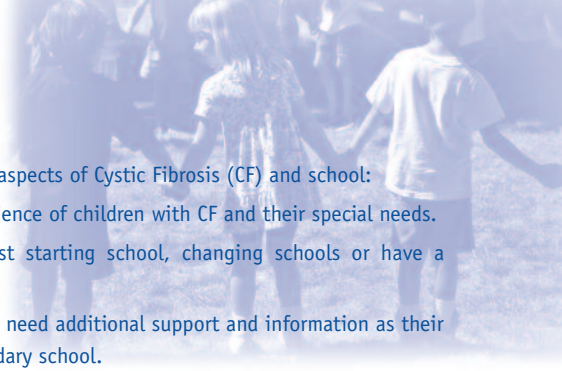
The Cystic Fibrosis Association of Ireland

School & Cystic Fibrosis

CONTENTS



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.

The Cystic Fibrosis Association of Ireland

The Cystic Fibrosis Association of Ireland is a voluntary, charitable organisation which was set up in 1963 to increase knowledge and awareness of CF and to give advice and support to people with Cystic Fibrosis and to their families.

The Association:

- Provides support and assistance to people with CF and their families:
  - There are 22 branches of the Association throughout the country, with approximately 2,500 members nationally.
- Funds Medical Research:
  - The Association funds Research Projects which help in the vital search for a greater understanding of Cystic Fibrosis. The ultimate aim is to find a cure for CF but in the interim, it is imperative that we promote research that will improve on current methods of treatment.
- Supports specialist CF Multi-Disciplinary posts in hospitals around the country.
- Provides a domiciliary physiotherapy service to people with CF (PWCF). This home-based service is provided to young children with CF and promotes training for parents in new breathing techniques.
- CFAI campaigns both locally and nationally for increased and improved services for people with Cystic Fibrosis. Our aim is to ensure that the best possible services are available to all of our members.

What is Cystic Fibrosis?

- Cystic Fibrosis (CF) is Irelands' most common, life-threatening inherited disease.
- CF occurs in approximately 1 in 1,600 Irish children.
- Approximately 1 in 19 people are carriers of the CF gene and where two carriers parent a child together; there is a 1 in 4 chance of the baby being born 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. For some 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 Cystic Fibrosis. 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. Children with CF need a higher intake of calories and protein than children without CF. Where nutrition is concerned, it is necessary for parents to consult with their CF clinic and dietician to construct an effective dietary plan for their children. A high fat, high calorie diet is usually required.

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.

Current Treatment

Current treatments include:

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

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.

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. Often friends and adult carers also learn the relatively easy physiotherapy techniques so they can help. 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

There is a strong recommendation to accept the principle that all people with cystic fibrosis (PWCF) have some type of bacteria in their respiratory secretions and that other PWCF may acquire these bacteria. The risks of picking up a CF related infection from other children with CF is high and for this reason 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. It is worth noting that due to abnormally increased resting energy expenditure in CF, children with CF can often be tired with increased hunger approaching meal times. Frequent snacks between meals and food supplements help address the energy requirements in CF.

Special Needs of Children With Cystic Fibrosis

The Need for Reasonable Accommodation

Reasonable accommodation is a term that everyone, including schools, is becoming increasingly familiar with. The concept is simple. Reasonable accommodation means providing special treatment or facilities in order to enable people to access a service. The significance for schools is that now students with disabilities have a legal enforceable right to reasonable accommodation where it would be impossible or unduly difficult for them to participate in school without such treatment or facilities.

It covers the formal rules and written policies of a school and also their practical implementation on a day-to-day basis.

The starting point in meeting the needs of a student with a disability is the assessment of those needs. This begins with looking at the barriers the student faces. These might be found in the attitudes of other people, in the processes of communication, in physical access or in the way the school is organised. For each school with a child with CF, a school will need to consult with the student's parents, relevant advocates or experts and, most importantly, the student themselves in order to understand what it needs to do to meet the young person's requirements in an optimal fashion.

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. In addition, some children with CF may feel reluctant to participate in school tours and other organised group activities due to their daily routine of physiotherapy and enzyme replacement therapy. However, by discussing concerns with the teachers and event organisers in advance, they could be encouraged to participate fully once they are satisfied that they will have proper opportunity to do their physio and take medications. Most children with CF will find supportive friends who are not only understanding but get actively involved in helping with their physio and fitting in with the special timetable and needs 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.

Facing up to these issues as well as the unpredictable outcome of CF may be very stressful for teenagers, requiring sympathetic understanding and counselling.

How Teachers Can Help

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. Although medical advice, support and bereavement counselling are available from most 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

In cases of advanced chronic lung damage and also during exacerbations, the level of lung function drops making it more difficult to climb stairs and accessibility may become a permanent obstacle and concern to children with cystic fibrosis. Access to classrooms and school facilities should be

made convenient for them. For example, an alternative to the use of stairs, such as a lift or ramp should be in place where classrooms are located on second and third stories of school buildings should changing rooms for each class be necessary. Alternatively, arranging class time-tables to ensure all classrooms are relatively close to each other can also help.

Frequent coughing fits will occur, even when a child is in good health. Teachers should be understanding in allowing the student access to cool drinking water in the event of such happening. Sitting beside a window or in a draft may aggravate or induce a coughing fit while sitting next to a radiator causing dust particles to rise, or in a dusty classroom will also cause coughing. While taking these issues into account suitable seating arrangements should be made for the PWCF. An allowance should be made for frequent bathroom breaks for students who may experience sickness from an upset stomach as a result of pancreatic insufficiency or related CF problems.

