

Cystic Fibrosis Canada

Education and Cystic Fibrosis

Students with cystic fibrosis

When people with cystic fibrosis (CF) attend school, they may need special permissions, services, or accommodations to maintain their health. This information will help elementary to post-secondary level teachers and professors understand how to meet the needs of students with cystic fibrosis, and ensure they reach their full academic potential.



Breathing life into the future®



“When accommodating a student with CF, you need to expect frequent and extended absences and be willing to spend extra time with that student when they are present, to reteach lessons they have missed. As a teacher, you have to balance your desire to push the student to keep them from falling behind, with the reality of reduced time for instruction and work completion. When a child with CF is a member of your classroom, the other class members, and staff, are witness to an amazing display

of courage and determination.”

Lisa Smith, Grade 6/7 Teacher, Sir William Osler Public School, Bradford, Ontario

What is cystic fibrosis?

Cystic fibrosis is the most common fatal-genetic disease affecting Canadian children and young adults.

Cystic fibrosis affects mostly the lungs and digestive system, but cystic fibrosis also affects the sinuses, liver, pancreas and the reproductive organs. The degree of CF involvement varies from person to person. However, the persistence and ongoing infection in the lungs, with destruction of lungs and loss of lung function eventually causes death in the majority of people who have cystic fibrosis.

Typical complications caused by cystic fibrosis are difficulty in digesting fats and proteins and vitamin deficiencies due to loss of pancreatic enzymes; and progressive loss of lung function. Each individual is affected with varying degrees of severity, and a person’s health can change significantly at any time. Therefore, the physical health and emotional attitude of a student with cystic fibrosis must be assessed on an individual basis.

What causes cystic fibrosis?

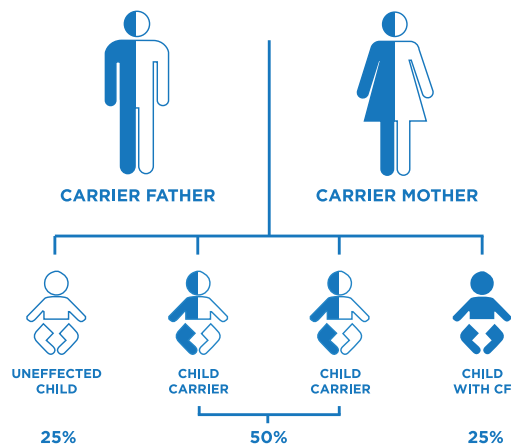
Cystic fibrosis is a genetic or inherited disease that individuals are born with. Cystic fibrosis occurs when a child inherits two abnormal genes, one from each parent.

Approximately one in every 25 Canadiansⁱ is a CF carrier, meaning they have one abnormal version of the gene responsible for cystic fibrosis. Carriers do not have, and can never get, cystic fibrosis. In most cases, they are not even aware they are carriers.

It is estimated that one in every 3,600 children born in Canada has cystic fibrosis. Almost 4,000 Canadian children, adolescents, and adults with cystic fibrosis attend specialized CF clinics. There is no cure.

When two individuals who are carriers have a child together, there is a:

- ◆ 25 percent chance the child will be born with cystic fibrosis (they will have two abnormal CF genes)
- ◆ 50 percent chance the child will not have cystic fibrosis, but will be a carrier (they will have one abnormal CF gene, and one normal gene)
- ◆ 25 percent chance the child will not have cystic fibrosis and will not be a carrier (they will have two normal genes)



Each pregnancy carries the same risk of a child inheriting an abnormal gene. For instance, two parents who are carriers may have several children with cystic fibrosis, or none at all. Carrier status (that is, finding out whether you or your partner has a CF gene) can be determined through genetic testing. If you, your partner, or child is a carrier, genetic counselling is available.

ⁱ CF carrier rates vary by ethnicity.

Effects of cystic fibrosis

People with cystic fibrosis may not appear to be sick. Many are physically active and have excellent school attendance records. However, cystic fibrosis greatly 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 recurring lung infections and lung damage.

People with cystic fibrosis follow a daily individualized treatment routine to control the accumulation of this mucus. Treatments include physiotherapy and inhalation of medications. Chest physiotherapy involves clapping and

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vibrating the chest wall to dislodge small mucus in the airways. As a 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 before school, upon arriving

home, and before bedtime. Some people may benefit from having chest therapy during the school day. This can be arranged through the local CF clinic, home care, and/or the school.

To help remove harmful mucus from the lungs, people with cystic fibrosis may cough frequently and should not be discouraged from doing so. Any attempt to suppress the coughing could be a health risk. Remember, cystic fibrosis is not contagious.

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

You can help younger students with cystic fibrosis 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 children to keep tissues and a means of disposal nearby.

People with cystic fibrosis should minimize their exposure to germs. It is important to practice good hand hygiene, which may include having an alcohol-based hand gel on the student’s desk and/or within the classroom.

Digestion

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

“Students with cystic fibrosis should be allowed to keep enzymes with them.”

