



WHEELED MOBILITY FOR CHILDREN AND YOUNG PEOPLE WITH OSTEOGENESIS IMPERFECTA

Introduction

When a child or young person has limited mobility they may benefit from a wheelchair to be able to go out and about to develop their independence and their fitness.

Mobility contributes greatly to achieving a healthy lifestyle and maintaining bone and muscle strength. Weight bearing activities such as standing, walking or crawling should be encouraged as much as possible as they help to build and maintain bone density.

Why might you consider a wheelchair?

Children with Osteogenesis Imperfecta (OI) are sometimes delayed in their physical skills and learning to walk can take time. The ability to walk can vary greatly at different stages of a child's life. A few children are not able to stand and may not learn to walk. Not being able to move around independently means they need to rely on adults and friends for help; this can be very frustrating.

Using a wheelchair to gain independence in their mobility can provide your child with lots of opportunity to explore and interact with their environment.

Self-propelling a wheelchair is also an excellent way for children with OI, who are not very mobile to increase their cardio-vascular fitness.

When might you consider a wheelchair?

Typically developing children start to move independently from around 10 months, first crawling then walking. Children with OI can take a little longer to learn these skills. If your child is ready and wants to move but finds it difficult then a wheelchair can be considered to give them other ways to explore and play. Once they are confident moving themselves indoors, children can then be encouraged to make the progression from buggy to wheelchair outside the home.

If your child has difficulty walking over long distances because of pain and tiredness, and this is impacting on family life or school then a wheelchair may be considered to support independence.

Short-term loan of a wheelchair may be needed to support mobility if your child is in plaster after a fracture or surgery.

If you feel your child would benefit from a wheelchair it is important to discuss this with a therapist who is experienced in assessing and fitting wheelchairs.

Manual vs Power Wheelchair?

A manual (also known as self-propel) wheelchair means your child will have to use their own strength to move themselves around. When a child self-propels, forces are applied through the arms to make the wheels move and muscles in the trunk are used to maintain balance and stability. This promotes strength and endurance.

A Power wheelchair uses a battery and motor to move the wheelchair which is controlled through a joystick or control panel. A power wheelchair can be helpful when self-propelling is very difficult. Power wheelchairs are often larger and heavier than manual chairs and so are more difficult to transport. Very young children can learn to operate a power wheelchair. In this case additional adult controls can be added for safety.

Things to discuss with your therapist when choosing a wheelchair

- ◆ Where will the wheelchair be used? – home/school/nursery/outdoors?
- ◆ Will the wheelchair be used for all mobility or short periods
- ◆ Can your child get in/out on their own?
- ◆ If using at school/nursery does the wheelchair need to fit under the tables?
- ◆ Where will you store the wheelchair when it is not being used?
- ◆ How will you transport the wheelchair? Will it fit in the car? (If your child travels seated in their wheelchair it is recommended that they have a headrest/extended backrest for safety)
- ◆ Can the seat width and length be changed as your child grows?
- ◆ Are there any accessories available to support your child in plaster?

Specific considerations for wheelchair set up for children with OI

The way that a wheelchair is set up can affect the position of the body in relation to the wheels which can restrict or improve their ability to propel.

To ensure the best set-up, it is important to seek advice from a therapist experienced in assessing and fitting wheelchairs.

Wheelchair set-up for children with OI should consider the following factors:

- ◆ **Shorter stature** – Some children with OI are smaller than their friends and standard sized wheelchairs do not always fit.
 - ◆ Height of the back rest may need to be much shorter to enable them to propel effectively.
 - ◆ The length of the seat may need to be shorter to ensure they can sit with their bottom against the back rest and their knees bent.
 - ◆ The height of the footplate may need to be raised to ensure they can sit comfortably with their feet well supported on the footplate.
 - ◆ They may find it more difficult to transfer into a wheelchair of standard height or need a reinforced footplate that can be used as a step.

- ◆ **Arm's and legs** – Some children with OI may have shorter arms and legs and they may be bowed from repeated fractures. This can affect positioning in a wheelchair.
 - ◆ Alterations to footplates and seat bases may be needed for differences in leg lengths.
 - ◆ Wheel size and positioning in relation to the seat may need to be changed to ensure a child is able to reach the wheels and propel effectively.
 - ◆ Arm rest height may need to be adjusted, or changed to side guards to ensure easy access to the wheels when propelling.
 - ◆ For power chair users, position of controls will need to be considered to ensure it is easy and comfortable to operate.
 - ◆ Wheelchair cushions may need to be modified or custom made to accommodate different shaped limbs or leg length differences.
- ◆ **Muscle strength and fatigue** – Some children with OI have generalised hypermobility and reduced muscle strength, especially in the core muscles that help them sit upright and stay balanced. As a result children tire easily, impacting on their ability to self-propel.
 - ◆ Lightweight wheelchairs set up for active users enable children to be more independent in their self-propelling for longer before becoming tired.
 - ◆ A fixed frame wheelchair has fewer moving parts so more of the pushing force goes through the wheels. They can also be lighter than a folding chair. However many people choose a folding chair as it is easier to store and transport.
 - ◆ Chair set-up is important to promote postural stability for effective self-propelling and prevention of postural or spinal deformities.
 - ◆ Mild contouring of wheelchair cushions may provide support at the pelvis for increased stability when propelling. A lap belt will ensure the child doesn't move around too much in the chair.
- ◆ **Fractures** – If your child or young person has a fracture this may limit their ability to self-propel. If they are in plaster it may alter their position in the wheelchair.
 - ◆ Some wheelchairs may have accessories that can be fitted to accommodate changes in position e.g. elevating leg rests to support a long leg plaster.
 - ◆ Lap belts should be secured firmly over the hips to stop the child moving around in the chair. It should be slightly padded and as wide as possible.
 - ◆ Spoke guards on the wheels can prevent fingers getting caught while propelling.
 - ◆ Anti-tip bars may be available.

How to request an assessment

If you feel your child needs an assessment for a wheelchair or would like further advice you can contact your local therapist or the Occupational Therapist or Physiotherapist in the highly specialist Osteogenesis Imperfecta team who may be able to make a referral to your local wheelchair services.

Alternatively a referral to wheelchair services can also often be made by your GP.

FURTHER INFORMATION

For more information please refer to additional BBS information sheets which can be found on our website – www.brittlebone.org or contact us using the details below.

CONTACT INFORMATION

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, Glasgow.

The information in this leaflet is correct as at 31st January 2017 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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who live with
Osteogenesis Imperfecta.*

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