FACTSHEET

School and Cystic Fibrosis

Introduction

This guide aims to provide information about all aspects of Cystic Fibrosis (CF) and school:

- for teachers who may have little or no experience of children with CF and their special needs;
- for parents whose children with CF are just starting school, changing schools or have a new teacher;
- for parents of children with CF who find they need additional support and information as their children progress through primary and secondary school.

Contents

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www.cftrust.org.uk

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What is Cystic Fibrosis?

- Cystic Fibrosis (CF) is one of the UK's most common, life-threatening inherited diseases.
- CF occurs in approximately 1 in 2,500 children.
- On average five babies with CF are born each week in the UK.
- One person in 25 is a carrier of the Cystic Fibrosis gene.
- If both parents are carriers of CF, in every pregnancy there is a one in four chance of having a child with Cystic Fibrosis.

It cannot be emphasised too strongly that there is no typical child with Cystic Fibrosis. So when reading this guide, please bear in mind that CF affects each child in different ways with varying degrees of severity, and each child's health can change considerably from month to month – or even day to day.

The best way to help children with CF at school is to treat them as individuals and be sensitive to their changing needs.

Medical symptoms

How CF affects the respiratory system

In CF the lungs function normally at birth but the mucus produced in them is abnormally thick. By blocking some of the smaller airways, this sticky mucus starts to cause lung infections and more serious damage can occur. About a third of children with CF suffer from asthmatic wheezing at times when their chests are particularly congested; and sometimes children with CF feel unusually tired after colds and chest infections.

The most noticeable feature of CF is a persistent cough. Although this is a non-infective cough it may be embarrassing in front of other children, especially as a severe attack of coughing occasionally leads to coughing up mucus or vomiting.

How CF affects the digestive system

The main digestive problem of CF is malfunctioning of the pancreas. The pancreas is a gland in the abdomen which produces insulin, and insulin regulates the amount of sugar in the blood. The pancreas also produces digestive juices or enzymes which pass into the intestines where they aid the digestion and absorption of food.

In CF the pancreas usually produces enough insulin. However, the small channels through which the enzymes normally pass are often blocked with the sticky mucus produced by CF. The effect of this blockage varies considerably, so that at one extreme there are newborn babies with CF who cannot digest milk and fail to gain weight or benefit from nutrition, whereas at the other end are the 10 per cent or so of people with CF whose pancreas performs some useful function throughout their lives.

Other health problems

Children with CF may be more prone to sinusitis, hay fever, arthritis, diabetes, heart strain and cirrhosis of the liver but these are fairly rare complications that usually develop in older children and adults with Cystic Fibrosis. Other complications of CF are the possibility of delayed sexual maturity and probable future infertility for boys with Cystic Fibrosis.

Current treatment

Current treatments include:

- Physiotherapy and breathing exercises
- Frequent courses of antibiotics
- Replacement of enzymes to aid digestion
- Use of extra vitamins

The main aim is to keep the lungs as normal and clear as possible. There are two forms of treatment – Physiotherapy and Antibiotics.

How the chest is treated in Cystic Fibrosis

Physiotherapy and breathing exercises

The aim is to clear the harmful mucus from the lungs. This is so vital that it usually forms part of the daily routine of every child with Cystic Fibrosis. There are several techniques available to clear mucus. Some children may need access to a tipping frame or foam wedge where they lie in a head down position (known as postural drainage) and perform a cycle of breathing exercises often combined with clapping and shaking of their chest wall so that any harmful sputum in the lungs is coughed up. This form of physiotherapy (often referred to as physio) is not painful even though it may look and sound rather alarming at first. Other children may do their breathing exercises using devices, such as a PEP mask or flutter, whilst seated in a chair.

The number of physio sessions children with CF have to fit into their day varies depending on the child's current state of health – extra sessions may be needed after a cold or chest infection. Because physio has to be done before meals, session times will be early morning, convenient breaks during the day and early evening. Many children will have to do physio twice or even three times a day and the length of each session lasts approximately 15-20 minutes but can vary depending on the needs of the child.
Often friends and adult carers also learn the relatively easy physiotherapy techniques so they can help.

