

Cystic Fibrosis



Cystic fibrosis is a genetic disorder that affects the lungs, pancreas and other organs. The mucous in these organs is thicker than normal and blocks ducts or airways. Common symptoms include breathing problems and digestive issues. The severity of the disease can vary significantly in childhood: some children will be in excellent health while others require frequent hospitalization. Depending on the stage of the disease and the organs affected, cystic fibrosis may be treated with medications, chest-clearing techniques, nutritional supplements and, in severe cases, organ transplants.

Implications for Planning and Awareness

- Meet with the student and parents early in the school year to discuss how the school can support this student's needs related to cystic fibrosis. This could include finding out about:
 - the student's strengths, interests and areas of need
 - specific symptoms that may affect the student at school
 - successful strategies used at home or in the community that also could be used at school.
- In collaboration with parents and health care professionals, develop a written management plan that aligns with school and jurisdictional policies and protocols. This plan should include specific information on:
 - the role of school staff in managing cystic fibrosis
 - steps for treatment at school, if applicable (e.g., chest-clearing techniques when emergency measures should be taken).
- If the student is taking medication during the school day, discuss with the parents possible side effects. Follow school and/or jurisdictional policies and protocols in storing and administering medication.
- If there are two or more students diagnosed with cystic fibrosis at the school, talk with their parents to find out if either of them is confirmed to be infected with b. cepacia. Non-infected individuals with cystic fibrosis should not be in the same room as infected individuals with cystic fibrosis.
- Collaborate with the parents and student to consider if, and how, they would like to share specific information on cystic fibrosis with peers. Consultation with health care providers, such as school or community health nurses, may be helpful.
- Learn as much as you can about how cystic fibrosis may affect learning and social and emotional well-being. Reading, asking questions and talking to qualified professionals will build your understanding and help you make decisions to support the student's success at school.

Your awareness needs to begin with conversations with the student's parents.



- Collaborate with the school and/or jurisdictional team to identify and coordinate any needed consultation and services.
- Develop a system for sharing information with relevant staff members about the student's condition and successful strategies.

Implications for Instruction

- Be aware that students with severe cystic fibrosis may have numerous absences from school due to medical appointments or treatments, or fatigue.
- Develop a communication strategy between the home and school to stay informed about absences, and to keep the student and family connected to the classroom learning.
- Assign the student a buddy who can help out with missed work or keep track of assignments, if absences occur.
- Make sure the student has access to water and drinks regularly. Students with cystic fibrosis are prone to dehydration.
- Be aware of and use caution around settings and substances that may cause infection or breathing problems (e.g., rotting vegetables, haystacks, marshes, riverbeds, construction sites). These are considerations when planning field trips or bringing materials into the classroom.
- Ensure the student maintains regular participation in physical education at a level appropriate to his or her stamina. Exercise helps to improve cardiovascular health and clear chest secretions.
- Emphasize good hygiene habits for all students to avoid passing on germs that may make a student with cystic fibrosis ill. These habits include:
 - frequent hand washing, especially after using the washroom and before and after handling food
 - not sharing utensils or cups
 - cleaning surfaces of exercise equipment before and after use.

Implications for Social and Emotional Well-being

- Engage the student and parents in planning for transitions between grade levels and different schools.
- Be aware that some students may feel uncomfortable taking their medications or doing treatments in front of their peers. Discuss this with the student and family and determine how best to support the student in the treatment regime.
- Be aware that students with cystic fibrosis may experience stomach pain and embarrassing gas. The student should always be allowed to go to the bathroom, as needed.

Parents know their children well and can offer insights on how to support their social and emotional well-being. There is strength in collaborating on strategies that could be used at home, at school and in the community.



As you consider the implications for this medical condition, think about the following questions:

1. Do I need further conversations with the parents to better understand this student's medical needs? Yes No
2. Do I need targeted professional learning?
If yes, what specific topics and strategies would I explore? Yes No
3. Is consultation with jurisdictional staff required?
If yes, what issues and questions would we explore? Yes No
4. Is consultation with external service providers required (e.g., Student Health Partnership, Alberta Children's Hospital, Glenrose Hospital)?
If yes, what issues and questions would we explore? Yes No
5. Is service to the student from an external provider required? Yes No
If yes, what outcomes would be anticipated?

Links for further information:

Canadian Cystic Fibrosis Foundation. "For Teachers." <http://www.cysticfibrosis.ca/en/publications/ForTeachers.php>

Cystic Fibrosis Foundation. School Transitions for People with CF and Their Families. <https://www.cff.org/Life-With-CF/Caring-for-a-Child-With-CF/Working-With-Your-Childs-School/School-Transitions-for-People-With-CF-and-Their-Families/>

Chronic Illness Alliance. "Cystic Fibrosis." <https://www.chronicillness.org.au/?s=Cystic+Fibrosis>

Please note:

These websites are for information only and the user is responsible for evaluating the content and appropriate uses of the information.

