Cystic Fibrosis

A PARENT'S REFERENCE



Foundation Care™
An AcariaHealth Solution



LIVING WITH CYSTIC FIBROSIS

You have just learned that your child has cystic fibrosis (CF). You likely have many questions about their new diagnosis:

- > **What is CF?**
- > **Are there treatments?**
- > **Are there cures?**
- > **How does this affect the life you expected your child to lead?**
- > **What will you need to do as a parent to raise a child with CF?**
- > **Can your child live a relatively normal life?**

Our team at Foundation Care is dedicated to helping your family care for your child in the most thoughtful and comprehensive way. We want you and your child to feel confident as you navigate life with CF. We hope you find this guide helpful. Remember, our team of experts are here to support your family every step of the way.

First Step: Processing

Learning that your child is living with a chronic disease can be a stressful experience. You may feel overwhelmed, angry, or afraid. It can be an emotional time as you process the diagnosis. Take time to do some research and learn more about the disease. As you become acquainted with your CF care team you'll find that having a support system can help immensely.

Next Step: Managing

Armed with a diagnosis, you'll start preparing to care for your child. You will start to acclimate to the changing needs of your family and the realities of your child's CF. It can be overwhelming to know where to begin. Here are a few suggestions that may help:

- > **Gain knowledge:** *Talk to your CF team, reference Foundation Care's educational resources, ask questions.*
- > **Find support:** *Get involved in support groups and connect with other parents who are managing the care of their children with CF.*
- > **Make a plan:** *Familiarize yourself with CF treatments and therapies. Consider what treatments are right for your child and for your family, and how your family may need to adapt.*

Future Steps: Stability and Hope

Now that you've learned more about CF, it's time to plan long-term for your child's future. People who are diagnosed with cystic fibrosis are living longer, more productive lives because treatments are evolving and improving. Here are a few things you can do to ensure that your child has the best possible future:

- > **Make a routine:** *Treatment of CF usually means taking either oral or inhaled medications at scheduled times. Fitting this into your life can be a challenge, but consistency is the key to success.*

- > **Be diligent:** *Once you have a routine, do your best to stick to it. Life can be unpredictable and cause you to miss or skip a treatment. Missing even one step of the treatment routine can cause setbacks. Talk to your CF care team for suggestions about how to stick to a schedule and what to do if a treatment is missed.*

Don't forget about your own needs: As a parent and a caregiver, it can be easy to push your needs to the side for the benefit of your children. We often forget that the best caregivers take time to recharge. Prioritize healthy habits so you can have the energy to help your children physically and emotionally.

Finding Your New Groove

There is no such thing as a universal normal, but there is a personal normal. Your normal is the usual everyday state of your life. Even after learning the diagnosis and taking steps to manage your child's CF, you may hope that things will go back to the way they were. It is important to understand that your normal has changed and that it will take time to find your new groove.

As your child grows up, the ways in which your family manages CF will change to suit your child's needs. Remember that although treatments may change and care plans may evolve, CF will always be part of your child's life. You may want to consider the needs that your child will have as they mature. Some adults living with CF may still need help with their physical care. Every CF patient's care is different, so being prepared can help ease the whole family into each new stage of care management.

People living with cystic fibrosis live full lives, chase big goals, and do extraordinary things. They go to school, make friends, play sports, have careers, get married, and have children.

CF does not stop dreams, but it may change timelines or cause roadblocks that need to be addressed. Talk to your care team about ways that CF may impact the life you imagined for your child. While these discussions may be hard to start, they help set realistic goals and frame a life plan.

Support for Siblings

Living with CF can be stressful for everybody involved, including siblings. Younger siblings may not understand why their brother or sister with CF receives so much of their parents' attention. Older siblings might feel left out because they're healthy or may not understand the diagnosis. Siblings may also have fears about what is happening to their brother or sister.

It's important to consider all your children as your family makes a plan for living with CF. Talk to your children. Let them know that your home is a safe place to ask questions and show emotion. Communication, at a level that is appropriate for the ages of your children, is key. Know that time spent together, even small activities that take only a few minutes, can be impactful.

Be sure to find and use available mental health resources. This will help you and your children handle the affects CF has on your family.



