Information on Osteogenesis Imperfecta for Primary Schools

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, relevant health professionals 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 uses a wheelchair or a walking aid, the environment should be assessed to ensure that the school is accessible, often an occupational therapist can assist in this area.

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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 health care team. 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. 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 if the child's needs change (e.g. if it is known that a child is having planned surgery).
- Please note that plan must be agreed upon between parent/carer and the school following consultation with relevant health professions.

Risk Assessment

This should be completed prior to starting school. The school will already have a template risk assessment plan in place which can be used as a guide. A risk assessment should detail all potential risks within the school environment and could be reviewed when needed. Additional risk assessments will need to be carried out for school trips/activity days or special events.

Educational Health Care Plan/Additional Support Needs

Consideration needs to be given to the child with OI who may require educational and practical support to access the curriculum. This need is individual to the child. Without this additional support they may not achieve their full potential. Support is necessary for break times / lunch times, physical activity sessions and when moving around in busy classroom/corridors. Independence and inclusion should always be encouraged. Children may have additional needs beyond their OI diagnosis.

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 schoolwork 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 can be a medical complication of OI which can occur at any age. This could affect interaction within the classroom / school environment, behaviour and ability to learn. Children should engage with routine screening in foundation stage. 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 support a child and for their peers to 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 or awareness sessions.

Drawing/Writing Skills

- Due to increased ligament laxity in their joints, often affecting their fingers, children with OI may have fatigue, joint aches and pains. This could affect the quality and quantity of their work and lead to a slower speed of writing.
- The child may benefit from pacing these activities, by incorporating rest and stretch breaks into the activity.
- Children with hypermobile finger joints may benefit from chunkier pens or pencils, or the addition of pencil grips. It is important to recognise handwriting issues early on. If you are concerned about this an Occupational Therapist can often complete a more formal assessment and make recommendations.

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.
- At times children might require simple pain relief medication e.g. paracetamol to manage their aches and pains. Create a plan for children to take this in school when required and follow local procedures for storage and administration.

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 cast and may require the use of a walking aid and/or wheelchair, during which time they may require more support / space than usual. Key areas for consideration should be:

Toilet Areas

- An accessible toilet and sink may be required, particularly if the child uses a wheelchair or walking aid. However, these spaces are often designed with adults in mind and may need further adaptions for a younger child.
- Specially adapted equipment /grab rails /small step can facilitate safe and independent toilet transfers and hand washing.
- Non-slip flooring should be considered.
- The area should be checked to make sure it is clean and dry before the child uses it.
- An occupational therapist can help identify solutions to help facilitate independence.

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.

Tables and Chairs

- Children should be sat on an appropriate size chair with feet flat on the floor and bottom to the back rest.
- Children may require some form of specialist seating for use in the classroom. Other times more simple measures such as a cushion and foot block 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 to reduce aches and pains. If a child is sitting on the floor, consider positioning them near a member of staff or at the edge of the group to minimise accidents such being stood on or tripping over others. Do consider a chair for them to sit on if the time required to sit is longer then 10-15 mins, or if completing activities such as writing on a white board.

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.

Activities and Social Opportunities

Playtime/Lunchtime

- Additional supervision is needed, especially for the younger child as they are often not yet aware of risks.
- As the child gets older and more aware of risks, supervision should continue but may be required from a sensible distance to allow social development, depending on the needs of the individual.
- 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 if they wish.
- 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. The child may require regular breaks and / or the use of a buggy / wheelchair during these times. Plan with parents in advance of these trips and do a risk assessment.

School trips should be accessible and inclusive. Consider transport arrangements, particularly if they use a wheelchair.

Physical Education

- The benefits of exercise are well documented for general health and well-being.
- Increasing general fitness can help manage fatigue.
- Children should be encouraged to participate in PE lessons and activities should be modified to allow participation.
- Running and jumping on uneven or unpredictable surfaces should be avoided and children should be encouraged to climb down from any apparatus. More detailed information can be found in the 'Including pupils who have OI' in mainstream PE lessons factsheet.
- Further guidance can be sought from a physiotherapist.

Compiled by the Brittle Bone Society in collaboration with BBS Medical Advisory Board and POINT (Paediatric Osteogenesis Imperfecta National Team). The information in this leaflet is correct as at 31st July 2021 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.

The Brittle Bone Society (BBS) is a registered charity in Scotland (SCO50854) and company limited by guarantee (SC677346), supporting the OI community throughout the United Kingdom and in Ireland.