Mission
To promote research, increase awareness and provide education, support and advocacy to Victoria's Cystic Fibrosis community.

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

2008

CYSTIC FIBROSIS AND SCHOOL

A guide for teachers

Cystic Fibrosis Victoria

You know that teaching is demanding in itself, and may wonder what else you need to know if the young people in your care include someone with Cystic Fibrosis (CF).

Having someone with CF in your class means that you are teaching a person who has a chronic illness; a condition that has no affect on intelligence; it does not interfere with the person's ability to participate fully; and is not contagious. You can have the same expectations in the classroom of a student with CF as you would of any other.

Cystic Fibrosis affects each person differently; however, the physical health and emotional attitude of the student with CF must be assessed on an individual basis.

Your student may be in kindergarten, primary school or high school.

WHATEVER THE AGE OR CONDITION, HE OR SHE IS AN INDIVIDUAL, NOT A DISEASE

Notes

The 'teen' age

BODY IMAGE

Young people with reduced height and weight and/or delayed puberty can have a hard time. They often look younger than their peers. Worse, they may be treated as though they are younger than what they are. Sometimes that's not easy to deal with. Sometimes it is just too easy for teenagers with CF to skip enzymes to lose weight. The important thing to emphasise with the person who has CF and other students is that appearance is only one thing that makes you who you are.

TO TELL OR NOT TO TELL

One of the most difficult decisions when you have CF is whether and when to tell people about it. It is a tough issue and there is no one right answer for everyone. It is important that the student with CF is supported in their decision and respect is maintained regardless of what they decide to do. CF is their story and choosing to tell it or not is their decision.

PUBERTY

For someone with CF, puberty tends to be delayed. This is particularly true if low weight, poor nutrition or lots of chest infections are an issue for him or her.

Infertility is common in boys who have CF. This is of particular importance during sex education as males with CF should still be encouraged to use protection with an emphasis on STD's.

What is Cystic Fibrosis and how do you get it?

Cystic Fibrosis (CF) is the most common genetically inherited life shortening condition affecting Australians today. A baby is born every 4 days in Australia and over 98% of parents are unaware of their carrier status beforehand. It affects more than 3000 children and adults in Australia.

People are born with CF. On average, 1 in every 25 Australians carries the gene that causes CF. In reality, this means that 1 child in every classroom is potentially an unknown carrier for the condition. Carriers do not have any symptoms and do not have CF. For a person to be born with CF, the gene must be passed on by both parents.

YOU CANNOT CATCH CYSTIC FIBROSIS, IT IS NOT CONTAGIOUS

CF was first recognised as a specific condition in the 1930's, at which time children with CF rarely lived to be toddlers. Today, with earlier diagnosis, greater understanding of the condition, improvements in treatment and better management people with CF can live successful, happy and fulfilled lives. The median age of survival (half live longer, half die younger) is 37years, with many people who have CF living well into their 30's, 40's and 50's.

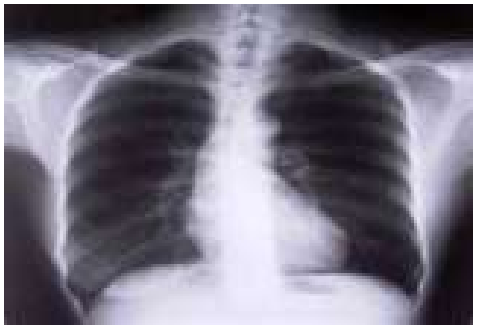
Almost all people with CF show some symptoms of the disease. Typically they live with mild, moderate or severe lung disease and gastrointestinal problems. People with mild or moderate CF usually appear healthy but this appearance may be misleading. They have to follow a fairly rigorous health regime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

Many children are used to living with chronic, controlled infections and even their parents may miss signs of a health decline. For these reasons, it can be hard to determine when a child needs extra support.

We have written this booklet at the request of many parents to assist teachers and the school understand cystic fibrosis and support these children through their important educational years.

How does Cystic Fibrosis affect the child?

When someone has CF, his or her cells are missing an essential protein, so chloride and sodium cannot be properly transported across the cell membrane. Mucus secretions become thicker and stickier. CF directly affects the respiratory, pancreatic and gastrointestinal systems. It can also affect the sinuses, liver, spleen and reproductive systems.



