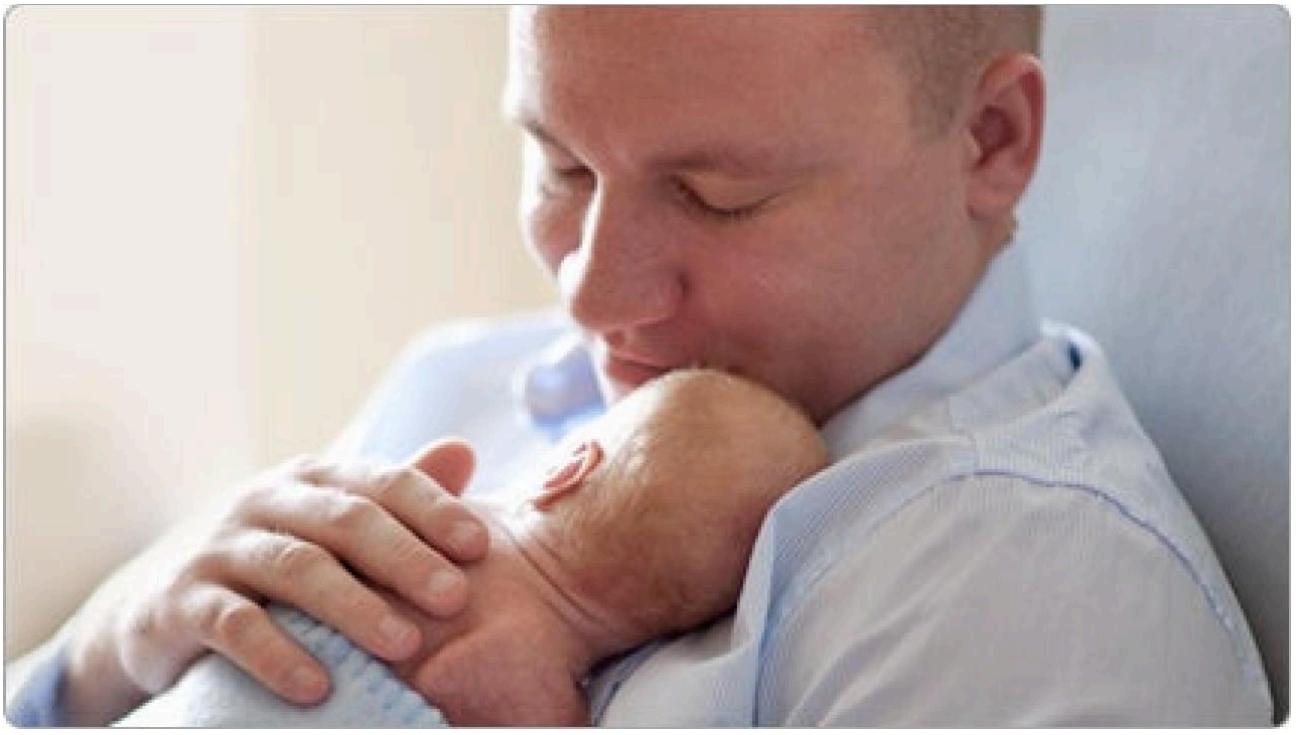

Cystic fibrosis and your baby

KEY POINTS

> Cystic fibrosis (also called CF) is a condition that causes thick mucus to build up in the body. This causes problems with breathing and digestion.

> CF is passed from parents to children through genes. A baby has to inherit a CF gene from both parents to have CF.

> All babies have a newborn screening test for CF so it can be found and treated early.

> Treatment can include medicines and chest therapy to help with your baby's breathing and digestion.

Download more information on cystic fibrosis <https://www.marchofdimes.org/sites/default/files/2023-07/mod_cystic_fibrosis_infographic.pdf>.

Cystic fibrosis (CF) is a condition that affects breathing and digestion. It's caused by very thick mucus that builds up in the body.

Mucus is a fluid that normally coats and protects parts of the body. It's usually slippery and slightly thicker than water. But in CF, the mucus is thicker and sticky. It builds up in the lungs and digestive system and can cause problems with how you breathe and digest food.

CF affects about 30,000 children and adults in the United States. It is one of the most common genetic conditions in this country. CF is more common in white babies (about 1 in 3,500) than in Hispanic, Native American or Alaskan Native babies (about 1 in 10,000), in Black babies (about 1 in 15,000 black) and in Asian babies (about 1 in 30,000).

What causes CF?

CF is inherited. This means it's passed from parent to child through genes. A gene is a part of your body's cells that stores instructions for the way your body grows and works. Genes come in pairs—you get one of each pair from each parent.

Sometimes the instructions in genes change. This is called a gene change or a mutation. Parents can pass gene changes to their children. Sometimes a gene change can cause a gene to not work correctly. Sometimes it can cause birth defects or other health conditions. A birth defect <https://www.marchofdimes.org/find-support/topics/planning-baby/birth-defects-and-your-baby> is a health condition that is present in a baby at birth.

