

Newborn Baby with Osteogenesis Imperfecta



Osteogenesis Imperfecta (OI) is also known as “brittle bones.” It is a genetic bone condition characterised by fragile bones that break easily. A person is born with this condition and is affected throughout his or her lifetime. As well as frequent fractured bones, people with OI often experience bone pain, muscle weakness, hearing loss, fatigue, joint laxity, curved bones, scoliosis, blue sclerae, dentinogenesis imperfecta (brittle teeth), and short stature. OI is caused by a genetic mutation that affects the body’s production of collagen, which can be found throughout the body, especially in a person’s bones and other tissues.

Brittle Bone Society

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*Supporting people
who live with bones
that break*

Introduction

Your baby has been diagnosed with Osteogenesis Imperfecta. Your baby may have fractures, which appear to have little or no apparent cause. It is important to realise that with the best care in the world, babies with brittle bones may still have fractures. Babies with brittle bones enjoy the same things as other babies. When handling your baby use slow, gentle movements. Plan ahead; avoid startling baby as this could cause a sudden movement that could result in fracture. Babies with brittle bones also like to be spoken/sung to, kissed, cuddled, rocked and stroked, as with any other baby, but just with a little more care, even when they have a fracture.

Handling

Always check that baby’s arms and legs are not caught in a blanket or any other objects as you lift, paying special attention to fingers and toes. Avoid lifting baby under the arms or around the ribs, as this could cause rib fractures. Lift with both hands wide and slide one under the buttocks and lower back, with the other hand behind the head, neck and upper back.

Should baby have a fractured arm or leg, they may find it more comfortable to be lifted on a foam pad or pillow.

The Brittle Bone Society (BBS) exists to support those living with **Osteogenesis Imperfecta (OI)**. Our vision is that all people affected by OI and their families will feel they have a Society that understands their needs, supports them through their difficulties and continues to work towards improving their quality of life.

Close contact with your baby is an important part of bonding with your baby, even when they have a fracture.

Nappy Changing

When you change the baby's nappy, do not hold him/her by the ankles. Slide your hand under the buttocks to lift the baby to replace or remove the nappy. It may be easier to slide a clean nappy under the baby before removing the dirty nappy, as this helps to avoid having to move baby twice.

Feeding

When breast feeding, avoid putting baby's arm around your back. Take care of their legs, which may lie against the body at an awkward angle.

If bottle-feeding make sure you change the side from which you feed (left or right) in order to prevent one sided head turning and altered head shape. Feed inclined on a pillow if necessary.

It is helpful to be aware that some babies take very small amounts of food, little and often, as they cannot manage very much at one time. They may tire quite easily when feeding.

If wind becomes a problem, then your GP may be able to prescribe Colic drops/Infracol. Traditional methods of winding may be too much for your baby. Please ask your specialist team for further advice if it becomes a struggle.

Bathing

Be well prepared before you start and get out everything you need. The baby is very slippery when soapy. A bath support sponge can be used, which supports baby's body and limbs.

Dressing

Choose cotton rich, lightweight clothing, as some babies with brittle bones tend to sweat quite heavily. Choose clothes that are easy to put on to reduce the need to bend baby's limbs when dressing. Choose a garment that is a size or two larger, or look for clothing that opens wide. This will allow you to place baby onto the garment and then fasten it. Avoid ribbons, frills and knitted fabrics with holes that may trap fingers. When dressing baby, always slip

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your hand up the sleeve and gently bring baby's arm back down. This helps avoid accidentally catching baby's arm in the garment.

Baby's clothing can be adapted by cutting down the main seams and adding Velcro or fasteners, allowing baby to be laid onto the clothes before fastening, rather than having to pull clothes over baby's head and limbs.

Positioning

A young baby's head shape is easily altered (this is necessary for birth), and this is more likely to happen in an infant with brittle bones.

In order to promote good head shape you may be taught alternate side head turns, so that pressure is not always on the back of the head. Your local physiotherapist can help teach you this activity. Side lying can also be used to improve head shape, but must be done with advice from your specialist team or local therapist.

Car Seats

Always use a car safety seat. Use of the harness and installation of your child's car seat should be carried out in line with the manufacturer's instructions. Your child should not remain in a car seat for long periods. If carrying out a long journey, take frequent breaks, removing baby from the car seat.

Fracture Management

Recognising that a fracture has occurred can be very difficult. Sometimes crying and swelling of the limb will reveal a fracture has occurred. It is rarely anyone's fault and may happen, even with the best care given. The first sign may be that the baby stops moving a limb. They may not always cry. Sometimes X-rays do not initially show up a fracture, so if any doubt, treat as if one may have occurred. Try to move baby as little as possible, and make sure baby has painkillers as advised by a doctor.

For further support and information please contact the Brittle Bone Society.

This factsheet was produced in conjunction with the Paediatric Osteogenesis Imperfecta National Team (POINT) - special thanks go to the Metabolic Bone Teams at Birmingham Children's Hospital, Great Ormond Street Hospital, Sheffield Children's Hospital and Royal Hospital for Sick Children, Yorkhill.

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