

Caring for a fragile baby

Handling

Always talk to the baby and warn them that you are going to move them. Use slow gentle movements and prepare ahead for where you are going to move baby.

If baby is comfortable and has no apparent fractures, handle him/her directly. Gently slide one hand under the buttocks and lower back and the other hand in behind the trunk and head. Spread fingers wide to give a larger area of support. This ensures baby's whole body length is supported evenly.

Avoid lifting around the rib cage/body. This can cause discomfort and possible fractures. Once baby is older it will be easier to know what he can tolerate.

Avoid catching fingers and toes in blankets or clothing when lifting.

Should baby be in discomfort, it may be easier to lift him on a small pad or sheepskin. Baby bath sponge supports are also useful for this.

The pad/support will ensure the arms and legs are supported which may be more comfortable when a limb is sore. This is also a good way for nervous friends and relatives to cuddle the baby for the first time.

Avoid pulling, twisting or trying to straighten arms and legs.

Daily care

When changing a nappy, do not hold baby's legs to lift his bottom but instead slide your flat hand under the buttocks to lift. To avoid too many lifts if baby has a fracture, put the clean nappy underneath and then remove the soiled one.

Some fragile babies are quite warm and sweaty. They may need only minimal clothing or coverings. Try to use natural fabric for clothing and bedding.

When dressing, avoid pulling the arms and legs through the clothes; rather try to bring the clothing over the limb whilst you support it. Clothes a larger size may be easier to manage and items that are front opening are often easier to put on.

Bathing can be fun. For small babies a bath sponge support shape such as those sold at Mothercare and Toys r Us are ideal.

Some babies like to sleep on a sheepskin or gel pad if they have sore limbs. Your nurse may be able to advise on these.

If fracture free, baby can be gently moved into semi side lying, with a supportive roll

placed behind them. This allows them to experience a different position when used on both sides. Support the upper leg with a small pad.

Transportation

Always use a car safety seat. Most first stage car seats with a seat wedge cushion (to fill the steep seat angle) will be suitable. The Jane Matrix system has a seat that goes flatter than most. These can be given out on loan by the Brittle Bone Society to help over a shorter period. If baby seems very small in the seat, add a small rolled up towel to either side of baby. This will help keep them snug in the middle of the chair.

Feeding

Try to keep baby's arms free from getting caught or twisted. A nursing cushion can be used for extra support.

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.

To wind baby, lean right over them before picking them up against your shoulder. You may be able to gently rub their back. If it is difficult to put baby up to your shoulder, try supporting them on a pad, lifting them up and gently rocking them up and down.

Recognising a fracture

Sometimes crying and swelling of a limb will reveal a fracture has occurred. It is rarely anyone's fault and may happen even with the best care given.

It may be the first sign is that baby stops moving a limb. They may not always cry. Sometimes x-rays do not initially show up a fracture so if in any doubt, treat as if one may have occurred. Try to move as little as possible, make sure baby has pain killers as advised by their doctor

Babies with fragile bones enjoy the same things as other babies. They like to be held, kissed and stroked, but just with a little more care.

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