RESPIRATORY SYSTEM

For the majority of people with CF, complications in the respiratory system are the most serious. The mucus produced by the exocrine glands in the lungs is normally thin, slippery and clear. In people who have CF, this mucus is thick and sticky and difficult to transport. Respiratory failure is usually the most common cause of death. Thick, sticky secretions interfere with the body's natural process of clearing infectious material from the lungs. The secretions clog up small airways, causing poor air exchange. With mucus unable to remove viral, bacterial and other particles from the airways, the lungs become a breeding ground for bacterial colonisation, a condition when certain bacteria take hold in the lungs and cannot be removed. Colonisation leads to repeated pulmonary infections, localised inflammation and scarring thus permanently damaging lung tissue.

SELF-ADMINISTRATION OF MEDICATIONS

Students with CF are encouraged to be independent with all their medications and to recognise the signs and symptoms of their condition.
Some of the self medication may include:

- Inhaling medication such as Ventolin
- Taking tablets such as enzyme replacements with food and salt tablets for dehydration
- Monitoring blood sugar levels and injection of insulin for CF related diabetes

TEASING AND BULLYING

Students with an illness may be a target of bullying and teasing because they are different. There can be many reasons why they may be a target, such as being small in stature, low in weight, taking tablets, eating extra food including "junk" food, persistent coughing and spitting out mucus, having time away from school or that they may have a feeding tube, portacath or PICC line.
Unfortunately some students may make jokes about CF being a life limiting illness; this can be traumatic for the individual.
Some students with CF may already have self esteem issues about their illness and bullying on top of that can disrupt their education, reduce enjoyment of school and add to further self esteem issues.

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 is to 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.

Other ways CF can interfere with school

FATIGUE AND ENDURANCE

A student with Cystic Fibrosis may tire more easily than their peers. This can be for a number of reasons such as:

Waking early for morning treatments – this in itself can be very tiring for someone with CF, especially if they have low lung function.

Have a chest infection – this can mean more time doing physiotherapy but also means more coughing which takes up more energy and can be very frustrating for the person, especially trying to be quiet in the classroom.

Low lung function – A student with CF who has low lung function will tire more easily than if they had a high lung function. This is due to; burning up energy breathing more; having lower oxygen stats; coughing more; spending more time doing physiotherapy; and having a lower appetite due to tiredness. Someone with low lung function may find it harder to keep up in sports but should still be included.

Malnutrition – People with CF require a high fat, high energy diet (120 – 150% of normal energy requirement). This means they are encouraged to eat foods high in calories, fat, salt and sometimes sugar. Meeting the energy requirement can be a struggle for some people and many people with CF look underweight. Some may require a feeding tube to meet their dietary needs.

PEOPLE WITH CF HAVE A LOW IMMUNE SYSTEM, THEREFORE OTHER STUDENTS WITH RESPIRATORY ILLNESSES, TUMMY BUGS (GASTROENTERITIS) AND CHICKEN POX DO REPRESENT A SIGNIFICANT HEALTH RISK TO THE PERSON WITH CF.
If a student in your class is unwell, please ensure that the person with CF is not put at risk.

The student with CF in your classroom may have the following respiratory symptoms:

- **Chronic Coughing -** be reassured that although the child with CF may cough a lot to clear their lungs, it is not contagious. Please do not discourage them as it is important they do not suppress the coughing.
- **Sputum production** - this may be occasionally tinged with blood.
- **Shortness of breath**
- **Pale appearance**
- **Frequent respiratory infections** - these are not contagious.

GASTROINTESTIAL SYSTEM

Another serious problem occurs in the gastrointestinal system. Everyone produces enzymes in the pancreas for digesting food. In someone with CF a combination of pancreatic insufficiency and thickened secretions which block the pancreatic duct means that enzymes cannot get to the small intestine to break down food so nutrients can be absorbed. Poorly digested fats and proteins pass through the body. This is called malabsorption.

You might notice that the student with CF has:

- **Excessive appetite or no appetite at all**
- **Poor weight gain, small stature and distended belly**
- **Occasional flatulence and stomach cramping**
- **Foul-smelling, excessive or urgent stools -** and the occasional unavoidable accident
- **A need for extra toilet privileges or extended time in the bathroom**

Other complications from CF may include fatigue, chronic sinusitis, late onset of puberty, CF related diabetes, liver cirrhosis and male infertility. The effects of CF are very individual. Not all people with CF have the same complications or symptoms, nor do they require the same care.

What about exercise?

Exercise plays an important role in the treatment of CF. Physical activity helps to strengthen the lungs, muscles and bones. It is also beneficial in the clearing of mucus from the lungs. For people living with CF, exercise is encouraged as much as possible. How much they are able to participate will depend on an individual person's level of disease and how the person feels from day to day.

