

## Advice for Schools

### Children with Osteogenesis Imperfecta



**Osteogenesis Imperfecta (OI)** is also known as “brittle bones.” It is a genetic bone condition characterised by fragile bones that break easily. A person is born with this condition and is affected throughout his or her lifetime. As well as frequent fractured bones, people with OI often experience bone pain, muscle weakness, hearing loss, fatigue, joint laxity, curved bones, scoliosis, blue sclerae, dentinogenesis imperfecta (brittle teeth), and short stature. OI is caused by a genetic mutation that affects the body’s production of collagen, which can be found throughout the body, especially in a person’s bones and other tissues.

Brittle Bone Society

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*Supporting people  
who live with bones  
that break*

#### Introduction

Osteogenesis Imperfecta (OI) is commonly called ‘*Brittle Bone Disease*’. It has a wide range of severity and this advice sheet has been written as a general information guide for teachers and carers of children with OI in nurseries and schools.

#### General

OI is a genetic condition which causes a defect in the formation of a fibrous tissue called collagen in the body. Collagen is normally present in bones, joints, ligaments, teeth and skin.

This defect can cause the following:

- Bones: more liable to break with little or no apparent cause.
- Back: may have curvature (scoliosis) or crush fractured vertebrae.
- Joints: are hypermobile (bendy) due to lax ligaments.
- Teeth: may be translucent or grey (Dentinogenesis Imperfecta).
- Skin: may bruise more easily.
- Hearing: hearing loss may occur, tends to start in late teens.
- Pain: generalised pain which may increase prior to drug treatment (if applicable.)

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- Height: usually shorter than peers.

It is advisable for the school to have a management plan outlining key people and roles in the event of an emergency, i.e. a fracture, a fire etc. or when the child is in plaster.

Staff need to know what to do if fracture is suspected – Do not move child, assess situation, phone for ambulance/parents.

During their childhood and adolescence the child may miss school due to treatment of fractures, planned orthopaedic treatment, outpatient appointments and medical treatment of their condition which can often necessitate a number of stays in hospital. Forward planning for school work & catch up time would be helpful.

### Housekeeping advice

#### **Toilet areas**

- A level access disabled toilet will be required if the child is a wheelchair user and specially adapted equipment to allow independence or minimise the assistance required to transfer from a wheelchair. The therapists involved will advise on how to assist a child to maintain their privacy and may issue the equipment, or give advice to the school as to where to purchase such equipment.
- An ambulant/mobile child may need equipment such as grab rails.
- The floor should be checked to ensure it is dry to prevent risk of falls.
- Toilet doors are often very heavy and awkward to open so children may need help to open them.

#### **Corridors**

- Clothes pegs should be at a height accessible to the child and preferably at the end of the line to prevent 'crushing' in the crowd.
- An early /late exit from the classroom to allow safe travel in the corridors is often helpful.
- The child may need supervision in corridors, particularly if the floor is slippery. This is obviously worse on wet days.
- Rugs are a trip hazard.

### Classroom

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## Seating

- Specialised seating or adaptations such as a wedged cushion may need to be provided. A physiotherapist or Occupational therapist should be able to advise.

## At a table -

- The hips and knees should be at right angles where possible.
- The chair should be pulled up to the table.
- The height of the table should be examined to promote good postural alignment in sitting. Feet should be on the floor to aid balance and posture.

## Floor time -

- A chair could be provided rather than sitting on the floor, to promote good posture and prevent deformity and joint pains. A friend sitting next to the child may alleviate the feeling of being 'different'.

## Walkways -

- Check for storage items protruding into walkways.
- Check floor around water and sand play areas.

## Things to be aware of

### Handwriting.

This may be messy, variable or laborious due to increased movement in the finger joints. The child may complain of pain following increased amounts of time spent writing. To improve this, chunky shaped and shorter pen/pencil/pencil crayons, easier flowing pens (gel or fibre tipped rather than traditional roller ball or blotchy fountain pens) angled boards or access to laptop/computer/PDA may be required. The speed of writing is often slower and therefore during an exam the child may require extra time in order to finish work. Appropriate medical letters can be provided to support this where needed.

