# Information on Osteogenesis Imperfecta for Secondary Schools

The transition from primary into secondary school needs to be planned and well managed. It is advisable to arrange a meeting, well in advance of the pupil changing school so that the key people involved in the pupil's education can meet him/her and parents, and vice versa. This gives everybody the opportunity to get to know each other, highlight specific needs that the pupil has and plan how these needs are going to be met. If the pupil 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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Dependant on an individual needs, it may be advisable at this initial meeting to develop a management plan specific to your school, which should include:

- School Entry Plan / Care Plan / Fracture Management Plan: The plan should describe the pupil'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 pupil'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: It is the school's responsibility to carry out a risk assessment prior to the pupil starting school. This should detail all potential risks within the school environment and should be reviewed at least yearly, and when there are any changes in needs. Additional risk assessments will need to be carried out for school trips / activity days, special events or a specific manual handling risk assessment following a fracture. Seek advice from local services where involved and local moving and handling teams / physical and sensory service. Independence and inclusion should always be encouraged.
- Educational Health Care Plan: The pupil may have had additional support within their primary school setting. Often this additional support may have been necessary for break times / lunch times and physical activity sessions. This is very individual and specific to the pupil and is most often related to their physical, medical and safety needs as opposed to learning needs. These support needs may continue into secondary school and will require reviewing on a regular basis.

Not all children with OI qualify for an EHCP but may still require additional support and strategies. It is advisable that children with OI are taught to promote their own self-management, understanding risks and advocating for themselves. They may require activities adapting to ensure inclusion. This needs guidance from their key workers. Do follow local procedures and apply for EHCP if indicated.

## 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 treatments. This can often necessitate a number of stays in hospital and school days missed. Forward planning for schoolwork and catch-up time would be helpful and returning to school as soon as possible after any absence event. In exceptional circumstances of prolonged absence, home schooling should be sought.

**Hearing Loss:** Hearing loss can be a medical complication of OI which can occur at any age. This could affect interaction with the classroom / school environment, behaviour and ability to learn. Parents should be the first contact for concerns regarding hearing loss.

**Personal, Social and Health Education:** OI impacts a pupil's health, and it can affect self-esteem, self-confidence, friendships, social-life and participation. Pupils with OI have the same needs as others to develop a healthy self-image and to understand their personal strengths, abilities, limitations and weaknesses. Secondary school plays an important role in the development of these skills especially as they progress into their teenage years. As with any pupil, teachers need to be vigilant about the potential for bullying and the risk of the pupil with OI being excluded from peer directed activities. (Please refer to the emotional wellbeing leaflet for more information).

**Fine motor skills / Handwriting:** A common feature of OI is joint hypermobility in the hands this causes fine motor challenges. Pupils with OI may also have changes to bone shape in their arms/hands which can result in difficulties with grip, power and stamina, leading to problems with handwriting. Provision of a laptop for longer pieces of work, extra time in exams or provision of a scribe may need to be considered. If you are concerned about this an occupational therapist can often complete a more formal assessment and make recommendations.

**Tiredness, Aches and Pains:** Due to bone deformities, bone pain and / or joint hypermobility, pupils with OI do experience pain frequently and can tire much quicker than other pupils of a similar age, especially following physical activity. Excessive pain may lead to absences. Discuss the management of this with the pupil, parent and school nurse; at times medication may be required. If pupils require simple analgesia to manage their pain, follow local procedures to enable an effective strategy for this during the school day.

## School Environment

Consideration needs to be given to the current physical abilities of the pupil, but also their potential for fractures. They may 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 and space than usual. Even when in usual health, a pupil with OI may require strategies for safety and to conserve energy such as or access to a lift and/or early exit from lesson to move in corridors when quiet; it is nice if a friend can accompany them, so they don't feel so isolated.

### Toilet and Changing Room Areas

An accessible toilet and sink may be required depending on the needs of the individual. It may also be necessary to have specially adapted equipment /grab rails / small step to facilitate safe and independent toilet transfers and hand washing. Wet floors, increase the risk of slips, caution should be taken in these environments to minimise these risks. An occupational therapist can help identify solutions to help facilitate independence.

### Lockers

If able to be provided, lockers should be at a height accessible to the pupil and preferably at the end to prevent the pupil being pushed / knocked during busy periods. If lockers are not available, then it is sensible to allow the pupil to leave heavy books/PE kit within an appropriate safe place to minimise the amount they have to carry.

### Tables and Chairs

Often pupils with OI are smaller than their peers and may like to use some form of specialist seating in the classroom. Other times more simple measures such as cushions and/or foot block may be recommended. Usually, an occupational therapist or a physiotherapist will have been involved in this process and should be able to advise further. If you notice a pupil would benefit from better seating, and local strategies don't help, please consider referral to an occupational therapist. Wheelchair users need tables that are accessible to them and at a good working height.

### Science and Technology

Seating for these lessons is usually a stool, more commonly with no backrest. If difficulties arise such as back pain, it may be necessary to consider an alternative option. If this is a concern, then please seek the advice of the occupational therapist involved with the pupil.

## Activities and Social Opportunities

### Physical Education

- The benefits of exercise are well documented both in terms of physical but also mental health.
- 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. Guidance can be sought from the physiotherapist involved with the pupil when planning their PE lessons. Please refer to the 'Including Pupils with OI in PE' leaflet for further information.

### Break times / Lunchtimes

Pupils with OI tend to eat more slowly and can sometimes have problems with their teeth and therefore you may notice that they take longer to eat their lunch. It is advisable for the pupil to enter the dining hall at less busy periods to avoid any unnecessary collisions / bumps.

### Transport

It is not appropriate to expect a pupil with OI to get on a busy school bus unless they have a guaranteed space on the lower floor with a friend. Families often help by transporting to and from school, but when that is not possible, appropriate school transport should be considered. This is particularly for the more severely affected students or following a fracture.

### School Outings

A pupil who can normally manage short distance walking within the school environment may not manage as well on a trip that involves moderate walking or activities. If so the pupil may require more regular breaks and / or the use of a wheelchair during these times. Planning with parents in advance of these trips and undertaking a risk assessment is important.

### Careers Advice / Work Experience

This should be appropriate to the pupil's interests as well as their physical capabilities. If they need support at school it is likely that they will need this for work experience and for post 16 education. It is important that any equipment needs are identified and addressed prior to starting the work experience placement. The therapists involved with the pupil may be able to offer support and advise further with this.

### General Advice

- Physical and psychological wellbeing should be always considered.
- If the pupil is receiving Bisphosphonate treatment for their OI they may tire / be in pain towards the end of each treatment schedule (for further information on this please refer to the Bisphosphonate treatment leaflet).
- Although a pupil with OI may be restricted in some activities, they should still be included in all aspects of their education and school life.

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.