Parents of children with CF are taught to do physio from the moment their children are diagnosed in early infancy or childhood. From about the age of nine most children can start doing part of the treatment themselves without help from the family. Most teenagers become completely independent and often friends and adult carers also learn the relatively easy physio techniques so they can help out at times when children with CF are away from home.

Physio may be combined with nebuliser treatment: a nebuliser is a small electric compressor that converts a liquid medication to a fine mist which is then inhaled and works directly in the lungs, combating infections and loosening the harmful secretions of mucus and sputum.

Frequent courses of antibiotics

The aim is to prevent or treat lung infections. These may be taken orally, inhaled via nebulisers, or given intravenously over a period of 10 – 14 days, either in hospital or at home.

Cross-infection

Although the risks are low for a child with Cystic Fibrosis picking up CF related infections from other children with CF, it is advisable to avoid contact with others with CF where possible.

How the digestion is helped in Cystic Fibrosis

It is possible to replace most of the missing enzymes with a substance called pancreatin. There are several preparations in capsule form. Usually they have to be taken with all snacks and meals to ensure good absorption and maximum nutritional benefit. Extra vitamins may also be recommended.

Enzymes are not drugs; they are supplements that should be taken by a child with CF immediately before meals and snacks (and sometimes also during the meal). They are often taken in large numbers which can look alarming but is, in fact, very safe. Parents should make a point of checking the school's policy on whether their child can carry enzymes or not.

Depending on the school policy, it is often the case that a child can carry these enzymes in a suitable container for use as necessary. No special storage is necessary. Most older children are able to manage their intake of enzymes well.

Smaller children may require a level of supervision to ensure they take their enzymes at the appropriate times.

Special needs of children with Cystic Fibrosis

The Special Educational Needs and Disability Act 2001 has changed previous legislation on special educational needs (Part 4 of the Education Act 1996) and introduced new anti-discrimination duties on education providers.

There is a new Code of Practice for special educational needs which provides practical advice to Local Education Authorities (LEAs). This came into force in January 2002.

There may be a significant period of absence from school and a little extra help may be needed to catch up with the rest of the class.

A child with Cystic Fibrosis may have special educational needs if, for example, CF prevents or hinders the child from making use of educational facilities of a kind provided for children of the same age in schools within the area of the local education authority (LEA).

For the vast majority of children with CF such needs will be met by their mainstream school (with outside help if necessary) without the need to arrange special educational provision by means of a statutory statement.

Parents' attention should be drawn to the Special Educational Needs: A Guide for Parents (available in English and other languages including Bengali, Gujarati, Hindi and Urdu) from the Department for Education and Employment (DFEE) – DFEE Publications Centre, PO Box 6927, London, E3 3NZ. Tel: 0845 602 2260.

Existing provision

All schools should have access to a Medical Officer, School Nurse or Care Assistant but they are not always on site and there is seldom any extra provision for children with Cystic Fibrosis. Parents are therefore dependent on the goodwill of teachers in allowing them – or other helpers who have had the relatively little amount of training needed to do physio – to come into school at times when extra physio or nebuliser treatment may be needed. On these occasions, they will need to use a small private room, such as the school medical room.

Sometimes teachers may be asked to arrange supervision for children with CF at lunchtime to make sure they eat well and take their medication. Patients should make a point of checking the school's policy on lunchtime supervision and arrange to meet staff to explain the child's nutritional and medical needs.

How does CF affect children's education?

Children with CF are just as academically able as their contemporaries and teachers should expect the same standards. They need to prioritise treatment in their daily routine – this may mean that they have less time than their peers to devote to homework and coursework. There may be significant periods of absence from school owing to chest infections or hospitalisation and a little extra help may be needed to catch up with the rest of the class. If the child is not too seriously ill, teachers may set work to be done in hospital or at home.

