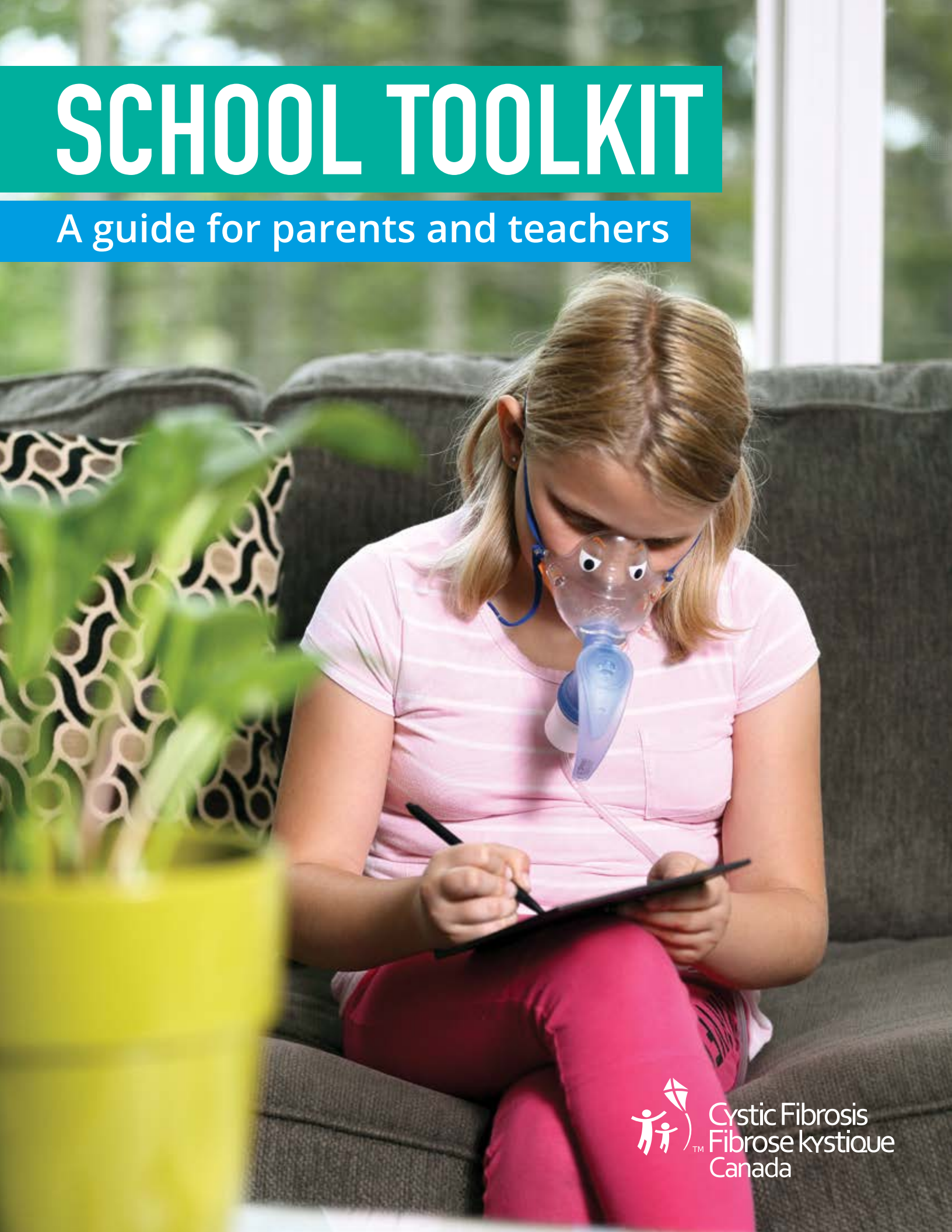
SCHOOL TOOLKIT

A guide for parents and teachers



Cystic Fibrosis
Fibrose kystique
Canada

WHAT IS CYSTIC FIBROSIS?

Cystic fibrosis (CF) is the most common fatal genetic disease affecting Canadian children and young adults. At present, there is no cure.

CF causes various effects on the body, but mainly affects the digestive system and lungs. The degree of CF severity differs from person to person; however, the persistence and ongoing infection in the lungs, with destruction of lungs and loss of lung function, will eventually lead to death in the majority of people with CF.

As CF is a genetic disease, it is **not contagious** and poses no danger to individuals without CF.

It is estimated that one in every 3,600 children born in Canada has CF. More than 4,100 Canadian children, adolescents, and adults with cystic fibrosis attend specialized CF clinics.

