Going to School with Cystic Fibrosis

An information guide for the parents of classmates

CYSTIC FIBROSIS Victoria

A student in your child's class has Cystic Fibrosis (CF).

Cystic Fibrosis Victoria has designed this information brochure to increase awareness about the condition and to answer some questions you may have.

WHAT IS CYSTIC FIBROSIS?

CF is an inherited genetic condition which mainly affects the lungs, digestive system and sweat glands. In CF there is a problem with the protein that controls the movement of salt in and out of the cells. Too much salt in the cells causes mucus to be very thick and sticky and to build up in organs like the lungs.

Common symptoms of CF may include:

- Persistent cough, particularly with physical effort
- Some difficulty with breathing or wheezing with effort
- Tiredness, lethargy or an impaired exercise ability
- Frequent visits to the toilet
- Salt loss in hot weather which may produce muscle cramps or weakness
- Poor appetite
- People with CF tend to develop a range of other associated conditions, the most common being CF related diabetes

Almost all children with CF show some symptoms of the disease. Typically they live with mild, moderate or even severe lung disease and gastrointestinal problems. Children with mild or moderate CF usually appear healthy, but this appearance may be misleading. They have to follow a fairly rigorous health regime at home and are required to see physicians frequently. Many children with CF fatigue easily and take a lot of medications to maintain their health.

If your child is unwell, please do not send them to school.

"PEOPLE WITH CF HAVE A LOW IMMUNE SYSTEM, THEREFORE OTHER CHILDREN WITH RESPIRATORY ILLNESSES, TUMMY BUGS (GASTROENTERITIS) AND CHICKEN POX DO REPRESENT A SIGNIFICANT HEALTH RISK TO THE PERSON WITH CF."

YOU CANNOT CATCH CF, IT IS NOT CONTAGIOUS

CYSTIC FIBROSIS AND THE LUNGS

When you have CF, the mucus produced by the exocrine glands in the lungs is thick and sticky. It clogs the breathing passages and, if not cleared, can lead to recurrent lung infections and lung damage. Every day the person who has CF has to undergo intensive physiotherapy treatment to clear this mucus from his or her lungs. Although a person who has CF may cough a lot, it is not contagious. People with CF may become accustomed to coughing and may not even be aware of it. It is important that they do not suppress this coughing.

CYSTIC FIBROSIS AND DIGESTION

The pancreas is a gland just below the stomach and one of its functions is to produce enzymes which break down food so that it can be absorbed by the digestive system. In CF the sticky mucus can make it difficult for the enzymes to reach the digestive system. As a result, the food eaten cannot be fully digested and people with CF may have difficulty in gaining weight. Because of their dietary needs, people with CF are on a HIGH CALORIE, HIGH FAT, HIGH SALT diet. It is important that they are not criticised for this because it is contrary to the generally promoted "healthy diet" in the community. It is possible to replace most of the missing enzymes with supplements called pancreatic enzymes.

What are pancreatic enzymes?

These are capsules that contain a combination of several body friendly enzymes to help the body digest and absorb necessary nutrients. When these enzymes pass into the stomach, they act like the bodies natural enzymes by breaking down food and increasing absorption in the small intestine. In addition, they improve the digestion of foods by helping the body turn fat, protein, and starch into the fuel it needs to grow, build muscle and maintain the best possible health. Enzymes need to be taken before eating lunch, or play lunch. They are not dangerous to other people and if they are accidentally consumed by another person, they do not pose any risk.

At childcare, kindergarten or pre-school the school staff may assist with the provision of enzymes. If the children are not able to swallow a capsule, the capsule is opened and the beads inside are swallowed with some pureed apple or similar.

ENZYME CAPSULES ARE SUPPLEMENTS, NOT DRUGS, &
DO NOT POSE A RISK TO OTHER PEOPLE IF CONSUMED.

SCHOOL PERFORMANCE AND PHYSICAL ACTIVITY

CF does not impair intellectual ability in any way and students should be encouraged to complete their full school education and plan future studies. Young people with CF should be able to participate in all the usual physical activities in the early school years, in fact it is beneficial to do so. In later years, with progressive loss of lung function some students physical ability will be limited.

HAND WASHING AND HYGIENE

Viral infections (eg. the common cold) are the most common cause of chest infections in CF. One of the most important things a person with CF and the people they have contact with can do to is minimise exposure to harmful germs and bacteria. Coughing and sneezing are common modes of transmission. Simple hand washing and/or using antibacterial hand gel and covering ones mouth when coughing or sneezing prevents transmitting viruses and is the best way to go about this. It is imperative that all students and teachers maintain this level of hygiene.

For more information on CF,
Cystic Fibrosis Victoria, and how you can help,
please visit **www.cfv.org.au** or
call **1800 633 685**

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