



# Caring for an Infant with Osteogenesis Imperfecta

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Babies diagnosed with Osteogenesis Imperfecta may have fractures which appear to have little or no apparent cause, even with the best care in the world. 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.

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## 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.
- There could be an increased risk of causing rib fractures if the baby is lifted under the arms or around the ribs.
- 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, seek advice from your local therapist. Close contact with the baby is an important part of bonding, even when they have a fracture.



## Nappy Changing

- 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.
- When you change the baby's nappy, do not hold or lift the baby by the ankles/ legs.
- Rolling baby to the side can also be helpful when cleaning.

## 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, it is helpful to 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.
- Babies may tire quite easily when feeding. 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.



## Winding

Traditional methods of winding may be too much for more severe babies. You should also consider rubbing the back instead of patting. If winding 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 bath support 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.

## 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. Depending on their severity this is more likely to happen in a baby with OI. In order to promote good head shape you should encourage regular position change. 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.

## 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.
- It is rarely anyone's 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.



## Notes

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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 January 2020 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](http://www.brittlebone.org). This information is available in accessible formats on request.