

FACTSHEET



This fact sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form.

Positioning and handling of babies with Achondroplasia

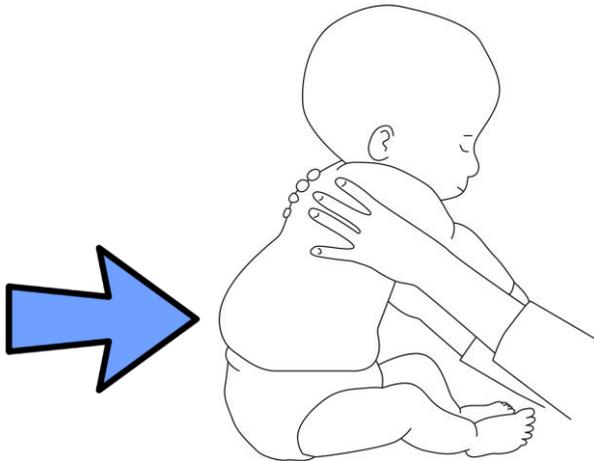
This factsheet will provide you with information on:

- Positioning and handling for spinal protection of babies with achondroplasia
- Facilitation of development
- Recommended Specialist Clinic Appointments
- Precautions

This handout has been developed by the Complex Musculoskeletal team at The Children's Hospital at Westmead, based on our clinical experience.

Care of the back

Many babies with achondroplasia have a flexible back, with a curve about two thirds of the way down. This is called a thoraco-lumbar kyphus. Kyphus is a word to describe an increased outward bend of the spine. If a baby's kyphus becomes fixed, this could lead to spinal complications. For this reason we recommend delaying sitting your baby up until they have the muscle strength to bring themselves into sitting. This could take as long as 2 years or more.



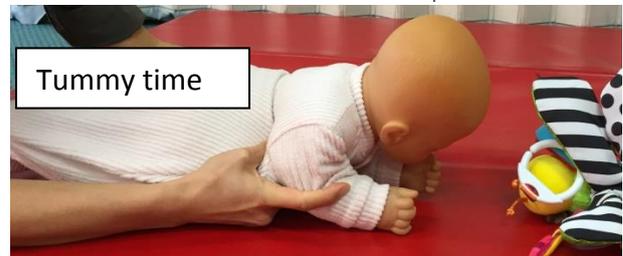
Major aims of positioning and handling for babies with achondroplasia:

- To reduce the risk of spinal cord complications, by supporting the head and neck.
- To reduce the risk of developing a fixed kyphus, by supporting the back.
- To encourage muscle strength and general developmental milestones.

The following information will help achieve these aims:

Positioning

The recommended positions when your baby is awake are on their tummy, on their side and on their back. In these positions there is less risk of developing a thoraco-lumbar kyphus. However, try to avoid too much time on their back as this can lead to a flat spot on their head.



Tummy time is the best position to develop strong neck and back muscles. It may take time for your baby to enjoy this position. Some ideas to encourage this position are:

- short but frequent periods in tummy time
- using a rolled up towel under your baby's chest on the floor

- using a favourite toy, reading a story and singing. Involving siblings to play with baby in tummy time can help to entertain your baby while they are on their tummy.

Sidelying is another position which can help stimulate muscle development and fine motor control. It is also a step towards rolling.



Laying on their back

Short sessions on their back can be good as an interactive play position, to encourage reaching and holding toys. As their fingers and hands are small, use rings and thin rattles.

Handling positions for your baby

When **lifting** your baby, place one hand to support their head and neck, and the other to support their lower back (kyphus region).

When **carrying** your baby, keep them in a fully reclined position. Make sure that you support your baby's head, neck, and kyphus region. Avoid carrying your baby in an upright position (except for burping).



Firmly support the kyphus and their head when carrying.

When **burping** your baby, support your baby upright against your chest and rub their back firmly. Your baby's back is better supported when being burped against your chest compared to on your lap. The rubbing motion is also preferred over patting. Try to limit the time spent in this upright position.

Feeding

Newborn

When breastfeeding, support your baby's head and neck, and use a firm hand to support their kyphus region. As

your baby grows bigger you may need to support your baby's kyphus region with a pillow and a firm hand on their lower back.

If bottle feeding, you may also support your baby's back using a pillow with a firm hand on their lower back.

Solids

Please make an appointment with your Children's Hospital at Westmead occupational therapist, to organise a Frazer chair for reclined seating. This is important to have **BEFORE** starting your child on solids. When your baby starts on solids they must be able to sit up to the **middle position of the Frazer chair** or 60 degrees to be able to swallow safely.



Precautions

- In every position please make sure your baby's head, neck and spine is well supported.
- Avoid allowing your baby's head to bend too far back or too far forward.
- Always check that their back is not curved in a rounded 'c' shape when holding, handling or playing with them. Ensure your baby is not left with their back in a curved position in equipment such as a car seat.
- Please make sure that your therapist is able to review your baby's car capsules, baby car seats and stroller when you come to your first clinic appointment.
- Babies should not be positioned in sitting unless in an appropriate reclined seat such as the Frazer Chair.
- Babies with achondroplasia should not be lifted up by the arms as their neck needs support when lifting. Please inform your GP and clinic nurse not to perform the pull-to-sit test on your baby.
- Baby slings and pouches, baby bouncers and rockers, jolly jumpers, baby swings, and baby walkers, are not recommended.

Communicating with your child with Achondroplasia

- When speaking to your child, make sure you are at your child's eye level as much as possible. For a young baby

with achondroplasia this will mean getting down onto the floor at the child's eye level.

- Babies need to see as well as hear adults speaking.
- Use short, simple sentences.
- Look at your child when talking to them.
- Smile and show that you are listening.
- Talk about what your child can see, and is doing.
- Sing songs and play simple games e.g. peek-a-boo.
- Respond to your child's sounds and babble in play by imitating them.
- Please make sure that, at all times during your interactions, your child is being supported and positioned correctly.
- If you have concerns, please speak to your Paediatrician or GP for a possible referral to a Speech Pathologist.

Recommended skeletal dysplasia clinic – Kids Rehab, The Children's Hospital at Westmead appointments:

The Complex Musculoskeletal Service, Kids Rehab offers a consultative service for babies and children with achondroplasia living in NSW and ACT. We provide you and your local service with support and education regarding positioning, handling, motor development and the equipment needs of your baby with achondroplasia. If you are not already linked in with our service, please ask your GP for a referral and your local therapist to contact us.

Your baby will be given regular appointments through the clinic in the first couple of years. These appointments will be made at time of diagnosis, 4 months, 8 months, 12 months, 18 months and 2 years. Appointments will then be annual until Year One of school. Regular annual or biannual review will then be suggested at the doctor's discretion.

In the first appointment a rehabilitation therapist will review your child to check positioning in car seat and pram, discuss correct handling and positioning and observe and discuss developmental progression. It is important that you let us know if your baby is starting day-care so we can provide education and advice to your baby's carers. At 6 months of age our team may recommend hydrotherapy. We look forward to ongoing involvement with you and your baby through our clinic.