Some older children take advantage of portable intravenous antibiotic equipment – rather like a small radio – which means they can attend their usual lessons, although they will obviously not be able to cope with the rough and tumble of the school playground or PE lessons during these times.

Usually physical exercise is extremely beneficial to children with CF because it helps to loosen the sputum in the lungs. So full participation in PE lessons is likely when the child is well, but

sympathetic understanding is appreciated from teachers at those times when a child with CF may feel unusually tired and lack energy after a cold or chest infection.

Social and psychological aspects of Cystic Fibrosis

Children with CF may be teased or picked on at school because of their persistent cough and the fact that in some cases they may be underweight and small for their age; in addition, they may find it embarrassing to take capsules and tablets with their meals.

The physio and dietary routines also have to be taken into consideration in the social lives of children with CF – it is difficult to accept a spontaneous invitation to a friend's house after school for instance as extra enzymes may be needed or physio sessions may be missed. But most children with CF find supportive friends who are not only understanding but get actively involved in helping with physio and fitting in with the special timetable of their friend with Cystic Fibrosis.

The most serious psychological problems of CF occur in adolescence when the rebellious behaviour shown by most teenagers may pose a threat to the health of a child with Cystic Fibrosis. Physio and diet may be neglected and some teenagers may deny the potential seriousness of CF as a form of coping mechanism. Delayed sexual maturity may cause anxiety: boys with CF face probable infertility (though not impotence) and some girls with CF will face considerable health problems if they become pregnant.

Facing up to these issues as well as the unpredictable outcome of CF may be very stressful for teenagers, requiring sympathetic understanding and counselling. These issues are covered in the CF Trust booklet Growing up with CF – see back page for details on how to obtain a copy.

How Teachers Can Help

The Cystic Fibrosis Trust Support Service can be contacted if teachers need further support and advice. Address and telephone number are listed at the back of this factsheet.

Consultation with parents

Parents of children with CF have learnt to cater for their children's special needs but they may well be anxious about how their child will cope with school. Teachers can provide invaluable reassurance by making a special effort to meet parents before the child comes into their class. In very exceptional cases, parents of a child with CF may not wish to meet their child's teachers and have been known to ask if they have a legal obligation to tell the school their child has CF (in fact they don't).

Parents' ways of coping with their children with CF differ as widely as the condition of the children themselves. The whole family – the parents, the child or children with CF, other siblings – will all be affected by the psychological pressures arising from the chronic nature of CF, the uncertainty about the future, the genetic aspects, worry, depression and the tiring routines of physio and supervising medication. The family may have to face up to the prospect of death. Although medical advice, support and bereavement counselling are available from CF hospital clinics, the pressures of coping with CF place enormous strains on relationships and family life.

Teachers may find that brothers or sisters of children with CF have problems at school too. Unaffected children may feel resentment at the time spent on their sibling/s with CF, which in turn makes them feel guilty. They may try to attract attention by misbehaving or may even withdraw into themselves.

Staff at schools can prove invaluable when a child with CF changes a class or teacher. A move from

primary to secondary education may mean another round of advising staff about Cystic Fibrosis.

Many schools have excellent and well established procedures for passing on information, but it is always worthwhile checking.

Practical help

Many teachers and other school staff quickly learn to do physio for those times when it is needed during the school day or on school trips away from home. In this way, children with CF can participate fully in school activities which are an important part of the growing-up process. They enable children to be less dependent on their home and family.

The Department for Education and Employment has produced a good practice guide –Supporting pupils for Medical Needs in Schools (1996). This useful guide, available to schools, provides valuable information about recording and monitoring medical needs. It suggests that the school, in partnership with a child's parents and, if appropriate, their GP, could draw up a Health Care Plan. This would be a clear policy, understood and accepted by parents and staff and provide a sound basis for ensuring that children with medical needs receive proper care and support at school.

