



Infant Care Suggestions for Parents

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The Osteogenesis Imperfecta Foundation, Inc. is the only voluntary national health organization dedicated to helping people cope with the problems associated with osteogenesis imperfecta. The Foundation's mission is to improve the quality of life for people affected by OI through research to find treatments and a cure, education, awareness, and mutual support.

Nurses who work in neonatal intensive care units and nursery departments have experience caring for very small and fragile infants. They can help parents learn the skills and gain confidence necessary to care for their fragile. The infant who has osteogenesis imperfecta (OI) has some special characteristics. The infant may have an unusually soft skull, startle very easily, have bone deformity and have fractures, often of the ribs or long bones, in various stages of healing.

Handling Suggestions

- All movements should be slow, methodical and gentle.
- Never push, pull, twist, bend, apply pressure or try to straighten arms or legs.
- Infants with OI **should not** be picked up under the axillae or around the rib cage because this can cause rib fractures.
- The head and trunk should be supported with one hand while the other hand supports the buttocks.
- Keep fingers spread apart to provide a wider base of support and an even distribution of support pressure.
- When lifting or turning the baby for feeding, dressing or diapering, apply support to the broadest possible area. One safe and effective way is to slide one hand underneath the child's buttocks to the back with some support under the head. Place the other hand on the chest and abdomen "sandwiching" the baby between the two hands.
- When diapering the baby, do not lift the baby by the ankles (as this could result in a fracture). Slide your hand under the buttocks to lift the baby to remove/ replace the diaper.
- Infants with fractures may be immobilized with a cast or splint to reduce motion and provide stabilization. Such infants must not be placed prone on their stomachs because suffocation can occur.
- Care should be taken when changing dressings and bedding to protect the infant's arms, wrists and fingers.
- When dressing the infant, bring garments over the limb; do not pull the limb through the sleeve or pants leg. Pulling, twisting or getting caught in clothing can cause fractures.

- It is important that babies with OI receive affection and are held and touched by parents and other caregivers.

Feeding

Infants with OI can be poor feeders. Some babies display a weak sucking reflex and may require small, frequent feedings. The combination of small stature, feeding problems, and slow growth may be mistaken for failure to thrive.

Breast milk is an excellent source of calories for virtually all infants including those with OI. Breast-feeding can create a special bond between the mother and child. Babies with all but the most severe forms of OI should be capable of being breast-fed. However, those with the most severe forms of OI may have breathing difficulties that interfere with the ability to suck. Rapid respirations can predispose to aspiration. If the baby is not able to breast-feed, the mother may opt to pump breast milk and feed the child breast milk from a bottle.

The same care should be taken in holding and positioning the infant for feeding as for other activities. When feeding the infant, the mother should be especially careful to avoid having the baby positioned with an arm behind the back or a leg pressed against the mother's body in such a way as to put pressure on it at an abnormal angle.

Burping should be done very gently to reduce the chance of fractures, especially of the ribs. Soft taps, possibly with padding over the hand, are recommended. To pick up the infant for burping, lay the baby on his/her back while the caregiver bends over to pick up the infant. The caregiver's shoulder should very gently touch the baby at which point the infant is supported under the back and positioned on the shoulder as the caregiver moves up and backwards. Gently rubbing the baby's back while taking gentle bouncing steps may also be beneficial.

Bedding

A standard crib mattress is most suitable for the baby with OI. Waterbeds and soft bedding should never be used.

Positioning

Infants who spend an extended period of time in the nursery should be repositioned regularly. The unusually soft skull can be flattened from prolonged time in any one position. Occasionally a gel pad is necessary to protect the back of the skull. Rolled blankets or sheets or soft foam wedges can support side lying. Rib fractures, a deformed chest, etc., will preclude placing the baby in the prone position (on the stomach).

Preparing for Discharge from the Hospital

Parent education should include explanation and demonstration of the procedures for holding, lifting, diapering, and general infant care. The return demonstration will ensure that the parents are comfortable with each skill. If possible demonstrate these skills to other family members and friends who will be assisting in caring for the child at home. Reading material such as the brochure *Caring for Infants and Children with OI*, available free of charge from the OI Foundation, should be given to the family.

Because new fractures are to be expected, parents should also receive training in conjunction with the orthopedic surgeon in how to recognize a fracture and how to protect the injured body part while traveling to the hospital or clinic. A letter on hospital letterhead, stating that the child

has been diagnosed with osteogenesis imperfecta, can facilitate obtaining appropriate care if the family returns to the Emergency Department or needs to seek treatment at a different facility.

Parents will need to acquire a **car seat** that, in some cases, will also be used as a **baby carrier**. A contoured foam insert may be needed to provide a good fit. See *Transportation* for details regarding car seats.

Parents should be advised to choose **clothing** with wide openings that allows them to slide the garment over the baby's arms or legs without pulling the limbs. Clothing without ribbons, buttons, pockets and ruffles is also safer for the baby.

Discharge planning should include referral to a local OI support group or contact with another family of a child with OI (with their approval). Referrals also should be provided to a pediatrician, a pediatric orthopedist, a physical therapist, and other services in the community that offer treatment and support for children with OI.

Car Seats

Car seats are geared to the child's weight and ability to sit up. All car seats should be approved for safety and anchored correctly in the vehicle. It is not safe to place foam padding between the plastic shell and the padded cover. This will compress in the event of a car accident. If a softer surface is required, it is better to use a folded thin baby blanket. Removable cotton slipcovers are suggested because they are cooler and some children with OI perspire excessively. It is always best to place a car seat in the back seat of the vehicle. Many parents place a label on the top edge of the car seat stating the diagnosis, physician name and phone number, emergency contact phone number, and HANDLE WITH CARE instructions in case a car accident occurs.

Infant Car Seats are designed for children under 20 pounds in weight. Features to look for include a well-padded harness and a head hugger support pillow. This type of U-shaped pillow is commercially available and is used to position the baby's head at midline. Small rolls or towels or other padding can be added to hold the child's hips in line. Some infant car seats can be fitted with a contoured foam insert.

For more information about osteogenesis imperfecta contact:



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