A B C

Typical complications caused by cystic fibrosis include:

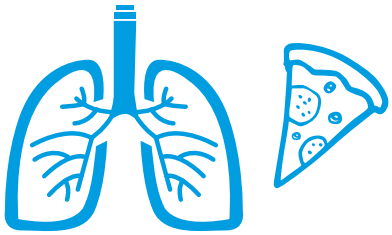
- ✔ Difficulty digesting fats and proteins
- ✔ Malnutrition and vitamin deficiencies because of inability to absorb nutrients
- ✔ Progressive lung damage from chronic infections and aberrant inflammation
- ✔ CF related diabetes
- ✔ Sinus infections

WHAT CAUSES CYSTIC FIBROSIS?

Cystic fibrosis is a genetic disease that occurs when a child inherits two abnormal genes, one from each parent. Approximately one in 25 Canadians carry an abnormal version of the gene responsible for CF. Carriers do not have CF, nor do they exhibit any of the symptoms of the disease.

When two parents who are carriers have a child, there is a 25 per cent chance that the child will be born with CF; there is also a 50 per cent chance that the child will be a carrier; and a 25 per cent chance that the child will neither be a carrier nor have CF.

HOW DOES CYSTIC FIBROSIS AFFECT THE BODY?



RESPIRATORY

- Since the mucus is thicker than normal it can block smaller airways, resulting in loss of lung function.
- The thick, sticky mucus can also retain bacteria, leading to chronic lung infections and deterioration of lung function.
- The most evident symptom of CF is a persistent cough, which some children with CF are self-conscious about.
- The cough is non-infective and serves as the body's mechanism to displace the mucus blocking the airways.

DIGESTIVE

- Mucus also blocks the channels through which the pancreas secretes enzymes, which help digest food. This makes it difficult to absorb nutrients and gain weight.
- Most children with CF need to take capsules of enzymes with snacks or meals to ensure they can digest the food. Not doing so may lead to cramping, gas, discomfort and pain.

WHAT ARE THE SYMPTOMS?

Cystic fibrosis is a multi-system disorder that produces a variety of symptoms including:

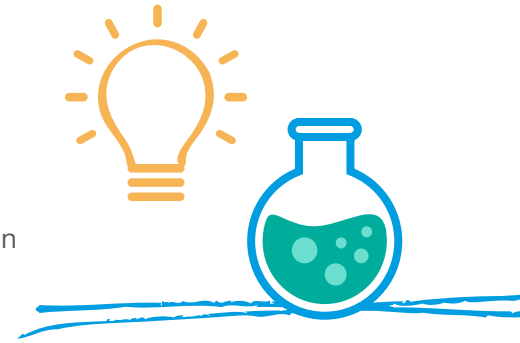
- ✔ Persistent cough with productive thick mucus
- ✔ Wheezing and shortness of breath
- ✔ Frequent chest infections, which may include pneumonia
- ✔ Bowel disturbances, such as intestinal obstruction or frequent, oily stools
- ✔ Weight loss or failure to gain weight despite possible increased appetite
- ✔ Salty-tasting sweat

HOW IS CF TREATED?

Current treatment plans include a variety of the following:

- ✔ Physiotherapy and breathing exercises
- ✔ Antibiotics
- ✔ Enzyme supplements to aid digestion
- ✔ Vitamin supplements

HOW CAN CF AFFECT A CHILD'S EDUCATION?



Whilst CF does not affect a child's cognitive abilities, it can impact their studies. Children with CF must dedicate a significant portion of their day to treatment, often waking up hours early to complete their treatment before the school day begins. This can lead to fatigue, as well as take away time that other students are able to devote to homework.

There is also the possibility of extended periods of absence from school due to hospitalization. If the absence is planned, parents can work with the child and their teacher to ask them for any work the child will miss and guidance on how best to keep them from falling behind. If the absence is unplanned, the child's teacher may be able to provide any work they might have missed over the course of their absence. If they will be away for an extended period, see if the hospital has a tutor who will work with the child to ensure that they keep up with their studies.

INFECTION CONTROL

Individuals with CF are at an increased risk of lung infection because bacteria and viruses get trapped and thrive in the sticky mucus. As a result, they are more vulnerable to getting sick by catching germs from other sick children. For this reason, children with CF must be kept at least 6 feet away from any individual with a cold, flu or other viral infection, both indoors and outdoors.

