



CARING FOR AN INFANT WITH OSTEOPOROSIS IMPERFECTA

Introduction

Babies diagnosed with Osteogenesis Imperfecta 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 OI will still have fractures. Babies with OI enjoy the same things as other babies. When handling a baby with OI use slow, gentle movements. Plan ahead; avoid startling the baby as this could cause a sudden movement that could result in a fracture. Babies with OI also like to be spoken/sung to, kissed, cuddled, rocked and stroked, as with any other baby, but just with a little more care.

Handling

- ◆ Always check that the 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 the 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 the baby have a fractured arm or leg, they may find it more comfortable to be lifted on a foam pad or pillow.

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

Nappy Changing

- ◆ When you change the baby's nappy, do not hold or lift the baby by the ankles/legs.
- ◆ 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 the 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 slightly 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.

Winding

Traditional methods of winding may be too much for the baby. If wind becomes a problem then speak with your GP about Colic drops/Infacol or similar medicines. Please ask your specialist team for further advice if this becomes a struggle.

Bathing

Be well prepared before you start and get out everything you need. A baby can be very slippery when soapy; it might be helpful to use a little less soap. A bath support sponge can be used, which supports the baby's body and limbs. Take care to clean skins folds such as the armpits and neck creases; cotton buds can be helpful. Make sure the creases are dried thoroughly, a hair dryer on a cool setting maybe helpful if the noise is tolerated..

Dressing

- ◆ Choose cotton rich, lightweight clothing, as some babies with OI can sweat quite heavily.
- ◆ Choose clothes that are easy to put on to reduce the need to bend the 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 the baby onto the garment and then fasten it.
- ◆ Avoid ribbons, frills and knitted fabrics with holes that may trap fingers.
- ◆ When dressing the baby, always slip your hand up the sleeve and gently bring the baby's arm back down. This helps avoid accidentally catching the baby's arm in the garment.
- ◆ At times of fracture, dressing may be tricky and it is likely the baby will have to be only partially dressed.

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

Positioning

The skull of a young baby may be quite soft. As a baby tends to spend time on their back a flattened area may develop on the head, often at the back. This is more likely to happen

in a baby with OI. In order to promote good head shape you will be taught alternate side head turns, so that pressure is not always on the back of the head. A 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 that is appropriate for the baby. Use of the harness and installation of your child's car seat should be carried out in line with the manufacturer's instructions. The baby should not remain in a car seat for long periods. If carrying out a long journey, take frequent breaks, removing the baby from the car seat.

(Please refer to our Car Seats and Prams factsheet for further information).

Fractures

Recognising that a fracture has happened can be very difficult.

- ◆ Crying, swelling or refusal to use a limb may be the first indication that a fracture has occurred.
- ◆ The baby may not always cry.
- ◆ A fracture may happen spontaneously or it may occur with only slight trauma (e.g. when a baby is being dressed).
- ◆ It is rarely any ones fault and may happen, even with the best care.
- ◆ Sometimes x-rays do not initially show up a fracture, so if any doubt, the baby should be treated as if one may have occurred.
- ◆ Try to move the baby as little as possible, and seek medical advice as soon as possible.



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 Yorkhill, Glasgow.

The information in this leaflet is correct as at 31st January 2015 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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*Working with People
who live with
Osteogenesis Imperfecta.*