Pancreatic enzymes must be taken with all 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. Although not harmful in small quantities, no medication should be shared with other students. Allow students to leave the classroom whenever the need arises.

Most people with cystic fibrosis have been taking enzymes since infancy, and can take them on their own. Enzymes must be taken immediately before eating. Students with cystic fibrosis 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 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 cystic fibrosis may forget, hide, or throw away their enzymes to avoid taking pills in front of their classmates. A student with cystic fibrosis who neglects to take enzymes will experience abdominal pain. If this becomes a problem, you may need to meet with the parents to arrange supervision for the child at lunchtime, and/or seek advice from school guidance counsellors. As with coughing, the less attention paid to the child’s diet and pill-taking, the more comfortable the child will feel.

Sweat

Physical activity helps to clear mucus from the lungs. Exercise also provides the psychological boost needed to make students feel like part of the group.

Individuals with cystic fibrosis may sweat more than others, and will have very salty sweat. Consequently, they 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. People with cystic fibrosis are at higher risk of dehydration. Ensure water, salty snacks or sports drinks are easily accessible during physical activities.

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

Other complications

The effects of cystic fibrosis vary from individual to individual. Other complications may include chronic sinusitis, late onset of puberty, CF-related diabetes (requiring insulin injections), liver disease and male infertility.

Psychological health

A student with cystic fibrosis has the same emotional needs as others in your class. Cystic fibrosis may make individuals feel different, even though the disorder can often be categorized as “invisible”.

If the child agrees, consider having a classroom discussion about cystic fibrosis. Peer education 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 student with cystic fibrosis 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 students.

Regular CF clinic visits, and possible periods of hospitalization, are facts of life for CF students. During hospitalization, it is important to keep pace with schoolwork. 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.

Accommodating elementary and high school students with cystic fibrosis



Some students with cystic fibrosis may benefit from having an individualized education program developed to ensure procedures are in place should the student require special permissions during exams, class trips, and to help ease the transition from primary to junior/secondary school. The

student, caregiver(s), and a school team are involved in creating these programs. Teaching assistants can also benefit students with cystic fibrosis by providing one-on-one support with schoolwork and treatments.

Accommodating post-secondary education students with cystic fibrosis

Supporting CF students

Post-secondary education can be a difficult time for anyone, and even more so for those with cystic fibrosis. Although cystic fibrosis will not prevent individuals from obtaining higher education, there are issues that need to be considered. The CF clinic team can help with options and strategies to keep students well during their academic career, as well as the application process.

Most colleges and universities have programs that can help students with required accommodations.

Accommodations that may be requested:

- ◆ Changing the required number of class hours per semester
- ◆ Providing a specific residence room (i.e., private room, or room with a private bathroom), on-campus housing or parking
- ◆ Changing class attendance rules; providing other options such as internet or video; and allowing late entry to class due to treatments
- ◆ Changing project due dates or exam dates due to illness or hospitalization
- ◆ Providing class notes during absences
- ◆ Providing the opportunity to finish coursework after the course has ended
- ◆ Accommodating dietary needs

Social considerations

Young adults with cystic fibrosis want to fit in and may not wish to have class/lecture discussions about cystic fibrosis. The social pressures faced

“Understanding the unique social pressures faced by students with cystic fibrosis can help professors ensure their students succeed.”

during young adulthood vary drastically from those faced during adolescence. Individuals with cystic fibrosis follow strict treatment regimes that may prevent them from attending social events and participating in the “party” lifestyle that many students become involved in during

their first years at university/college. Understanding the unique social pressures faced by students with cystic fibrosis can help professors ensure their students succeed.

CF students' facts at-a-glance

The Facts

Cystic fibrosis:

- ◆ Does not affect mental ability
- ◆ Is inherited, and is therefore not contagious
- ◆ Is a genetic disorder of the lungs and digestive system

A student with cystic fibrosis:

- ◆ May need special medications, which are not habit-forming and do not alter attitude or behaviour
- ◆ May cough frequently, and should not be discouraged from doing so
- ◆ Should minimize exposure to germs, and practice good hygiene

There are striking variations in the severity of cystic fibrosis, and each person should be treated as an individual. Discuss your student’s medical condition with him/her or their parents/caregivers.

In the 1960s, most children with cystic fibrosis did not live long enough to attend kindergarten. Today, half of all Canadians with cystic fibrosis are adults over the age of 30 — they should be encouraged to pursue their academic, career, and life goals to the fullest.

Connecting Canadians with Cystic Fibrosis

Join the My CF Canada Network, Canada's first-ever social network designed by CF patients specifically for CF patients to connect and share important information about living with this severe and potentially fatal genetic disease. Canadians with cystic fibrosis can discuss the treatments, programs and services available in their province/region, via video chat and instant message, share stories and personal issues, and receive support for advocacy and fundraising initiatives from a much broader community.

Cystic Fibrosis Canada acknowledges Novartis Pharmaceuticals Canada Inc. for the collaboration that has made the My CF Canada Network possible.

Sign-up today at www.mycfnetwork.com

For more information about cystic fibrosis, visit cysticfibrosis.ca

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