Suggested Language for Explaining CF to Children & Teens

	What is CF?	*CF and the Respiratory System*	*CF and the Digestive System*
Pre-School	Cystic fibrosis is a disease that kids are born with. Many kids can't say cystic fibrosis, so they call it CF for short. Some kids call it "sixty-five roses" because that sounds a lot like cystic fibrosis. CF causes the body to make thick, sticky mucus. When you think of mucus, you might think of snot, which is that sticky stuff inside your nose. But mucus isn't just in your noise – it's in a lot of places in your body. People with CF have mucus that is extra thick and sticky, which means it can get "stuck" in places like your lungs or your stomach. Because of this, people with CF usually cough a lot and have to take special medicines to help their stomach use the food they eat.	Healthy lungs make mucus, which helps to keep them working properly and makes it easier for us to breath. The mucus in CF lungs is very thick and sticky, which can clog up inside the lungs and any germs they breathe will get stuck inside the mucus and grow, making them more sick. People with CF have to breathe in special medicines to help the mucus thin out and get out of their lungs and also to help kill the germs that are always getting trapped. People with CF also have to do things to help get the mucus out of their lungs, like coughing, special breathing exercises, or wearing a vest that shakes the mucus loose.	Mucus isn't just found in noses and lungs. Mucus is inside the digestive system – the group of parts inside your body that helps you turn your food into energy and nutrients to help you grow. One of these parts is called the pancreas. The pancreas helps give the stomach something special called enzymes, which turn fat and protein into energy. In people with CF, thick mucus blocks the passage from the pancreas to the stomach, so the enzymes cannot get to the food to turn it into energy or get the nutrition into the body. So, people with CF take enzyme medicine , vitamins, and minerals with their food to help the body use the food.
School Age	Cystic fibrosis (usually called CF for short) is a disease that causes the body to make thick, sticky mucus. Mucus is the sticky, slimy stuff that's made inside your body. Runny noses are really just noses with mucus coming out. Mucus in your body acts sort of like oil in a car's engine – it keeps everything lubricated and helps things move through your body. In kids with CF, this thick, sticky mucus usually causes problems in two major areas: the lungs and the digestive system. This is why people with CF cough a lot and have to take enzymes to help their stomach digest the food they eat. CF is a disease that you are born with – it is not something that you can catch by being around others with the disease.	Healthy lungs produce mucus, which protects the airways and makes it easier to breathe. But for a person with CF, the mucus is thick and sticky can clog up the lungs. This creates a place where bacteria can easily grow — and bacteria cause infections. People with CF usually cough a lot to clear mucus out of their lungs. Sometimes someone helps break up the mucus and shake it loose by clapping on the person's back. Some people wear a vest that helps to do the same thing. People with CF also do breathing treatments with a nebulizer machine, which takes liquid medicine and vaporizes it so that it can be breathed directly into the lungs Breathing treatments also help by adding moisture and delivering medicine into the lungs. Breathing treatments help by adding moisture and delivering medicine to thin the mucus and fight infection into the lungs. A person who is trained in helping people breathe better, called a respiratory therapist, can help teach people with CF to do special breathing exercises that help get rid of extra mucus.	The airways and lungs are not the only thing affected in a person who has cystic fibrosis. Mucus-producing cells line the digestive tract, including the stomach, intestines, liver, and pancreas. The pancreas produces enzymes that help digest food and hormones that help absorb sugar. When thick mucus in the pancreas clogs up the narrow passageways, it can make it difficult for people to digest food and get all the vitamins and nutrients they need. Because the pancreas is not working properly, it can't deliver the enzymes needed to break down protein and fat in food. This is why people CF take enzyme pills with their meal to help digest their food. Some vitamins, like A, D, E, & K can only be absorbed by the body with fat, so people with CF may also take vitamin and mineral supplements to give their body the nutrients it needs to grow.

Adapted by Kirsten Black, MS, from http://www.kidshealth.org

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	What is CF?	*CF and the Respiratory System*	*CF and the Digestive System*
Adolescent	CF is a genetic disease that affects the body's epithelial cells, which are found in many places, including the sweat glands, the lungs, and the pancreas. In a person who does not have CF, the epithelial cells produce a thin, watery mucus that acts like a lubricant and helps protect the body's tissues. In a person with CF, an error in these cells causes problems with the balance of salt and water in the body. The body responds by making thick mucus. The thicker mucus doesn't move as easily, blocking the lungs and sometimes other ducts and passageways, causing infections and breathing problems. The two organs that are most affected are the lungs and pancreas, where the thick mucus causes breathing and digestive problems. The thicker mucus has trouble moving out of the lungs, so bacteria can remain and cause infections. The thick mucus can also be found in the pancreas — an organ that produces proteins called enzymes that flow into the intestine to support the body's digestion process. Because the mucus can block the path between the pancreas and the intestines, people with CF have trouble digesting food and getting the vitamins and nutrients they need from it.	To loosen mucus, people with CF exercise regularly and may use inhalers (like people with asthma use) or nebulizers that help deliver medication to the lungs. Coughing helps people with CF clear the mucus from their lungs. They may also take antibiotics to prevent or fight lung infections. Chest physical therapy may also be an important part of a person's CF treatment routine. After lying down in a position that helps drain mucus from the lungs, the person may have someone, like a parent, bang on his or her chest and back to loosen the mucus. Many people with CF now use a therapy vest that shakes the chest allows them to be more independent by doing their therapy on their own. Despite all of the efforts to clear the thick mucus from the lungs, bacteria may still get trapped inside the mucus. This means that people with CF get frequent lung infections that can damage their lungs over time. Sometimes these require strong antibiotics along with stays, or "tune-ups" in the hospital.	The thick, sticky mucus in someone with CF can also keep the intestines from absorbing important nutrients like fat and vitamins from food. This means that people with CF may be short and underweight for their age, and they may get sick a lot because their bodies can't fight infections well. About 85% to 90% of CF patients have pancreatic insufficiency. This means that the body doesn't pass certain chemicals, called enzymes, from the pancreas into the intestines properly. These enzymes are necessary for a person to digest fat, starch, and protein. People with pancreatic insufficiency need to take prescribed enzymes with meals and snacks to help them digest their food properly and get the nutrition they need to grow and develop. Enzymes need to be taken with every meal and most snacks. They should not be chewed or crushed up, and the dose should only be adjusted by the dietitian or doctor. People with pancreatic insufficiency might have problems with growth and weight gain, and they might also have frequent and bad-smelling bowel movements. As people with CF grow older, they may also develop other illnesses, such as diabetes (a disease in which a person's blood sugar is too high) or osteoporosis (a weakening of the bones). People with CF also need extra calories and nutrients to help them fight infection and keep their lungs strong, particularly if they get sick with colds or the flu. With the right balance of nutrition, extra fat and calories, and prescribed supplements, though, people with CF can keep themselves healthy.

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