Children with Cystic Fibrosis should grow and develop normally with proper care.

Plan to spend time each day for therapy and medicine to keep your child healthy.

You should expect your child to go to school, play sports, and do what all other children do.

Plan for your child to be an adult, go to college, have a successful career, and get married.

Plan for the future! Although there is no cure for CF at the moment, new treatments are continually being discovered through ongoing research to help improve the quality of life and life expectancy of those with CF.

Cystic Fibrosis occurs:

1 in 3,000 Caucasian births

1 in 30 people are carriers for CF

30,000 people in the United States have Cystic Fibrosis

More than **45%** of the CF population is age 18 or older and the average life expectancy continues to increase.

Additional Resources

Arkansas Cystic Fibrosis Care Center:
www.arkansasCF.com

Cystic Fibrosis Foundation:
www.cff.org

Genetics Home Reference: Cystic Fibrosis
www.ghr.nlm.nih.gov/condition/cystic-fibrosis

Cystic Fibrosis in Diverse Communities:
www.lung.org/lung-disease/cystic-fibrosis/

Clinical and Functional Translation of CFTR:
www.cftr2.org

Cystic Fibrosis

What you need to know

Arkansas Children's
HOSPITALS · RESEARCH · FOUNDATION

#1 Children's Way | Little Rock, AR 72202

For more information or questions, please contact the Cystic Fibrosis Center or the Genetics Department at Arkansas Children's Hospital

Cystic Fibrosis Center: (501) 364-1006
Genetics Department: (501) 364-2966

Arkansas Children's
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Arkansas Children's Hospital is an accredited Cystic Fibrosis Care Center by the National Cystic Fibrosis Foundation

Congratulations on the birth of your baby!

Your baby had a positive newborn screen for cystic fibrosis (CF). Further testing shows your child has a diagnosis of CF.

There are many benefits detecting CF early:

- Start treatments to control symptoms
- Improve nutrition
- Ensure normal growth

This brochure is to inform you about CF, provide resources for additional information and help guide your next steps.

If you have more specific questions, talk with a CF newborn screening expert such as a doctor, nurse specialist or genetic counselor.

What is Cystic Fibrosis?

Cystic Fibrosis is an inherited, chronic disease that affects the respiratory, digestive and reproductive systems.

A non-working gene and protein product cause the body to make thick, sticky mucus that can clog the lungs, leading to infection, and blocks the pancreas from making enzymes needed to help digest and absorb food.

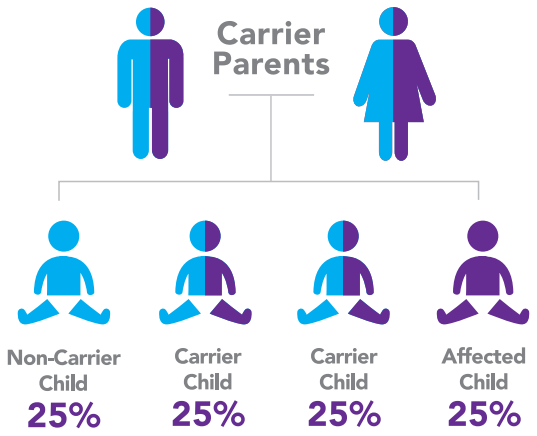
How do you get Cystic Fibrosis?

Cystic Fibrosis is a genetic condition. This means it's inherited - just like eye color, hair color or height. Genes, or genetic traits, are passed along to children in a natural process that cannot be controlled.

There is nothing you or your partner did that caused this to happen.

We all have two copies of the CF gene – one from each parent. To have CF, a person must inherit two copies of the CF gene that have been changed and do not work properly. If both parents are carriers CF, this means they have one copy of a changed CF gene, but do not have the disease.

Each time two carriers of the CF gene have a child; their child has a 25% chance of having CF, a 25% of not having CF, and a 50% chance of having one CF gene or being carrier.



What are Cystic Fibrosis symptoms?

The symptoms differ between people with CF range from mild to severe. The most common symptoms include:

- Persistent cough
- Frequent lung infections
- Chronic sinusitis or nasal polyps
- Wheezing or shortness of breath
- Poor growth or weight gain
- Frequent greasy, loose stools

How do you treat Cystic Fibrosis?

People with CF should receive their medical care at specialized, accredited CF Care Centers. These CF Centers have a team of healthcare workers with expertise and special training in treating CF.

People with CF require daily treatments to stay healthy. There are many therapies available to treat the symptoms of CF:

- Airway clearance therapy clears mucus from the lungs
- Medicine to help thin mucus and fight bacterial infections
- Enzymes to digest and absorb food
- Supplements for weight gain
- Eating a healthy, high-calorie diet with vitamin supplements
- Routine exercise
- Avoid tobacco smoke

Additionally, it is important to get regular immunizations and an annual flu shot. Also, keep scheduled appointments with your doctor.