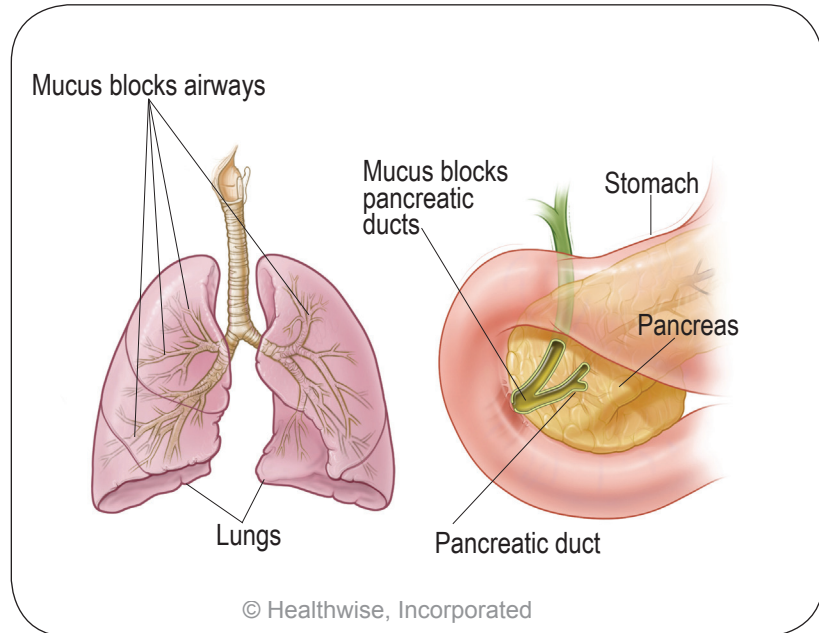




Cystic Fibrosis in Children

Introduction

Cystic fibrosis is a lifelong illness that causes mucus to become thick and sticky. Mucus is the slippery substance inside the nose, throat, sinuses, and airways. The mucus builds up and clogs passages in the body, often in the lungs and pancreas. This can lead to serious breathing problems and lung disease and serious digestive problems. It also can lead to problems with your child's growth and development.



Cystic fibrosis is a genetic disorder. This means that a child must inherit a specific gene from both parents to get the disease.

Cystic fibrosis cannot be cured, but it can be treated. Your child will be able to go to school and take part in social and sports activities. Your child may go on to college, find a career, and find a partner. There will be health challenges, but your child can lead a full life. New treatments are making it possible for people with cystic fibrosis to live longer and longer.

What are the symptoms?

Your child's symptoms will depend on how the disease affects different parts of the body. Common symptoms include:

- ◆ Salty sweat or skin.
- ◆ Changes in appetite. Your child may eat more or less than usual.
- ◆ Low energy.
- ◆ Weight loss.

- ◆ Unusual bowel movements, including diarrhea, constipation, or greasy or very smelly stools.
- ◆ Problems breathing, or getting tired easily while playing.
- ◆ A cough that does not go away, or wheezing.

Over time, symptoms may get worse. It may become very hard for your child to breathe, exercise, or be active. Mucus in the lungs can cause frequent, serious infections and lung damage. Cystic fibrosis can lead to other health problems such as diabetes and osteoporosis.

How is it treated?

The goals of treatment are to:

- ◆ Prevent infections.
- ◆ Reduce mucus in your child's lungs, making it easier to breathe.
- ◆ Help your child stay active.
- ◆ Help your child eat healthy foods.

Your child's treatment will depend on what kinds of health problems cystic fibrosis causes.

You and your child will work with a team, which can include your doctor, nurses, dietitians, physical therapists, social workers, and lung therapists.

Your team may suggest:

- ◆ Medicines to open the airways in your child's lungs and make breathing easier.
- ◆ Medicines to make mucus thinner.
- ◆ Enzymes taken by mouth that help your child digest food better.
- ◆ Antibiotics to fight lung infections.

Your doctor probably will suggest chest percussion and posterior drainage. These involve clapping your child's chest to loosen mucus and having your child lie in certain positions to help the mucus drain.

Your child also will need regular tests to check how well the lungs and digestive system are working and to keep track of his or her overall health.

How can you help your child at home?

Home treatment can make your child feel better and live longer.

- ◆ Give your child many types of high-calorie foods. This will help your child gain and keep weight and have energy. A dietitian can help you plan meals.
- ◆ Encourage your child to exercise. Exercise helps loosen mucus and improves oxygen flow. Upper body exercises, such as swimming or rowing, strengthen muscles that are used for breathing. Talk to your child's doctor about the right type of exercise for your child.
- ◆ Give your child lots of fluids. Children who have cystic fibrosis can have a hard time replacing salt or water in their bodies.
- ◆ Add salt to your child's food, especially during hot weather, to replace the salt lost through sweating.
- ◆ Follow your doctor's directions for chest percussion and postural drainage.

- ◆ Take your child to get all the recommended childhood vaccines, as well as the pneumococcal vaccine.
- ◆ Do not smoke or let anyone else smoke around your child or in your house.

Help yourself

You and your child will struggle at times. To help yourself:

- ◆ Focus on your child's strengths. Let your child know that you love and believe in him or her.
- ◆ Do the best you can, but know that you cannot control everything.
- ◆ Learn what you can do to help your child, but also teach your child self-care. Children who take part in their own treatment often stay healthier.
- ◆ Get support if you need it. A support group or counselor can help.

When to call your doctor

Call 911 anytime you think your child may need emergency care. For example, call if:

- ◆ Your child has severe trouble breathing. Signs may include the chest sinking in, using belly muscles to breathe, or nostrils flaring while your child is struggling to breathe.

Call your doctor now or seek medical care right away if:

- ◆ Your child's cough is worse.
- ◆ Your child has wheezing that is new or that gets worse.
- ◆ Your child has a fever.

Watch closely for changes in your child's health, and be sure to contact your doctor if:

- ◆ Your child has more trouble breathing than usual.
- ◆ Your child has lost weight or is not gaining weight.