Your baby has to inherit a gene change for CF from both parents to have CF. If they inherit the gene change from just one parent, they have the gene change for CF, but they doesn't have the condition. When this happens, your baby is called a CF carrier.

What problems does CF cause?

Babies who have CF have very thick and sticky mucus that builds up in the body. When this mucus builds up in the lungs, it blocks airways and causes breathing problems and infections. Airways are tubes that carry air in and out of the lungs. As a baby with CF gets older, lung infections can get worse. This can lead to serious, and sometimes deadly, lung damage.

When mucus builds up in the digestive system, it blocks tubes in the pancreas, an organ in the belly. This can make it hard for the body's digestives system to break down food. When this happens, your baby may not get the nutrients they need to grow and stay healthy.

Some cases of CF are more serious than others. Babies who have CF are often sick with infections and need a lot of special medical care.

How do you know if your baby has CF?

All babies have newborn screening tests <https://www.marchofdimes.org/find-support/topics/parenthood/newborn-screening-tests-your-baby> for CF. With newborn screening tests, CF can be found and treated early.

Before your baby leaves the hospital, their health care provider takes a few drops of blood from their heel to test for CF and other conditions. The blood is collected and dried on a special paper and sent to a lab for testing.

If newborn screening results aren't normal, it simply means your baby needs more testing. Your baby's provider can recommend another kind of test, called a diagnostic test. This test can check to see if your baby has CF or if there is some

other cause for abnormal test results.

Your provider may recommend that your baby have a sweat test to see if they have CF. This is a simple, painless test that checks the amount of salt in your baby's sweat. Babies with CF have more salt in their sweat than healthy babies. Your baby's provider also may recommend a genetic test for your baby.

If your baby does have CF, they may have these signs and symptoms that can be mild or serious:

- Coughing or wheezing
- Having lots of mucus in the lungs
- Many lung infections, such as pneumonia and bronchitis
- Shortness of breath
- Salty skin
- Slow growth, even with a big appetite
- Meconium ileus, when meconium gets stuck in a newborn's intestine. Meconium is a baby's first bowel movement. It can be green, brown or black in color.
- Bowel movements that are frequent, loose, large or look greasy
- Stomach pain or bloating

If your baby has CF, how are lung and breathing problems treated?

Many lung infections in babies who have CF are caused by bacteria that don't usually cause problems for healthy babies. If your baby has CF, medicines like antibiotics often cannot get rid of all the bacteria in their lungs. These infections can lead to lung damage.

Your child's treatment depends on the kind of symptoms they have and how severe the symptoms are. Certain medicines can help children with CF breathe better and prevent infections. Some come as a mist that your child breathes into the lungs. Medicines used for CF include:

- **Mucus-thinners.** Medicines like dornase alfa (Pulmozyme®) help thin mucus, making it easier to cough out.

- **Bronchodilators.** These medicines help open the airways to clear mucus from the lungs. Albuterol (Proventil® and Ventolin®) is an example.
- **Antibiotics.** These are medicines that kill infections caused by bacteria. Tobramycin (Tobi®) is a common inhaled antibiotic, and azithromycin is a common antibiotic taken by mouth.
- **Ibuprofen.** This medicine can help reduce lung redness and swelling that make breathing difficult.
- **Hypertonic saline.** Inhaling this salt-water mist helps draw more water into the airways. This helps thin the mucus.

Your child's provider may recommend that they get lots of physical activity or that you use other therapies to vibrate (shake) the chest to help loosen mucus in her lungs. This can make it easier for your child to cough mucus up and out of the lungs.

If your child's CF becomes life-threatening, a lung transplant may be an option. This is a major operation that is becoming more successful in treating CF.

If your baby has CF, how are growth and digestion problems treated?

Some children with CF gain weight and grow normally. But many grow more slowly than other children.

Most children with CF need to take special medicines that help their bodies get nutrients from food. This helps with weight gain and digestion.

To help them grow, children with CF need healthy, high-calorie meals. They need extra vitamins, especially vitamins A, D, E, and K. A dietitian with experience in treating children who have CF can help you create your child's meal plan for a healthy weight gain. A dietician is a person who has special training in helping people eat healthy.

Some teens or young adults with CF may get CF-related diabetes. This is usually treated by getting shots of insulin at mealtimes. It's important to keep diabetes under control so that it doesn't cause more lung problems.

More information

- Cystic Fibrosis Foundation <http://www.cff.org/>

See also: Genetic counseling <https://www.marchofdimes.org/find-support/topics/planning-baby/genetic-counseling>; Cystic Fibrosis infographic <https://www.marchofdimes.org/sites/default/files/2023-07/mod_cystic_fibrosis_infographic.pdf>

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