Teachers have a general legal duty to act in loco parentis but aren't contractually obliged either to administer medicines or supervise children taking them. There is nothing to prevent teachers doing so, with a parent's consent, provided they are insured by their employer. Schools have their own policy and LEAs have produced their own guidelines and may offer indemnity to staff. The Department for Education and Employment says: "LEAs and self-governing schools have a responsibility to make appropriate provision for the health and safety of children including the administration of medicines when necessary".

Children with CF often learn from an early age to administer their own antibiotics, and set up their nebulisers, and teachers who may find the whole prospect alarming will soon be reassured by the matter-of-fact way in which most children with CF carry out their daily treatment routine.

Teachers who are worried about this aspect of supervising children taking drugs at school should consult the child's GP or their teaching union for more specific guidelines. The CF Trust Support Service (address on the back cover of this booklet) can also be contacted if teachers need further support and advice.

GCSE examinations

The Joint Council for the GCSE (standing agreement No 4) advises that 'Examining Groups are required to take all reasonable steps to enable candidates with permanent long-term or temporary handicaps or indispositions to demonstrate their attainments'. Such steps can include, 'under suitable safeguards', the award of a grade should a candidate, 'for legitimate reasons', be absent from an examination. Additional time may be permitted, normally up to 25%, for all types of examination:

- a candidate may receive treatment, if necessary, during a supervised break;
- arrangements, subject to approval from the Examining Group, may be made for candidates to take examinations outside their own centre (e.g. at home or hospital);
- disabled candidates may be permitted additional time to complete course work or a reduction in the amount of course work negotiated with the Examining Group.

Please note that in order for a Pupil to be considered for concessions at GCSE level they need to have documented their special needs over a number of years. A child with CF should, therefore, be included on the school's register of

special needs as soon as possible and no later than year 9 which is the beginning of their GCSE course. A record should be kept of any absences from school (duration and reason) which could be presented to the examining Group on request.

Careers advice

Most children with CF now survive into adulthood and yet there is little careers advice at present. Although people with CF can cope with most jobs, there are some physically demanding or environmentally unsuitable occupations that teenagers and adults with CF should avoid where possible. The Cystic Fibrosis Trust Support Service is very willing to give advice and answer queries relating to career and job prospects.

Sex education

Adolescents with CF may require special sex counselling owing to the possible problems of delayed sexual development, the danger of pregnancy for girls with CF and the probable infertility facing boys with CF. Perhaps because relatively few children with CF reached adulthood in the past, there is no special provision at present, although both the child and their parents will receive this information from the team looking after them at their specialist CF Centre.

Further reading

CF Trust Support Service

The CF Trust Support Service has trained staff to help answer any question not covered in this booklet. The telephone numbers are:

Special Educational Needs

Available from:
DFEE Publications Centre
PO Box 6927
London E3 3NZ
Tel: 0845 602 2260
Special Educational Needs: A Guide for Parents
Ref: HMSO. ISBN 0 85522 445 2 23/0207/066/1B94a

Supporting Pupils With Medical Needs
(available for schools only)
Ref: 1112587611096125 3

Further information

For further information about any aspect of Cystic Fibrosis, please contact:

Cystic Fibrosis Trust
11 London Road
Bromley
Kent BR1 1BY
T 020 8464 7211
www.cftrust.org.uk
enquiries@cftrust.org.uk

Helplines

General helpline	0300 373 1000
Welfare Grants helpline	0300 373 1020
Benefits helpline	0300 373 1050

Other publications

The Cystic Fibrosis Trust publishes a range of publications on a wide variety of topics relating to Cystic Fibrosis. You can view our complete publications list, order publications and download publications free of charge from the CF Trust website www.cftrust.org.uk/publications. Alternatively, you can telephone the CF Trust switchboard on 020 8464 7211.

We would welcome your feedback on this or any other Cystic Fibrosis Trust publications. Please email publications@cftrust.org.uk.