

Living with cystic fibrosis

Living with cystic fibrosis (CF) may bring different challenges at different stages of life.

What to expect at different ages and stages of life with CF, and how to talk with children and family about CF:



Some key things to know about raising a child with CF

Raising a child with CF may include social, emotional, and psychological challenges. Like all children, children with CF go to school, have friends, enjoy hobbies, exercise, and play sports.

Parents of a child with CF are encouraged to:

- Take actionable, concrete steps to keep your child safe without over-protecting them. Schedule yearly flu vaccinations for the entire household. Provide them fat-soluble, CF-specific vitamin supplements
- Encourage them to exercise regularly
- Gradually give your child more responsibility for self-care and decision-making as they move through adolescence

How can I talk with my child about CF?

You can talk to your child about CF at any stage, when you feel comfortable. *What* you say may depend on 3 things: your child's age, personality, and ability to understand the information. Your child's care team can provide tips for starting the conversation with your child.

These early conversations help children understand:

- What CF is and that they will always have it
- Why it's important to eat right, follow their treatment program, and clear their airways
- That as they get older, they will be able to manage their own CF care

What should I know about teens with CF?

Teens are right in the middle of the change from childhood to adulthood. They are gaining more independence and may start to manage their own CF care. Encouraging your teen to stick to their CF treatment plan will help them stay on track while they enjoy typical teenage milestones, such as:

- Dating
- Getting a driver's license
- Having a first job
- Planning their future education

Teens may be self-conscious about having CF. They may be embarrassed by their cough and by having to take medicine or treatments at school. They may be lighter or shorter and get tired faster than their friends.

Encourage teens to explain to friends that:

- CF is what they have, not who they are
- No one can get sick from their cough. The cough helps clear their lungs
- Medicines help them digest food, fight infection, and provide them with vitamins



Adult life with CF

As people with CF grow into adulthood, new issues may arise concerning independent living, career, family planning, and travel. Your CF care team can guide you through these transitions.

Independence

Most adults with CF do their own CF care and live on their own. Your respiratory therapist can tell you which airway clearance techniques are best for you when you live independently.

Family planning

Young adults with CF may face marriage and family issues. People with CF are likely to have a hard time getting pregnant or fathering a child because of fertility issues. Your care team can arrange for fertility tests to help determine if you may have any issues with fertility.

Career

Here are some key questions to consider when you are choosing a career that uses your unique skills and interests:

- Will this career or job schedule offer me the flexibility I need to fit in my treatments, medicine routines, and care team visits?
- Will I have access to quality health insurance?
- Will I be exposed to substances that will irritate my lungs (smoke, dust, or chemicals) or expose me to germs that could cause lung infections (day care center or healthcare setting)?

Talk with your CF social worker and care team about things to look for and what to avoid in the workplace. Because working and living everyday with CF can be challenging, some people with CF choose to work for employers who offer flexibility or choose to be self-employed.

Travel

Just because you have CF doesn't mean you can't travel for pleasure or business. It's easier to do with preparation and planning.

Visit with your care team a few months before your trip. They can:

- ✓ Do a medical checkup and arrange for tests or treatments you should have before you leave
- ✓ Talk with you about ways to manage your CF while traveling, and help you locate a CF care center close to your destination
- ✓ Prepare medical documentation for travel (health summary, oxygen documentation, customs certificate to explain why you are traveling with a large supply of medicines and equipment)

Want more information and useful tips about living with CF?

Go to www.Everyday-CF.com*

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