

A Teacher's Guide to Cystic Fibrosis



Canadian Cystic
Fibrosis Foundation

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Students with cystic fibrosis

If you have a student with cystic fibrosis (CF) in your class, it is important to have an understanding of this chronic disorder. CF can cause severe respiratory and digestive problems, but it is not contagious and has no effect on intelligence. CF affects each individual differently with varying degrees of severity, and a person's health can change considerably from month to month—or even day to day. Therefore, the physical health and emotional attitude of a student with CF must be assessed on an individual basis.

What is cystic fibrosis?

Cystic fibrosis is the most common fatal inherited disorder affecting young Canadians. CF causes a build-up of thick mucus in the lungs leading to severe respiratory problems. Meanwhile, mucus and protein build-up in the digestive tract results in extreme difficulty in digesting and absorbing adequate nutrients from food.

It is estimated that one in every 3,600 children born in Canada has CF. At present, approximately 3,500 Canadian children, adolescents, and adults with cystic fibrosis attend specialized CF clinics.

What causes cystic fibrosis?

People are born with CF. Cystic fibrosis occurs when a child inherits two defective versions of the gene responsible for CF, one from each parent. About one in 25 Canadians carries a defective version of the gene responsible for CF. Carriers do not have cystic fibrosis, nor do they exhibit any symptoms of the disease.

Each time two parents who are carriers have a child, there is a 25% chance the child will be born with cystic fibrosis; a 50% chance the child will be a carrier; and a 25% chance the child will neither be a carrier nor have CF.

Outwardly, children with CF may not appear to be sick or look any different from their classmates – many are physically active and have excellent school attendance records. However, children with CF have a condition that affects breathing, digestion, and sweat production.



Breathing

In individuals with cystic fibrosis, the mucus produced in the lungs is thick and sticky. It clogs the airways and, if not cleared, can lead to recurrent lung infections and lung damage.

Each day people with CF follow an individualized treatment routine to control the accumulation of this thick and sticky mucus. Treatments include

physiotherapy and inhalation of medications. Chest physiotherapy, usually done by a parent or caregiver, involves clapping and vibrating the child's chest wall to dislodge small mucous plugs in the airways. As the child gets older, alternate techniques may be prescribed to increase and promote independence.

Chest therapy is usually performed two or three times a day – typically once before school, once upon arriving home, and once before bedtime. Some children with CF may benefit from having chest therapy done during the school day. This can be arranged through the local CF clinic, home care, and/or the school.

To defend the lungs against the harmful mucus accumulation, a student with CF may cough frequently – and should not be discouraged from doing so. Any attempt to suppress the coughing could be a health risk. Remember, CF is not contagious.

Paying undue attention to the coughing can be very embarrassing. If you accept it, students in the class will likely follow your example.

You can help students with CF feel more comfortable by making it easy for them to slip out of the classroom for a drink of water, or letting the child have a water bottle at his/her desk. Many children have been taught to clear their mucus into a tissue after they cough. Therefore, encourage your student with CF to keep tissues and a means of disposal nearby.

Physical activity helps your student to clear mucus from the lungs. Exercise also gives children the psychological boost needed to make them feel like part of the group. Include the child with CF in all games and activities in which he/she is able to participate. However, the child's tolerance level and the extent to which he/she can participate can vary from time to time, even from one day to the next.

Digestion

The gastrointestinal problems associated with cystic fibrosis result in malabsorption of fats, proteins, and carbohydrates. Individuals with CF usually require pancreatic enzyme supplements to aid digestion; vitamin supplements; and a special diet with increased calories and protein. When teaching your class about proper nutrition, be sensitive to the child with CF who has a diet that may appear unhealthy by most nutritional standards.

Your student with CF may need to take pancreatic enzymes with meals and snacks. These enzymes help the body absorb nutrients from food, and reduce both the number and bulk of stools, and the amount of flatulence, abdominal pain, and distension. These enzymes are not habit-forming, nor will they alter a student's attitude or emotional behaviour. Pancreatic enzymes are naturally occurring products derived from an animal source. They are not a prescription product, and would not cause any harm if accidentally ingested by another child. Students may still need to make a quick exit to the washroom, so allow them to leave the classroom whenever the need arises.