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. Children will also learn to do physiotherapy by themselves when needed during the school day.

Teachers who are worried about the aspect of supervising children taking food supplements and/or enzymes at school should consult the child's GP or their teaching union for more specific guidelines. The CF Association can also be contacted if teachers need further support and advice.

State Examinations

The Present Situation for Certificate Examinations in Ireland

Under present regulations governing the administration of state examinations, special arrangements may be made for a candidate when it is indicated in advance of the examination that the candidate has difficulties which preclude him or her from performing optimally in the examination. Special consideration is sometimes sought during or after an examination on the grounds that unforeseen circumstances arose during the course of, or around the time of, the examination which interfered with a candidate's performance.

Special Arrangements Requested Before an Examination

Application for special examination arrangements on the grounds of a specific learning disability or of a physical disability is made by schools to the Department of Education and Science on prescribed forms to be completed by school authorities. The form requests information on the following:

i Name of examinations for which special arrangements are being sought.

ii Whether the candidate avails in school of any special facilities for studying or communicating.

iii Reasons for applying for special arrangements.

iv The nature of the special arrangements that are being requested.

v Particulars of previous Certificate examinations taken by the candidate.

vi Details of assessment by a guidance or remedial teacher.

vii If the candidate had received remedial or special help at school.

viii The candidate's attendance record.

ix The candidate's general ability.

x The candidate's application to studies.

xi A psychologist's report if available over the past 12 months.

xii Three samples of a candidate's written work under examination conditions.

xiii A report of a psychologist or medical doctor supporting the case for special arrangements.

A parent/guardian is required to complete a form consenting to an interview/assessment by a psychologist from the Department of Education and Science (should the Department consider this necessary) and to the results of the interview/assessment being made available to the Department.

There is provision for a range of special arrangements

i **Time** (allowance of 10 minutes extra time per hour where a scribe or mechanical aid is used or a candidate is visually impaired).

ii **Means of Access to Questions:**
- a Reading an examination paper, without elaboration or explanation, to the candidate.
- b Provision of modified questions, substituting alternative questions for those which refer to visual material, such as diagrams, photographs, and maps.
- c Provision of braille translations.
- d Provision of enlarged print in the examination papers.
- e Provision of low vision aids for reading questions.

iii **Means of Presenting Responses:**
- a Recording of answers on tape or word processor.
- b Dictation of answers to a scribe.
- c Sending a script to a supervising examiner when the examiner encounters difficulty in reading it.

iv **Alternative Accommodation/Time Arrangements:**
- a Taking the examination in a special room in a school or in a hospital.
- b Alteration in the time at which the examination is taken (e.g., to allow attendance at the funeral of a close relative).

There is no indication on a candidate's certificate of results that special arrangements were in place for the examination.

School Transport

The School Transport scheme is operated by Bus Eireann on behalf of the Department of Education & Science.

How Can Transport be Obtained?

The school principle applies through the school Inspector to the School Transport Section of the Department. Every request for school transport for a special needs pupil is passed to Bus Eireann by the Schools Transport Section. Bus Eireann then check with the relevant local transport office to see whether the pupil can be facilitated on an existing service. If this is not possible, the introduction of a new service is investigated.

More detailed information regarding school transport can be obtained from the Department of Education & Science, School Transport Section, Portlaois Road, Tullamore, Co. Offaly. Telephone: 057-93-24351/2/3/4/5/6.

Home Tuition

A number of children with cystic fibrosis will at times experience unavoidable absenteeism from school due to illness and hospital stays on occasion. Even children with CF who are well, will need to attend regular outpatient clinics and annual review assessments. For this reason, they may need additional home tuition in order to catch up with work they have missed. Home tuition is intended to provide education for children with a significant medical condition causing major disruption to their attendance at school. An application for home tuition can be made through the school at which the child is present. Forms are available from the school principle or from the Department of Education & Science.

Careers Advice

Most children with CF now survive into adulthood. 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. Advice should be sought from the careers guidance teachers in the school or medical teams can be asked their views also.

Conclusion

Cystic Fibrosis is a genetic disorder with many complications and it is hoped that this booklet has helped to explain its origins, health and psychological problems, current treatment and the hope for the future. It is the way children with CF are treated and understood that determines the extent to which they are able to cope with school and lead normal lives.

FURTHER INFORMATION

The Department of Education & Science
Special Education Section
Cornamaddy, Athlone, Co. Westmeath
Tel: (090) 648 3600
www.education.ie

Department of Education & Science
School Transport Section
Portlaois Road, Tullamore, Co. Offaly
Tel: (057) 932 4351/2/3/4/5/6

Equality Authority
2 Clonmel Street, Dublin 2
Public Information Centre Lo Call 1890 245 545
Tel: (01) 417 3333
www.equality.ie

National Disability Authority
25 Clyde Road, Ballsbridge, Dublin 4
Tel: (01) 608 0400
E-Mail: nda@nda.ie
www.nda.ie

Further enquiries about literature, including booklets produced by the Association can be obtained from:

THE CYSTIC FIBROSIS ASSOCIATION OF IRELAND

CF House, 24 Lower Rathmines Road, Dublin 6, Ireland
Tel: +353 (01) 496 2433 Fax: +353 (01) 496 2201
LoCall: 1890 311 211

Email: info@cfireland.ie Web: www.cfireland.ie