NUTRITION

People with CF need to maintain a high-calorie, high-fat, and high-sodium diet to keep a healthy weight. They also need the right combination of vitamins and mineral supplements to ensure their bodies' nutritional needs are being met.

As children with CF grow up, their nutritional needs will change. Read on for guidelines and dietary needs for people living with CF at different ages. If you have questions about the specific nutritional needs of your child, please consult your CF care team.

0-12 months: It is recommended that during your baby's first few months of life he or she has only breast milk or formula. When your baby is 4-6 months old and is holding their head up, keeping food in their mouth, and sitting up with some help, pureed solid foods can be added to their diet. Slowly incorporating a variety of strained fruits, vegetables, and meats will help your baby get closer to eating the calories needed for good nutrition and growth. When your child is 8-12 months old and has become comfortable with pureed solid foods, you will want to start serving high-calorie finger foods and gradually boost calories with safe solid foods. Be sure to serve solid foods in small pieces, and supervise your child to decrease the risk of choking.



For snacks:

- > **Cheese**
- > **Nuts and trail mix**
- > **Peanut butter**
- > **Muffins or biscuits with butter**
- > **Bagels and cream cheese**
- > **High-fat meats, such as bacon, sausage, pepperoni, or hot dogs**
- > **High-fat yogurts and ice cream**
- > **Milkshakes** (making them with a drink supplement product, such as Scandishake, adds calories, carbohydrates, fat and minerals)

12-24 months: Most toddlers need 1,000 to 1,300 calories daily; however, a toddler with CF may need 30%-50% more calories, or 1,300 to 1,900 calories daily. Encourage your child to drink whole milk instead of water or juice, as whole milk contains the fat and calories necessary for good growth and nutrition. Serve your child a variety of high-calorie finger foods at meals. Make an effort to give your child a high-calorie breakfast as it will fuel the rest of their day. Offer your child 2 to 3 snacks per day between meals.

When preparing meals:

- > **Use whole milk instead of skim milk**
- > **Add extra cheese to foods like omelets, burgers, sandwiches, and pizza**
- > **Use butter, margarine, or mayonnaise generously**
- > **Choose fatty cuts of meat**
- > **Avoid low-calorie or low-fat versions of foods**
- > **Add calorie enhancers, such as Duocal, to your child's food**
- > **top salads with foods like avocados, nuts, cheese, and meat**
- > **Add whipped cream to desserts**

3-7 years old: Children in this age range should consume around 2,000 to 2,800 calories a day. Their diets should consist of dairy products, grains, starches, fruits, and vegetables. In these developmental years, children living with CF will eat about the same amount as children who do not have CF; it is vital for parents of children with CF to choose foods that are higher in calories for their children.

12-17 years old: A teenager with CF may need as many as 3,000 to 5,000 calories a day. Their daily intake should consist of 15%-20% protein, which means that 600 to 1,000 calories should come from sources like meat, milk, fish, soy products, eggs, and nuts.

You can help your child eat right and meet their nutritional goals by finding foods that supply more energy per bite. Focus on quality over quantity. The suggestions above will help you choose foods that pack more benefits per bite for people living with CF.

Pancreatic Enzyme Replacements

People with CF have a hard time digesting and absorbing food which occurs in the small intestine. Pancreatic enzyme replacements, or simply “enzymes,” are prescribed by healthcare providers and can help absorb and digest food.

Vitamins

The fat-soluble vitamins A, D, E, and K are important for immune function, growth, and healing. These vitamins are usually absorbed along with fat. People with CF have trouble

digesting fat, making these important vitamins hard to absorb. Your child will need to take his or her vitamins along with pancreatic enzymes to help with absorption. Regular, over-the-counter vitamins are typically not prescribed. Instead, doctors will suggest specific vitamins for that will most help your child.

Exercise*

Studies show that regular exercise slows the decline of lung function and strengthens the heart. Exercise helps people with CF enjoy a healthier lifestyle. When encouraging your child to exercise, there are three things to think about:

- > **Does your child enjoy the activity?** *If not, they may not stick with it and get the health benefits.*
- > **Does the activity enhance your child’s social life?** *Exercise can be a great way to connect with family and make new friends. Children often find companionship through exercise, promoting participation.*

*Please note: Before exercising, ask for an exercise test from your doctor. This shows if your child’s heart and lungs can handle the strain and what level of activity is most appropriate.

