



INFORMATION ON OSTEOGENESIS IMPERFECTA FOR PRIMARY SCHOOLS

Starting Primary School

The transition into primary school needs to be planned and well managed. It is advisable to arrange a meeting well in advance of the child starting school. Attendees should include key workers involved in the child's education, and parents. This gives everybody the opportunity to get to know each other, highlight specific needs that the child has and plan how these needs are going to be met. If the child with OI is a wheelchair user, the environment should be assessed to ensure that the school is accessible. Often an Occupational Therapist can assist in this area.

It is advisable at this initial meeting for you to develop a management plan, which should include:

- ◆ **School Entry Plan / Care Plan / Fracture Management Plan:** The plan should describe the student's needs and how the school plans to meet these needs. The plan must also detail procedures to be followed if an emergency arises. Procedures need to be agreed between the parent and the school, following consultation with the relevant medical practitioners. Plans should be reviewed annually or if the child's health needs change. The plan should identify the key people and their roles in the event of an emergency. For more information please refer to the *Brittle Bone Society Fracture Management Guidelines*.
- ◆ **Risk Assessment:** This should be completed prior to starting school. A risk assessment should detail all potential risks within the school environment and could be reviewed on termly basis. Additional risk assessments will need to be carried out for school trips / activity days or special events.
- ◆ **Statement of Educational Needs:** Consideration needs to be given to the child with OI who may require additional support during their time at school. This is very individual and specific to the child. It is most often related to their physical, medical and safety needs as opposed to learning needs. Often this additional support is necessary for break times / lunch times and physical activity sessions.

Learning Considerations

Absence: During their childhood and adolescence a child may miss school due to both planned and unplanned treatment of fractures, surgery, out-patient appointments and medical treatment of their condition. This can often necessitate a number of stays in hospital. Forward planning for school work and catch up time would be helpful. Return to school as soon as possible after any absence event should be planned. In exceptional circumstances of prolonged absence, home schooling should be sought as soon as possible.

Hearing Loss: Hearing loss is a medical complication of OI which can occur at any age and in children with any type of OI. This could affect interaction within the class-room / school environment, behaviour and ability to learn. Parents should be the primary contact for concerns regarding hearing loss.

Personal, Social and Health Education: OI impacts a child's health and well-being. It can affect self-esteem, self-confidence, friendships, play and participation. As with any child, teachers need to be vigilant about the potential for bullying and the risk of the child with OI being excluded from peer directed activities.

There are many creative ways to be support a child and their peers learn more about OI, be it self-directed or teacher led. It is important to consult with the child and potentially their family prior to any teaching.

Considerations within the School Environment

Consideration needs to be given to the current physical abilities of the child, but also the potential for fractures. They may therefore have periods of time in plaster and may require the use of a walking aid or wheelchair, during which time they may require more support / space than usual. Key areas for consideration should be:

Toilet Areas

- ◆ A level access disabled toilet and sink will be required if the child is a wheelchair user.
- ◆ Specially adapted equipment /grab rails / small step can facilitate safe and independent toilet transfers and hand washing for more mobile children

Cloakroom/Corridors

- ◆ Clothes pegs should be at a height accessible to the child and preferably at the end of the line to prevent the child being pushed / knocked during busy periods.
- ◆ Cloakrooms and corridors should be kept clear of clutter
- ◆ An early / late arrival / exit to and from the classroom allows for safer travel in the corridors. A friend can accompany them so they don't feel isolated.

Tables and Chairs

- ◆ Children may have some form of specialist seating for use in the classroom. Other times more simple measures such as a wedged cushion may have been provided/ recommended. Usually an Occupational Therapist or a Physiotherapist will have been involved in this process and should be able to advise further.
- ◆ If the child is in a wheelchair then the table needs to be accessible for them and at a good working height.

Floor Time / Assemblies

- ◆ Sometimes a child may be more comfortable sitting on a small chair rather than the floor. This can prevent fingers getting trodden on by other children and may reduce joint aches and pains.

Activities

- ◆ If the child is shorter than their peers a small step may be needed to enable participation within activities. Other times the child may be in a wheelchair and the activity may need to be adapted.

Drawing / writing skills

- ◆ Due to increased laxity in their joints, often affecting their fingers, children with OI may have fatigue, joint aches / pains, messy or variable work and slower speed of writing.
- ◆ The child may benefit from pacing these activities, by incorporating rest and stretch breaks into the activity. If you are concerned about this an Occupational Therapist can often complete a more formal assessment and make recommendations.
- ◆ Children with hypermobile finger joints may benefit from chunkier pens or pencils, or the addition of pencil grips.

Tiredness, aches and pains

- ◆ A child with OI may tire more quickly than other children of a similar age. They may experience aches and pains, especially following physical activity.
- ◆ Pacing activities and giving the child the option of 'time out' for resting may help.

General Housekeeping

- ◆ Floors should be dry and clutter free as possible to minimise the risk of trips and falls.
- ◆ A child may need help with doors that are heavy and difficult to open.

Playtimes / Lunchtimes

- ◆ Additional supervision may be needed especially for the younger child as they are often not yet aware of safety issues.
- ◆ As the child gets older and more aware of safety considerations supervision may be required only from a distance.
- ◆ It can be a good idea to have a 'quiet area' where the child can go with a few friends and undertake other play activities as opposed to 'running around' in the playground with large numbers.
- ◆ If a child has a specialist seat in the classroom it can be beneficial to have this available at lunchtimes also.
- ◆ As with handwriting children may struggle with the use of cutlery. If this is an area where you notice a child is struggling then an Occupational Therapist may be able to complete an assessment.

School Outings

A child that can normally manage short distances walking around the school may not manage as well on trips that involve moderate walking or activities. If so the child may require more regular breaks and / or the use of a buggy / wheelchair during these times.

Planning with parents in advance of these trips should take place in conjunction with a risk assessment.

PE / Activity Days

- ◆ Exercise promotes muscle and bone strength, which can help prevent fractures and improve a child's bone density.
- ◆ Increasing general fitness can help manage fatigue.
- ◆ Children should be encouraged to participate in PE lessons and activities as independently and safely as possible. Activities can be modified to allow participation.
- ◆ Running and jumping on hard surfaces and jumping off gym apparatus should be avoided. A paediatric physiotherapist can assist in this area and more detailed information can be found in the *Brittle Bone Society Including pupils who have OI in mainstream PE lessons factsheet*.

The care plan with school should:

- ◆ Describe the child's needs and identify how needs are to be met
- ◆ Details procedures in the event of an emergency
- ◆ Identify key people and corresponding roles in the event of an emergency
- ◆ Be reviewed annually or before the child's needs change (e.g. if it is known that a child is having planned lower limb surgery)
- ◆ Please note that plan must be agreed upon between parent/carer and the school following consultation with medical practitioner.

Compiled by the Brittle Bone Society in collaboration with the Paediatric Osteogenesis Imperfecta National Team (POINT) - special thanks go to the Metabolic Bone Teams at Birmingham Children's Hospital, Bristol Royal Hospital for Children, Great Ormond Street Hospital, Sheffield Children's Hospital and Royal Hospital for Sick Children Yorkhill, Glasgow.

The information in this leaflet is correct as at 31st January 2015 but we cannot guarantee that it will be accurate and current at any given time. This leaflet is not intended in any way to replace the advice of your doctor or other medical professional. Leaflets are available online at www.brittlebone.org. This information is available in accessible formats on request.



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*Working with People
who live with
Osteogenesis Imperfecta.*