



REGISTERED CHARITY No. 272100

## FACTSHEET 5

# EDUCATION

*"providing support to people affected by  
Osteogenesis Imperfecta"*

### *What is Osteogenesis Imperfecta?*

The more accurate term for brittle bones is Osteogenesis Imperfecta (OI). The term "brittle bones" refers to a range of conditions resulting from abnormalities in the protein structure of the bones. This causes the bones to break more easily than normal.

Fractures have to be managed individually as they occur and bones are carefully re-set to prevent deformity.

There are different types of brittle bones and some children are of normal stature and appearance and are simply more fragile than is usual and others, who are more severely affected, can be of short stature and are often unable to walk. It can be an inherited condition and the mildly affected child may have one parent with the condition.

### *What has to be considered at school?*

#### **Fractures**

Children with brittle bones are much more likely to fracture than normal but there is no general indicator and some are more vulnerable to breaks than others. It seems that individual children go through a 'bad spell' when they fracture several times in a short space of time but they may then go for a number of years without fractures.

There is some evidence to show that adolescents do not fracture as frequently as young children. Some children are born with fractures, others fracture soon after birth and others may be a little older, eg learning to walk, when they have a fracture. By the time, children reach school age, the family will have acquired considerable experience of the condition and the causes of fracturing.

It is very important to know that fractures can be caused by normal behaviour, eg. closing a door or turning over in bed. Whilst every effort should be made to prevent the opportunity for a fracture to occur, teachers will not held responsible if a break does occur at school.

It is natural to be concerned about a child who is very fragile in the school environment but if a placement is properly planned and resourced, the vast majority of children with brittle bones should be able to receive their education in mainstream schools.

Children with brittle bones may require statements and the protection these afford. For more information see **FACTSHEET 6 - ASSESSMENT AND STATEMENTING**.

## **Effects of Fracturing**

Children with a severe form of this condition may have spent much of their early life lying on their back, either in hospital or at home in plaster. They may, as a result, have missed out on a range of “life experiences” including pre-school provision. This in turn may have affected their confidence as well as their learning. Some of these children may have had between 50 - 100 fractures during their childhood. The constant risk of fracture, the associated pain and the cycle of treatment may understandably make them anxious.

Medically, each fracture requires assessment and re-setting. In some instances fractures may be treated and the child may be able to return to school while it heals. With more severe fractures it is likely that the child will need to spend time in hospital, sometimes on traction, and then a further period at home. It is recognised that education remains important for these children whilst they are in hospital. It will be very helpful for school staff to liaise with the hospital teachers to ensure a consistent programme. In some instances home teaching is appropriate until the child is able to return to school. Occasionally a local special school may have the facilities for a child to continue to receive their education on a temporary basis until they are able to return to their mainstream school. The essential point is to ensure that the educational provision made has the flexibility to meet the changing requirements of the child.

## **Handwriting**

Some children with brittle bones have joints in their hands, which are more mobile than is usual and their hand and arm structure may also be impaired by the effect of previous fractures. Approximately 80% of severely impaired children are either left-handed (as they have fewer fractures in this hand) or hold their pens in an unusual manner. It may be necessary to experiment with different types of pen, the width of lines on paper, size of sheet etc. Also plastic pen-holders, a triangular pen or felt tip pens may be helpful. Many children may also need attention to their seating arrangements, desks or worktops. The child's occupational therapist will be able to advise. Because of lack of opportunity children with brittle bones may not have learnt to form their letters correctly before starting school and as for all children, a reliable handwriting scheme paying particular attention to letter formation is a basic requirement. To some extent, increased muscle tone compensates for ligament laxity in the hands and fingers of many children, but even so they may find it difficult to write for long periods and may write more slowly than other children. This may present difficulties eg note taking at secondary level. Handouts or copies of other pupil's notes may be helpful. If the pupil knows in advance that notes will be supplied they are then able to concentrate on the work in hand. Many children may prefer to use a keyboard but they still need to practice and maintain their writing skills

## **Mobility**

Children who are very susceptible to fracturing often use specialist wheelchairs for safety as well as support. A child who breaks a limb may temporarily need to use a wheelchair or the limb may simply be protected with splints and the child be allowed to return to school. Some children may use other mobility aids such as sticks and crutches. This may make them vulnerable to knocks and bumps and the school may need to develop strategies to keep them as safe as possible.



### **Physical Education**

Most forms of PE are not suitable for children with severe forms of this condition. Swimming is recommended and non-weight bearing and non-restricted exercises may also be suitable. Some children may be able to take part in some forms of PE - but please check with parents and medical advisers that it is suitable for them.

### **Playgrounds and Corridors**

The school will need to consider time spent outside lessons when children are not under the close supervision of an adult. Children in wheelchairs may be able to join their peers in the playground, especially if there is a quiet area. Other children with brittle bones may be more at risk of accidental injury and may need to be restricted to a quiet area, perhaps with a few friends. In the winter months they may need to stay indoors. This may raise questions about additional supervision particularly for younger children. Children walking with sticks or crutches may be vulnerable at times when large numbers of children are moving about, eg, between lessons and at playtimes. You may need to use a simple strategy of asking the child to wait to the end or allowing them to leave a couple of minutes before the end of a lesson. This should be discussed with all staff involved with the child and a consistent approach worked out - so a pupil will neither be unjustly penalised nor given the opportunity to take advantage of such an arrangement

### **Toilet Needs**

Some children especially those with short arms and wheelchair users, may need assistance in using toilet facilities. Special arrangements may need to be made. It is essential that these needs are checked and planned for before a placement is made so that the child is not caused embarrassment - and the accompanying loss of confidence which may result.

### **Protection and Over Protection**

Because the children are physically 'fragile' and the results of fractures may be serious, there is an understandable tendency to overprotect on the part of all adults working with them. For the most part they are intelligent children and it is particularly important that they are given every opportunity to practise social skills, make decisions for themselves and gradually learn to become independent young people. It is important that this element of their education is considered/reviewed alongside the academic curriculum

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