To help prevent the spread of bacteria and germs, teachers are encouraged to ensure students practice proper hand washing practices are being followed by their students. Many schools will supply the classrooms with alcohol-based hand sanitizer and tissues for coughs and sneezes. If possible, allowing children with CF to keep a personal bottle of alcohol-based hand sanitizer and tissues at their desk will enable them to keep their space as hygienic as possible and minimize the transfer of germs.

As CF disturbs the digestive system, children with CF require frequent trips to the washroom. To minimize disruption, seating children with CF on the perimeter of the classroom (near the door) and allowing them to quietly excuse themselves when needed will draw less attention and help make them more comfortable. Please note that these washroom breaks can take up to 15-20 minutes; to make children with CF more comfortable, teachers should refrain from sending other students to check on them. Instead, teachers should call the office or send another teacher.

OTHER STUDENTS WITH CF

If there is another student with CF that attends the same school, they must be separated at all times. People with CF can spread or get particularly dangerous germs from each other, which can exacerbate symptoms and lead to a faster decline in lung function.

Infection control guidelines recommend that people with CF attending the same school should not be in the same room at the same time unless they live in the same household. Please try to keep them at least 6 feet away from each other at all times. It is also recommended that people with CF avoid sharing common objects such as pens, toys and computers.

CF AND PHYSICAL ACTIVITY

Children with CF are no different than any other child. They want to run around, rough and tumble and keep up with the other children. Exercise is a critical part of treatment as it helps to loosen the mucus in the lungs, making it easier to clear.

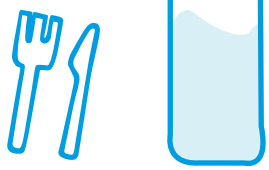
Teachers and parents should encourage children with CF to be active and to participate in whatever activities they feel comfortable taking part in. Please note that after a bout of illness, children with CF might feel exceptionally weak or exhausted and may need to sit out from any physical activity until they have fully recovered.

CF depletes the body of salts, which can lead to dehydration. Children with CF need to have access to fluids and salty snacks, especially during periods of physical exertion.

NUTRITION, EATING AND HYDRATION

Children with CF typically consume a high-fat, high-salt diet according to their nutritional needs and digestive abilities.

As CF reduces the function of the pancreas, pancreatic enzymes (pills) need to be taken with all meals/snacks to help digest food. These pills are taken with water and can be administered without supervision. They pose no danger to other students unless consumed in extremely large quantities.



If children with CF forget to take their enzymes before eating, there's a 30 minute window within which they can still be taken. After 30 minutes, they will no longer be effective. One missed dose should not cause any problems, but multiple missed doses can lead to intestinal problems. If possible, try to keep a backup supply in the child's locker or the school's office in case they forget their pills at home or run out during the day.

It is also important that children with CF have access to water at all times throughout the day. As previously mentioned, CF depletes the body of salts and it is critically important that children with CF are able to hydrate themselves whenever they feel the need.

HOW CAN TEACHERS HELP?

Children with CF spend more time during the day with their teachers than their parents, and as a result teachers might notice changes or symptoms that a parent does not. If teachers suspect anything out of the ordinary, they should contact the parents of the child in question just to make sure they're aware of any changes in the child's health.

Some teachers choose to learn physiotherapy in case it's needed at any point throughout the day or while students are on field trips and are away from home for an extended period of time. By doing so, they allow children with CF to fully participate in school and be less dependent as they grow. This, of course, is voluntary and should be discussed with the parents.

Teachers might also find it helpful to meet with the child's parents prior to the beginning of the school year to discuss the child's specific health requirements and ask any questions not covered in this guide. Teachers can also get in touch with Cystic Fibrosis Canada by phone or social media (contact information is listed on the back of this guide) and Cystic Fibrosis Canada can provide further insight or information.

KEY FACTS FOR TEACHERS

- **Cystic fibrosis (CF) is a genetic disease and is not contagious**
- **Typical complications caused by CF include difficulty digesting fats and proteins as well as lung damage from infections**
- **Symptoms include:**
  - Persistent cough with productive thick mucus
  - Wheezing and shortness of breath
  - Frequent chest infections, which may include pneumonia
  - Bowel disturbances, such as intestinal obstruction or frequent, oily stools
  - Weight loss or failure to gain weight despite possible increased appetite
- **Children with CF are more vulnerable to catching germs from sick children**
  - Proper hand washing practices and disinfection procedures must be followed
- **Children with CF require frequent trips to the washroom**
- **They will act no differently from any other child**
- **They can participate in any physical activities that they are comfortable with**
- **Please allow them unlimited access to fluids and their salty snacks**
- **To assist their digestion, children with CF must take pancreatic enzymes before eating**
- **If they forget, they can still take them up to 30 minutes after eating**