### Tiredness

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Due to bony deformity and/or joint hypermobility a child may find that they tire during school work, particularly PE and it is our experience that a child may need 'time-out' for resting, particularly in the early years.

### **Aches and pains.**

A child with the more severe OI will need a variable amount of time to rest either reclined in their wheelchair or on a flat surface (bed or floor). This will help prevent the build up of back pain and may help prevent further deterioration of the shape of the back bones (crush fractures). A child that spends the full day in their wheelchair should be given time to get out of the chair to lie or move about on the floor. This will help prevent pains in the hips/knees and muscle shortening that can give rise to other problems.

Children with mild OI often suffer from a large degree of hypermobility and may therefore need rest periods from very busy activities. To minimise back pain and fatigue the child may need either to use a rucksack on both shoulders, use a locker in a central location, have a second set of textbooks at home or have someone to carry their school bag.

### **Playtimes/Lunchtimes**

#### **Outside play**

For the younger child supervision is required as at this age the child is not yet aware of safety issues. In order to promote independence the child might be more effectively supported from a slight distance, in order that they do not feel 'singled out'. Older children may require a space/area of their own with a few friends.

#### **Seating**

If a child has specialist seating in the classroom then they will benefit from this seating while having their lunch, in order to promote good posture and prevent aches and pains.

#### **Cutlery**

A child may have been provided with specialised chunky or shaped cutlery to improve skill and independence.

#### **Social**

A more able bodied/older pupil could offer help and support to a child with OI or use a 'buddy system'.

### **School trips**

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A child that can normally manage short distances walking may not manage on a trip that involves moderate walking or activities. If so the child may require the use of a wheelchair/buggy for longer distances, use of this during the trip should be planned. Many children can self propel their wheelchair but will tire over a longer distance. A parent or carer may need to accompany the child.

### **Physical Education/Activity days**

A child should be given the opportunity to be included in the lesson as much as they are able; this may require the help of a classroom assistant. Exercise is important for all, for general fitness and strength.

Parents and teachers should discuss the activities that will be on the curriculum before the child starts to join in. This will help to exclude any activities that are not suitable and will open up discussion of how to enable the child to participate.

### **Things to avoid**

- Jumping off objects, suggest climbing down.
- Bouncing e.g. trampoline/trampettes and sitting down activities such as horse riding, sledging, and quad biking.
- Sports that may lead to a fall, e.g. ice skating, roller blading, horse riding, skiing and skateboarding.
- Contact sports, particularly when at competitive level. Junior football often doesn't involve tackling or pile ups so may be safer. In the case of a mildly affected individual more severe tackling may be prevented by use of a bright coloured T-shirt or team band for quicker recognition. Education of peers may be useful. Some children enjoy skills practice, such as dribbling, kicking, throwing, or catching, but not contact sports.

### **Good/ beneficial activities**

- Music and movement. A wheelchair user could be placed on the floor to allow for imaginative movement.
- Racquet sports such as Table tennis, Badminton, Rounders and Tennis. Often a shorter adapted racquet is required in younger children.
- Ball skills such as throw and catch.
- Balance skills, particularly if child has joint hypermobility as often balance games and exercises are part of their Physiotherapy programme.
- Swimming – an excellent sport for children with OI.

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- Hydrotherapy with the guidance of a physiotherapist can be beneficial.

### Adaptations

- Climbing apparatus. A child could climb just a short height then travel sideways to develop foot placement skills.
- Gymnastic floor work. A soft mat or crash mat could be used for practising forward rolls. Medical approval should be sought before doing such floor work to ensure the spine is strong enough for these activities.
- Athletics. Throwing could be carried out with light-weight versions in a more severely affected individual e.g. a foam javelin stick, tennis ball or plastic discus – be innovative!
- If no alternative activity can be found then the child could carry out a programme designed by their Physiotherapist with the aid of their classroom support assistant. Or a simple light-weight gym programme and cardiovascular exercise. This may include walking practice with an aid.

For further support and information please contact the Brittle Bone Society.

This factsheet was produced in conjunction with the Paediatric Osteogenesis Imperfecta National Team (POINT) - special thanks go to the Metabolic Bone Teams at Birmingham Children's Hospital, Great Ormond Street Hospital, Sheffield Children's Hospital and Royal Hospital for Sick Children, Yorkhill.

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