- > **Is the workout demanding enough?** *Make sure the workout is physically challenging to a level that is helpful. People with CF benefit from regular participation in cardiovascular activities that exercise their heart and lungs.*

Other things to think about:

- > **Involve your child** *in a variety of activities. This will help them meet new people and figure out what activities are of most interest to them.*
- > **Reward your child** *when they join group events. Positive reinforcement can help your child’s confidence and build healthy habits.*
- > **Plan active playtime as often as possible.** *Exercise can feel less like exercise when your child is having fun. Active playtime is also a good way to build bonds between your child with CF and his/her siblings.*
- > **Keep TV and video game time to a minimum and encourage your child to want to be active.** *Creating this healthy balance will benefit your child for a lifetime.*

CHILDCARE AND SCHOOL

Caring for a child with CF is a full-time job. Parents who work outside the home often find themselves caught in the difficult struggle. They may have to choose between providing care for their child or going to work to meet financial needs. Children with CF need more care than a typical childcare provider can offer. Families with children diagnosed with CF often educate a close friend or family member to care for their child.

What can you do if no one is available? Many states have a solution: Prescribed Pediatric Extended Care Centers (PPECCs). PPECCs have been around for more than 20 years. A PPECC is a medical daycare center for children with special healthcare needs, for which standard daycare centers are not equipped. Here, children receive medications and treatments by trained professionals such as nurses, therapists, and nurse assistants. A PPECC can be less expensive than home health nursing, and Medicaid and Medicare usually cover the cost of the service.

Some private insurance companies also recognize the cost savings and will cover PPECC services.



The Americans with Disabilities Act (ADA) may help if you are having trouble finding a daycare for your child or if you experience discrimination. Under the ADA, a daycare provider cannot refuse to care for a child simply because the child has a disability. The daycare provider would need to prove that bringing the child into the daycare setting is considered an “undue hardship”. This is determined on a case-by-case basis. To find out more about the ADA, call 800.514.0301, or visit their website at: [justice.gov/crt/about/drs](https://www.justice.gov/crt/about/drs).

Starting School

Preparing to send your child to school can have its struggles, especially when dealing with school systems. Your child’s daily CF treatments must be completed, even when he or she is at school. Here are a few guidelines to help make the best choice:

- > **Search for the right school:** Start searching about six months to a year before you plan to enroll your child. The law requires all public schools to accommodate your child’s special needs. Most private schools are not required unless they receive federal funding. Make sure you’ve done your research.
- > **Know your child’s rights:** The Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973 protect

your child’s right for accommodations at a public school. These acts require that schools offer children with special needs an Individualized Education Program (IEP). Some IEP accommodations are:

- > **Allow time during the school day for airway clearance therapy or to take medicine**
 - > **Adjust rules to grant your child the responsibility of taking his/her own medicines, like enzymes**
 - > **Create a plan to receive homework or tutor when your child is ill or in the hospital**
 - > **Adjust or waive attendance rules**
 - > **Grant access to a private room, and do not limit access to a bathroom or water**
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- > **Be your child’s biggest advocate:** You know your child’s needs better than anyone else. Before the school year begins, contact the school administrators to build your child’s IEP and 504 plans. If your child’s needs change, schedule a meeting with administrative staff. This will make you feel confident in your child’s education.

Know Your Insurance

Make sure you are aware of your insurance coverage and the patient assistance programs available to you. Visit [cff.org](https://www.cff.org) for details about the Cystic Fibrosis Foundation’s Compass Program, including information about assistance programs and reimbursement. If you prefer to speak to a Foundation Care Representative directly, call **877.291.1122**.

PROFESSIONAL CARE DISCLAIMER

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

References

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Also available from Foundation Care:

- > A Teen's Guide: Managing Your Life 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

CFLifestyleFoundation.org

CysticFibrosis.com

CFResearchInstitute.org

Everyday-cf.com

CFFoundation.org

Attainhealth.org/BloomingRoseFoundation



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