The student with CF may cough more during exercise but should always be encouraged to participate in the activity. This may be an embarrassment to the student, and if so a discussion between the student with CF, parents and the teacher can help to provide a strategy to deal with this embarrassment.

Exercise is also beneficial emotionally. It can help lower stress levels, promote self esteem and also help build friendships.

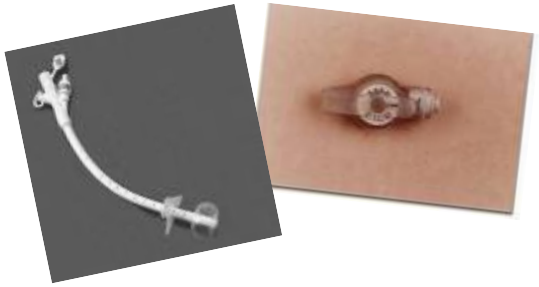
DEHYDRATION

Most people with CF have a reduced tolerance to heat, especially when exercising. People with CF lose a particularly high level of salt through their sweat. You may even notice salt crystals on their faces after strenuous activity. This causes an increased risk of dehydration and electrolyte imbalance. The student with CF should carry water or sports drinks, eat salty snacks or take salt tablets during hot weather.

Dehydration can lead to tiredness, difficulty concentrating, feeling grumpy or irritable, loss of appetite, nausea or vomiting, headaches, cramps, thirst and sunken eyes. Dehydration can also make sputum harder to cough up as it becomes even stickier; bowel blockages can also occur.

GASTROSTOMY TUBE

Some people with CF have a gastrostomy tube to help with severe malnutrition. This is a feeding tube that goes directly through the abdominal wall into the stomach. A plastic button sits on the outside of the abdomen. Supplemental liquid nourishment and some medications can be administered through this button. This is rarely done at school. In some instances the tube can become dislodged. If this occurs, contact the student's parents immediately.



SPECIAL DIET

People with CF are usually encouraged to consume large meals that are high in protein, fat, salt and calories, and they need daily supplemental vitamins. A child torn between eating and playing may want to eat a little and run to the playground. He or she needs time and encouragement to eat every meal. Some students need a mid-morning or mid-afternoon snack to help maintain proper nutrition.

WHEN TEACHING YOUR CLASS ABOUT PROPER NUTRITION, BE SENSITIVE TO THE STUDENT WITH CF WHO HAS A DIET THAT MAY APPEAR UNHEALTHY BY MOST NUTRITIONAL STANDARDS.
Healthy eating is eating what is good for you;
what is healthy for one person, may not be so for another.

How is Cystic Fibrosis treated?

MEDICATIONS AND TREATMENTS

These are numerous and time-consuming and often vary throughout the year, depending on whether the person is having an exacerbation (a worsening of lung condition) or a "well" period. They also vary depending on the person and the severity of his or her CF.

Daily respiratory medications are aimed at clearing thickened secretions, opening airways and preventing or controlling respiratory infections.

Some common types of medications a person with CF may take include:

- **Bronchodilators** - these sometimes cause a student to become overactive, with a fast heartbeat and trembling hands
- **Anti-inflammatory medications**
- **Antibiotics**
- **Steroids -** a person my experience mood swings, irritability and an increased appetite
- **Vitamins and supplements**

These medications may be given orally, intravenously, through metered dose inhalers or in aerosol form using a nebuliser.

PHYSIOTHERAPY

People with CF may require chest physiotherapy to help remove the thick secretions in their lungs and to control the potentially harmful mucus. This is usually done at home, 1-4 times daily, but sometimes a child may need treatments at school.
Various inhaled medications are used to open the airways either by an inhaler or nebuliser. Then a mixture of percussion, vibes and breathing exercises are used to dislodge small mucus plugs in the airways. This usually causes coughing, which enables the person to 'cough up' the mucus.
These techniques open and help clear the airways, decrease infections and improve air exchange.

HOSPITALISATIONS

Time away from school is inevitable for students who have CF. Many people with CF will have 2 week "tune-up's" to have intravenous antibiotics and extra chest therapy. Parents may request that you provide school work for the student. In addition to hospitalisations are hospital based check-ups; these often take a day.

It is hard coming back to school and fitting back into the classroom environment. Sending an encouraging note and messages from class mates can often lift the student's spirits.

What is 'healthy eating' for cystic fibrosis?

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.
CF can make it difficult for sufficent 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 child is 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, AND DO NOT POSE A RISK TO OTHER PEOPLE IF ACCIDENTLY CONSUMED.