What Is Cystic Fibrosis?

Cystic fibrosis (CF) is an inherited condition that affects the lungs, digestive system, and other parts of the body. Normally, our cells produce thin, slippery mucus, sweat, and digestive juices that help protect organs and keep things moving properly. CF makes the fluids thick and sticky, clogging the lungs and pancreas (an organ that helps with digestion).

Babies are tested for CF at birth, so most are diagnosed right away. Signs of CF include poor weight gain, coughing, repeated lung infections, trouble pooping, and large, smelly stools or diarrhea. A unique sign parents sometimes notice is that their child's skin tastes salty because of the extra salt in their sweat. Symptoms can be different from person to person and may come and go.

There is no cure. But improved treatments are helping people with CF live longer, healthier lives.

Frequently Asked Questions (FAQ)

How common is cystic fibrosis?
Cystic fibrosis is rare. About 1,000 people are diagnosed with it each year in the United States. It can affect anyone, but is most common in white people with Northern European ancestry.

What should I do if I suspect my child has cystic fibrosis?
Most babies are diagnosed through the newborn screenings, but not always. Because cystic fibrosis is less common in people of color and screenings don't pick up on every CF variant, they are more likely be diagnosed later. If you're worried, contact a medical provider, even if the newborn screening was negative. Early treatment makes a big difference.

What kind of help is there for cystic fibrosis?
Ways to manage CF usually include:

- **A care team:** This may include specialists, respiratory therapists who help with breathing, social workers, mental health providers, and your regular doctor.
- **Lung care:** Medicines, equipment, and airway-clearing therapies can help with breathing.
- **Digestive support:** Taking medicine with meals and snacks can help with digestion and weight gain. Vitamins and certain supplements may also be beneficial.

What other conditions are common in people with cystic fibrosis?
People with CF may develop other conditions such as diabetes, liver disease, arthritis, an enlarged spleen, and weak bones.

Talking with a Medical Provider

When talking with medical providers or specialists, you might want to:

- **Bring and take notes:** Keep a journal of symptoms, when they happen, and anything that seems to trigger them. Take notes during visits and ask for a summary before you leave.
- **Ask questions like:**
  - "Who should be part of my child's care team?"
  - "What support does my child need at home and school?"
  - "How can we lower the risk of infections?"

What You Can Do at Home

CF care is lifelong. It may help to:

- **Seek support:** It's normal to feel sad, overwhelmed, and angry. Support groups are available online and in person for people with CF and their families.
- **Be active:** Regular physical activity can improve breathing, strengthen bones, reduce stress, and help prevent complications like diabetes and heart issues.
- **Eat well:** A high-calorie, high-fat diet, along with vitamins and minerals can help manage symptoms.
- **Manage stress:** Make time for fun activities with your child – and for yourself.

Learning about cystic fibrosis and getting help is a journey. You're not alone.

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About This Series

This series of handouts on health conditions was written by clinicians in Weill Cornell Medicine's Pediatric Mental Health Integration Program, partners in the ACT for Youth CYSHCN Program Center of Excellence at Cornell University.