



**Connective Tissue
Dysplasia Service**

Centre for Children's Bone Health

the
children's
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Babies with Osteogenesis Imperfecta EVERYDAY CARE

Osteogenesis Imperfecta (OI) means "brittle bones". This means that babies with OI have bones which are thin and fragile. Certain movements and positions which are normal for babies without this condition may be more likely to cause fractures. Understanding about OI and some simple positioning and handling principles can help reduce the fracture risk. OI is a condition which children are born with and means that they will continue to require special care and everyday adaptations throughout life.

HANDLING



- Always evenly support the whole body so that undue pressure is not placed on any particular part – this is easiest by holding the head and back with one hand and buttocks with the other.
- Use the flat palm of your hand when lifting, never push in with your fingers.
- Movements should always be slow, methodical and gentle.
- Always take care to note where the baby's arms and legs are when lifting or carrying. This is to avoid arms or legs getting caught or twisted.
- Never handle or lift the baby around the ribs
- Never lift baby under the shoulders

- No bouncing or vigorous rocking when trying to settle
- No pulling or shaking of arms or legs – especially when pulling to sit

POSITIONING

The following positions are safe:

- Lying on back, on a firm but padded surface.
- Side lying – place rolled towels behind back for safety.



- Tummy time – placing baby against your chest in a reclined position is the safest method.



- Reclined sitting – no more than 45° incline with appropriate back support.



- Regularly alternate positions, changing if baby seems unsettled.
- Never place baby in an upright, sitting position.
- Never force baby into a position in which it doesn't seem comfortable.

NAPPY CHANGING

- Place your hand under baby's bottom, using the palm to lift by the buttocks. Place the nappy under with your other hand.
- Never lift by the ankles - this can put undue pressure on the lower limbs causing a fracture.



FEEDING



- Support baby's back using a pillow
- Use standard handling techniques for burping

DRESSING

- Lie baby on back for dressing, rolling from side to side.
- Never pull at hands or feet when passing them through clothes.
- Always press on your hand, and not baby's body when doing up fastenings etc.
- Make sure baby is well supported at both head and neck when placing clothes over the head.

BATHING

- Be well prepared – have nappy, change of clothes, towel etc and soap ready and in easy access
- Use standard handling techniques when placing baby in and out of the bath – always support head and back
- Baby bath seats with firm back support can be useful to help free your hands for washing
- A small piece of non-slip matting in the bath may be useful

FRACTURE MANAGEMENT

Identification – things to look out for which may indicate that baby has a fracture

- Obvious deformity, unusual posturing / positioning of limbs
- Swelling, bruising or warm to touch
- Not moving a limb or part of her body
- Generally unsettled despite normal attempts to comfort
- Pain with lifting / handling / dressing / nappy changes etc.
- Hearing a crack or loud noise with handling or during play

Management

- DO NOT TRY TO CORRECT POSITION IF DEFORMITY IS PRESENT
- Minimal handling whilst making sure baby is as comfortable as possible
- Simple splinting or bandaging when appropriate, as taught by your physiotherapist
- Contact your doctor

PLAY / DEVELOPMENT

Babies affected with OI may not have the same gross motor abilities as other babies their age (e.g. sitting, rolling, crawling). These skills usually develop but can take extra time and children with OI may perform some activities in a different way. Cognitive and play skills are unaffected in babies with OI. Normal opportunities for play and stimulation are important within physical limits.

Safe positions for young babies for play

- Lying on back
- Lying on side
- Reclined sitting

Toy choice

- Soft, light weight toys
- Avoid toys in which fingers may get caught
- Avoid heavy, hard toys which could result in fracture if baby was to drop / or bang them against its body
- Avoid loud noises, such as loud music or television when the baby is around. The bones in the ear are also very fragile and loud sounds can predispose babies with OI to hearing loss.