Dear Educator,

(name of child) (name of school)

(**I/We**), the (**parent/guardian**) of _____who will be attending _____ in grade ____ this fall, would like you to be aware that they have cystic fibrosis. Cystic fibrosis (CF) is a rare genetic disease that primarily affects the lungs and the digestive system due to a buildup of thick and sticky mucous. As CF is a genetic disease, it is not contagious and poses no danger to other students. I'm sending you this letter to share information about CF and living with the disease and to ask that you help them maintain their health during the school year.

There are various challenges that could potentially arise for _____ in school. (**I/We**) would appreciate the opportunity to meet with you to further discuss their needs, but below are the most important things for you to know:

Eating and hydration

- → Pancreatic enzymes (pills) need to be taken with all meals/snacks to help digest food. These pills are taken with water and can be administered without supervision. A backup supply will be made available in the office if needed.
- → If they forget to take their enzymes before eating, there's a 30 minute window within which they can still be taken. After 30 minutes, they will no longer be effective. One missed dose should not cause any problems, but multiple missed doses can lead to intestinal problems.

Hygiene

- → Individuals with CF are at an increased risk of lung infections because bacteria and viruses get trapped and thrive in the sticky mucous. As a result, they are more vulnerable to getting sick by catching germs from other sick students.
- → Please try to keep them at least 6 feet away from any individual with a cold, flu or other viral infection, especially indoors
- → Encourage proper hand washing among students in the washroom and by making alcohol-based hand sanitizer available in the classroom.
- → Encourage students to cough or sneeze into a tissue, dispose of it properly and wash their hands with soap and water. If tissues are not available, encourage everyone to cough or sneeze into their inner elbow.
- → Please allow _____ to keep a water bottle, a box of tissues, a trashcan and alcohol-based hand sanitizer at their desk.

Other CF students

- → If there is another student with cystic fibrosis that attends this institution please try to keep them separated as much as possible.
- → People with CF can spread or get particularly dangerous germs from each other, which can lead to worse symptoms and a faster decline in lung function.
- → Infection control guidelines recommend that people with CF attending the same school should not be in the same room at the same time unless they live in the same household. Please try to keep them **at least 6 feet away** from each other at all times.
- → It is also recommended that people with CF avoid sharing common objects such as pens, toys and computers.

Physical activity

- → Exercise is a critical part of their life and health and they should not be excluded from any activities that they are comfortable participating in.
- → Cystic fibrosis depletes their body of salts, which can lead to dehydration. During any physical activity, they need to have access to plenty of water as well as salty snacks, which we will supply.

Washroom

- → Please allow them to use as much time as they need to use the washroom. They require frequent access to the washroom and may be gone for up to 10-15 mins.
- → If you wish to check on them, we ask kindly that you do not send another student. If possible, call someone from the office or another teacher to limit discomfort.
- → To minimize disruption, seating them on the perimeter of the classroom nearest the door will allow them to quietly excuse themselves.

Keeping in touch

- → Please notify me if you notice anything out of the ordinary during the day, such as excessive coughing, trouble with physical activity or unusual thirst.
- → You may notice symptoms that (**I/We**) won't, as you are with them during the school day

Hospital stays

- → They may need to be away from school for several weeks at a time due to hospital stays and treatments.
- → You will be notified if they are scheduled to be in the hospital or if an unforseen hospital stay occurs.
- → If possible, sharing of any lesson plans you have prepared would be greatly appreciated so they can keep up with school and not fall behind

(name of child)

Aside from the above, _____ is a regular child and possesses the same cognitive abilities as any other student. We hope that they are not treated any differently or made to feel like they are abnormal in any way and appreciate your understanding and support.

If you have any questions or concerns, please do not hesitate to get in touch:

Parent/guardian 1

Home no. _____

Cell no. _____

Work no. _____

Parent/guardian 2

Home no. _____

Cell no. _____

Work no. _____

Thank you very much. We are looking forward to a fun and healthy school year!

Sincerely,

Parent/guardian 1

Name _____

Relationship to Student _____

Signature _____

Parent/guardian 2

Name _____

Relationship to Student _____

Signature _____

Working towards our vision of a world without cystic fibrosis

Cystic Fibrosis Canada
Fibrose kystique Canada

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2016-08 I Cette publication est aussi disponible en français.

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