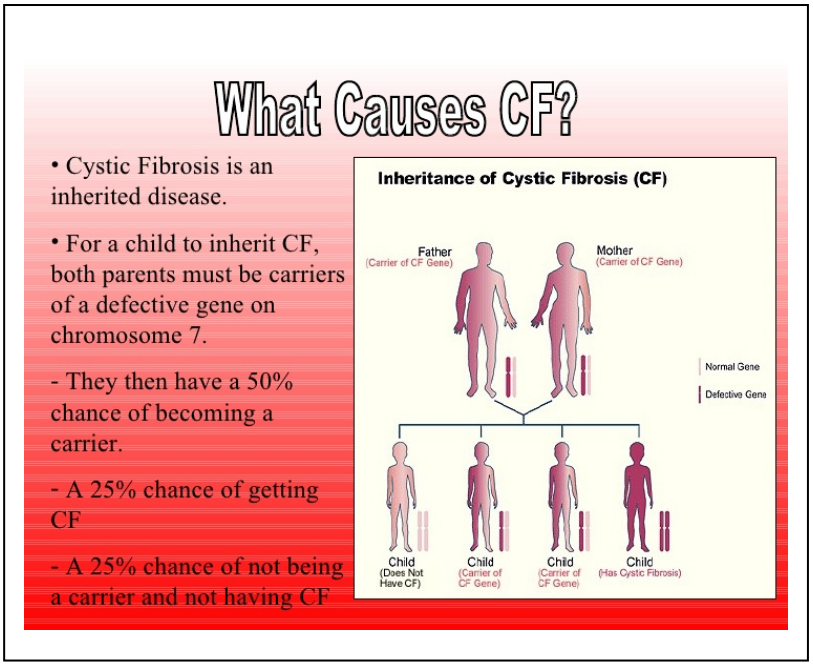
SEND Bulletin NO.18



Cystic Fibrosis

Cystic fibrosis is a genetic disease that affects a number of organs in the body (especially the lungs and pancreas) by clogging them with thick, sticky mucus. This also affects the child's digestion. It is the UK's most common life-threatening childhood disease. Until the 1930s, babies born with cystic fibrosis rarely lived to be more than a few months old. Now, average life-expectancy is about 31 years and rising. Most children with cystic fibrosis can expect to reach adulthood and enjoy active and fulfilling lives. Pupils with cystic fibrosis are academically as able as their peers, but hospitalisations and chest infections can result in frequent or prolonged absences from school.

Children with cystic fibrosis may be small and underweight for their age. A daily routine of physiotherapy and exercise is essential for every sufferer, to prevent irreparable lung damage. This can be very time-consuming and frustrating. Some pupils will also be embarrassed by having such arrangements made for them. Most of those with cystic fibrosis will need to take medication (enzymes in the form of pills or powders) at meal times.

Some cystic fibrosis sufferers may also develop diabetes, for which it may be necessary to take insulin and moderate their diet. These pupils may need to use the toilet more often.

Key characteristics

The most noticeable feature of cystic fibrosis is a persistent cough. Although not infectious, it may be embarrassing in front of other people, especially as a severe coughing attack occasionally leads to coughing up mucus or vomiting.

A child with cystic fibrosis may also suffer from:

- repeated chest infections and low resistance to all infections
- tendency to prolonged diarrhoea
- poor weight gain

- particularly salty sweat
- digestive problems
- lack or loss of energy
- frequent absences from school (sometimes prolonged).

Support strategies

You may need to:

- make provision for daily physiotherapy in a quiet room with a dedicated teaching assistant who has been appropriately trained. Nebuliser treatment may also be necessary. The number of physiotherapy sessions that take place each day varies according to the child's current state of health. The length of each session will vary from 15 minutes to an hour
- ensure that special supplements are taken with all meals and snacks. These come in capsule form and need to be taken in large quantities
- provide work for the child to do at home or liaise with the hospital or home tuition service during prolonged absences
- encourage independence in taking responsibility for their own treatment (such as the taking of enzymes with food and pacing themselves during PE)
- encourage physical exercise, although the illness can result in energy loss and this must be taken into account during PE and other physical activities.

Support agencies

- Cystic Fibrosis Foundation (USA): www.cff.org

- Cystic Fibrosis Trust: www.cftrust.org.uk

If you have any interesting information or resources which you would like to share with your colleagues via this fortnightly bulletin please e-mail them to me:
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Many thanks

Anne