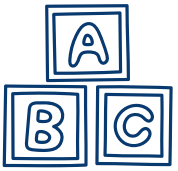
Starting Nursery or Pre-School with Osteogenesis Imperfecta

It is advisable to make contact or arrange a meeting well in advance of the child's start date, consult with key workers involved in the child's care, 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 uses a mobility aid e.g. wheelchair, the environment should be assessed to ensure that it is accessible.

Young children with OI would benefit from the opportunity to attend nursery or pre-school.

It is advisable at this initial meeting that a management plan is developed, which should include a care plan, a fracture management plan and relevant risk assessments.



Supervision

Children with OI require additional physical support and/or supervision when compared to their peers. This support is variable according to severity of their OI, age and their stage of development. It is in these early years that most gross motor skills are attained and a time where accidents and falls are most likely. It is recommended that children should have supervision when moving and interacting with others to promote safe acquisition of gross motor skills without falls which may lead to fractures. This should be identified and planned for at the initial planning stages so that it does not delay the child attending nursery. It may be possible to offer extra staff support from within the nursery setting, with applications for additional funding from the local offer. Support may be sought from key workers, professionals and parents to ensure appropriate recommendations are made. This may form part of the evidence for an EHCP application, however may not be applicable to all children and therefore should be guided by the education setting in the first instance.

Considerations within the Environment

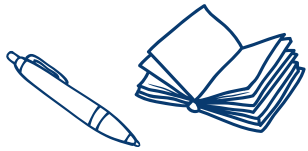
Consider the current physical abilities of the child, and their potential for fractures. They may need periods of time in cast, and/or require the use of a walking aid or wheelchair, during which time they will require more support/ space than usual. Key areas for consideration should be:

Toilet areas:

- Consider the space, heights and accessibility of toileting areas.
- For children in nappies, a suitable change area should be identified to accommodate the needs of staff and the child. Staff can refer to the "Caring for an infant with OI" factsheet for advice on safe handling and nappy changing techniques.
- For children that use the toilet, consideration of toilet/potty and sink height should be included in a risk assessment. Some children may require equipment to support access, safety and independence.
- Toilet areas often get wet. Staff should be extra mindful of this when supervising a child in this area.
- The child's occupational therapist can be contacted for advice on accessing toileting areas and promoting independence.

Corridor/cloakroom

- Clothes pegs should be at a height accessible to the child and preferably at the end of the line to prevent being knocked during busy periods.
- A staggered entry/exit to/from the classroom area to allow safe access is often helpful.
- The child needs supervision particularly if the floor is slippery. This is obviously worse on wet days.
- Loose rugs may be a trip hazard and should be removed where possible.
- Cloakrooms and corridors should be kept clear of clutter.



Classroom:

Seating and positioning at the classroom table

- Children need an appropriately sized table and chair to allow good postural alignment with feet supported. For some children, specialised seating or additions may need to be provided. A physiotherapist or occupational therapist should be able to advise with regards to sitting posture.
- Wheelchair users should be able to access a table at an appropriate height to participate in group activities.

Floor Time: Some children may find it uncomfortable sitting on the floor, and may prefer to sit on a cushion or a chair. Most children should be able to sit on the floor without difficulty and this can be encouraged, it is advisable to position them towards the edge of the group.

Standing Activities: e.g. Painting Easel, Sand/Water Play: As many children with OI are shorter than their peers a wide-based stable step or a lower play surface could be used to enable the child to reach the activity. For a wheelchair user alternative play positions and equipment may be required to allow participation. The child's therapist may be able to advise on this.

Things to be aware of:

Fine motor activities

Due to increased laxity in their joints (joint hypermobility), often affecting their fingers, some children may take longer to develop fine motor skills. They should be given lots of opportunities to develop these skills. Shorter or chunky shaped crayons, pencils and brushes may be easier to hold for children with immature fine motor skills. Contact the child's Occupational Therapist if there are any concerns regarding fine motor or pencil skills.

Tiredness and Pain

- Children with OI often tire more quickly, and may experience aches and pains, particularly following physical activity. Children may need to rest more regularly than their peers.
- Wheelchair users should be given opportunity to change their position regularly throughout the day, including time out of their wheelchair.
- Some children need simple analgesia to help manage their pain which will need to be administered in nursery at times; discuss this with parents.

Lunchtimes

- Some children may take longer to eat, particularly if their teeth are affected.
- Appropriate seating should be used at lunch to ensure good posture and safety.
- Some children struggle with using cutlery and so may have specialised cutlery to improve skills and independence. An Occupational Therapist may be able to complete an assessment to support provision of mealtime equipment.

Play time and Friends

- It is important for all children to build peer relationships and make friends. Play can pose additional challenges for a child with OI. Additional supervision may be needed during these interactions to promote inclusion and maintain their safety.
- Other children may benefit from a discussion with staff on how to be a good friend and help them understand the risks in play.

Outdoor Play, Games and Activity Days

- Exercise is important for all children as it improves health and wellbeing.
- All physical activities can and should be modified to ensure inclusion for all children.
- Advice can be sought from the child's physiotherapy team to help adapt activities; at these times the use of the child's classroom assistant may be required for extra support. Sometimes the child may have specific physiotherapy exercises which could be incorporated into the child's daily activities.
- Playground equipment should be risk assessed on an individual basis dependent on the abilities of the child. Higher risk activities such as climbing, jumping off things, bouncing, tumbling or high-impact games should be avoided. Advice can be sought from the child's therapy team if needed. See PE leaflet for further information.

Trips and Outings

These should be well planned with risk assessments and care plans as required. Consider planning regular rest breaks when walking. Children may require use of a buggy or wheelchair for longer distances or if out for extended periods of time. Additional adult support will need to be considered. Trips should be accessible and inclusive. Consider how to transport the child, particularly if they are a wheelchair user.

Notes

Scan to donate to the BBS

If you found our factsheet helpful and would like to support the BBS in continuing to provide resources, you can donate by scanning our QR Code

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.