# **Lung Health for a Child With Cystic Fibrosis**

If your child has cystic fibrosis, you need to work closely with your child's health care provider and the others on their care team. This helps your child stay healthier, feel better, and have a better quality of life. It also slows the decline in your child's lung function.

Your child's provider may suggest many ways to maintain lung health. These include treatments to clear their airway, medicine, and exercise.

## **Airway clearance therapy (ACT)**



ACT helps loosen and clear mucus from the airways. This helps your child breathe better. It may also lower their risk for infection. There are several ways to do ACT. Work with your child's health care provider to figure out the best one for your child.

ACT often includes certain ways to breathe and cough. Your child may also use a special device to loosen mucus. They may wear a vibrating vest.

Your child may also have chest physical therapy (CPT). It can help loosen and clear thick fluids from the lungs. You will work with a physical therapist to learn how to do CPT. CPT often includes three methods:

- **Postural drainage.** This places your child's body in positions that allow mucus to drain.
- **Percussion.** This is a clapping method to loosen mucus.
- Coughing. This helps remove mucus.

#### Medicine

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Your child may need medicine to prevent or treat lung problems. Many are taken with a nebulizer. This is a device that turns medicine into a mist that your child can breathe in (inhale). Medicines can include:

- **Antibiotics.** These can prevent or treat lung infections. They may need to be used for short or long periods of time. They may be taken by mouth, inhaled, or given by IV.
- **Bronchodilators.** These help to open airways.
- Anti-inflammatory medicines. These help to decrease airway swelling.
- Medicines to thin secretions. These include dornase alfa or hypertonic saline.
- CFTR (cystic fibrosis transmembrane conductance regulator) modulators. They can help the defective CFTR protein work correctly. With cystic fibrosis, the CFTR protein does not work well because of changes in the CFTR gene. Mucus then becomes thick and sticky. And there are blockages in the lungs and digestive system.
- Oxygen therapy. This may be used to treat low levels of oxygen in your child's blood when they are physically active or attending school or work.
- **Nutrition supplements.** These may be taken when healthy eating is not enough. They may include calcium, multivitamins, oral pancreatic enzymes, sodium, and vitamins A, D, E, and K.

#### Nutrition

Your child's nutrition can also improve lung health. It can limit infections. It also helps with other problems. You will work with your child's health care provider and care team to do one or more of the following:

- Increase the number of calories your child eats.
- Give your child more foods high in antioxidants. They can reduce damage from inflammation in the body.
- Give your child pancreatic enzymes to help the body absorb nutrients.
- Give your child vitamins to replace those not well absorbed from food.

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## **Preventing infection**

Your child is at a higher risk for lung infections. There are several ways to help prevent them.

- Vaccines. It is important to remain up to date with your child's vaccines. Talk with your child's health care provider about what vaccines your child needs.
- **Handwashing.** This is important for you, your child, and their caregivers. It can help prevent infections from spreading from one person to another. Wash your hands with soap and clean water for at least 20 seconds. Or use a hand sanitizer with at least 60% alcohol. Be sure to wash your hands after coughing, sneezing, chest physiotherapy, and spending time in public places.

#### **Exercise**

Encourage your child to be active. Exercise helps your child stay healthier. It improves your child's overall condition. It can help them feel better physically and emotionally. It also helps to loosen mucus. That makes it easier to breathe. Talk to your care team about what types of exercise and school sports are safe for your child. There also may be community resources for adaptive exercise and sports programs.

#### Follow-up care

Every 3 months your child should see a health care provider who is trained in treating cystic fibrosis. If a cold or other breathing problem occurs, your child may need to see their provider more often. Your child can see their regular provider for minor problems not related to their condition.

It's important that all providers are aware of your child's medical condition and recent changes. Update them about new medicines, infections, and routine vaccines.

Be sure to keep all follow-up appointments. Explain cystic fibrosis to your child in terms they can understand. Then they can ask providers questions during visits.

### When to contact your child's doctor

Contact the health care provider right away if your child:

- Has more coughing or more sputum.
- Has symptoms that get worse, or new symptoms.
- Is wheezing.
- Has decreased appetite.
- Has a fever of 100.4° F (38°C) or higher, or as advised by the provider.
- Has chest pain or tightness.
- Has belly pain.
- Is coughing up blood.

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## **Call 911**

Call 911if your child has any of these:

- Wheezing that gets worse or doesn't get better after treatment
- Shortness of breath or trouble breathing
- Trouble swallowing or talking
- Chest pain or chest tightness that gets worse or doesn't get better after treatment
- Blue, purple, or gray skin color
- Fainting or loss of consciousness

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