Most children with CF have been taking enzymes since infancy, and can take them on their own. Since enzymes are action-limited, they must be taken immediately before a student eats. Students with CF should be allowed to keep enzymes with them. The CF clinic can provide a letter for the school if necessary. In most cases, a student can carry a day's supply of enzymes in a lunch box, and take them with lunch and snacks. Parents are responsible for providing the correct number of pills and a proper storage container.

Occasionally, some children with CF may 'forget', hide, or throw away their enzymes to avoid taking pills in front of their classmates. A student with CF who

doesn't take enzymes will experience abdominal pain, and need to go to the bathroom more often than usual. If this scenario becomes a problem, you may need to meet with the parents to arrange supervision for the child at lunchtime. As with coughing, the less attention paid to the child's diet and pill-taking, the more comfortable the child will feel.



Sweat

Individuals with CF may sweat more than people who do not have CF, and will have very salty sweat. Consequently, children with CF can lose a great deal of body salt through perspiration, and salt crystals may actually form on their skin. In very warm weather and with prolonged exertion, this can be a problem. Drinking plenty of fluids is important, and it is often recommended that they drink sports drinks or have a salty snack handy.

Individuals with CF may also need to add salt to their diet to replace the excessive amounts they lose through sweat.

Psychological Health

A student with CF has the same emotional needs as others in your class. Cystic fibrosis may make a child feel different, even though the disorder can often be categorized as 'invisible'.

If the child agrees, consider having a classroom discussion about CF. Peer teaching has been shown to be particularly successful. Involving the parents and the affected child, or a member of the medical team, may be beneficial.

A child with CF may find it hard to participate in group situations. A teacher can help strengthen a child's self-image by encouraging the student to excel at what he/she can do best, and by stimulating valuable relationships with other children so that he/she gains acceptance in the classroom.

Finally, regular CF clinic visits, and possible periods of hospitalization, are facts of life for individuals with CF. During hospitalization, it is important that a child with CF keep pace with regular schoolwork. The hospital schoolteacher may ask you to provide lesson plans and materials. For the most part, hospital visits are planned, giving you time to pull materials together. Encouraging notes and messages from classmates can often lift the student's spirits while in hospital.



Summary

- Cystic fibrosis does not affect mental ability.
- CF is inherited, and is therefore not contagious.
- CF is a disorder of the lungs and the digestive system.
- A student with CF may need special medications. These are not habit-forming and do not alter attitude or behaviour.
- Individuals with CF may cough frequently. It can be harmful to try to restrain this cough either physically or through the use of cough suppressants.
- Students with CF may need to slip in and out of the classroom, to attend to their health needs. It is important to recognize and support this need.
- There are striking variations in the severity of CF, and each person should be treated as an individual. Discuss your student's medical condition with parents/caregivers.
- CF is often misdiagnosed as pneumonia, chronic bronchitis, asthma, celiac disease or malnutrition. If you are concerned about a student's health, you may inform the parents/caregivers of the symptoms you have observed (such as constant cough, unusual appetite, frequent bowel movements), and suggest that they seek medical advice.
- Not long ago, many children with CF did not live to reach school age. Today, children with CF are growing into adults, and planning for post-secondary education, careers and families. By helping them make the most of their school years, teachers can help them achieve these long-term goals.

What is the CCFF?

The CCFF is a Canada-wide health charity that funds CF research and treatment programs; provides supplementary funding to specialized CF clinics, and lung transplant centres across Canada; promotes public awareness of cystic fibrosis; and raises funds for these purposes. The CCFF also undertakes advocacy initiatives with, and on behalf of, Canadians with CF, to enhance their quality of life.



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For more information about cystic fibrosis, please contact your local CCFF chapter, or:



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