

Physiotherapy advice for babies with Spina Bifida

Physiotherapy advice for babies with Spina Bifida V1.0 Approved by NHS Lothian Patient Information Team: Oct 2020 Review date: Oct 2023

Information for parents and carers

Physiotherapy for babies with Spina bifida

Spina bifida means 'split spine' and is caused by a fault in the development of the spinal cord.

This leaflet will focus on the physiotherapy advice for your child's condition.

As spina bifida affects the spine, hips, legs and feet to varying degrees, your baby will be seen by a physiotherapist soon after birth. They will look at the movement and muscle activity of your child's legs.

They will provide advice on how to position your baby and show you how to stretch out tight muscles. They will also advise on how to help with your baby's development. Your physiotherapist will discuss which advice is appropriate for your child and indicate this with a ticked box.

Physiotherapy home programme

Positions for lying

Lying on back

- Once the wound on your baby's back has healed your baby should be positioned on their back, with hips as straight as possible, when in the cot/pram.
- Your baby should always be placed on their back to sleep with their feet at the bottom end of the cot to reduce the risk of cot death, as recommended by www.nhs.uk.

Follow up care

Most babies will be followed up by a community physiotherapist on discharge from hospital. They will provide advice to ensure that your baby progresses with their development.

Your child will also be followed up at the spina bifida clinic where a specialist team, including physiotherapy, will be able to offer advice and support.

Any further questions?

Contact a member of the Neurology Physiotherapy team

Royal Hospital of Children and Young People Edinburgh EH16 4JT

Tel: 0131 312 1079

Websites

The following websites provide further information:

www.sbhscotland.org www.shinecharity.org.uk www.sbhi.ie www.spinabifidaassociation.org

Development

Your baby needs to learn about the world around them and how to move in it. In the early days they will be developing skills to hold up their head, roll over, move on the floor and sit up.

Tummy time is very important. It helps to stretch out the hip muscles and helps develop the muscles needed to allow your child to move. Babies sometimes need to get used to this, but it is very good for helping the neck, back and arm muscles become strong to prepare for sitting and crawling.

Helping your baby's early development

Place your baby in a variety of positions, on their back (once the wound on their back has healed) on their sides and on their tummy.

Sit your baby on your knee facing you, supporting their head, and talk and sing to them. Encourage them to follow objects and your face with their eyes. Encourage them to look at their hands and feet.

Try lying your baby reclined on your chest and encourage them to lift and turn their head. Place them on their tummy with a small rolled up blanket or towel under their chest to help them to play in this position.



@Sarah Crombie

©Sarah Crombie



©Physiotools

Lying on side

- Place a firm roll behind baby's bottom and back to prevent them rolling backwards.
- Place a small pad e.g. folded towel between their knees.
- Place a toy or rolled up pillow case in front of their legs to stop their hips from bending too much. Ensure this is nowhere near their face.

Lying on tummy

- Try to have tummy time for one hour, twice a day, to help stretch out your baby's hips.
- Place your baby with hips straight and flat on the bed. Sometimes a thin rolled blanket under the hips is needed. This can be reduced in size as the hips become less flexed.
- Consider a rolled blanket at either side if baby's bottom does not stay in the middle.
- You may be advised to position the feet with additional support.



Stretches

Do not start these stretches unless you have been taught by a physiotherapist and advised which ones are required for your baby.

- Stretches should be carried out regularly throughout the day, either at each nappy change or any suitable time (3-4 times daily if possible)
- Try to do stretches when your baby is relaxed and not 'pushing against you'
- The stretch should be gently done until a resistance is felt to the movement, then held at that point
- When stretching the muscle, hold the stretch for a few seconds and if it feels like it is getting more relaxed, try to take the stretch a little further
- Each stretch should be held for approximately 60 seconds and repeated 3 times
- If your baby is becoming upset and starting to wriggle, stop stretching and wait until they have settled before trying again
- If you are unsure about the stretches do not continue and seek advice from the physiotherapist.

Use the following images to help with hand placement, keeping the stretching hand as close to the joint being stretched as possible.

Skin and limb care

As your baby may have reduced feeling around their bottom, or in their legs, it is very important to take care of their skin and their joints.

This becomes even more important as your child gets older.

- Every day, you should look for the following signs of skin damage - red marks, cuts or scratches, blisters, burns or bruises
- It is much easier to prevent skin damage than to treat it. Your child needs to change position regularly
- If your child's skin becomes reddened, think about the cause and remove the pressure/cause. If the skin does not return to normal colour within 20 or 30 minutes, seek help from a health care provider
- If your child has an area of skin breakdown, special dressings or treatments will usually be necessary to help heal the sores
- Babies with spina bifida can sometimes get themselves into unusual positions. If your baby is in a position which looks like joints are under strain, move them into a more comfortable looking position. Please ask your baby's physiotherapist for advice if you are unsure about best positions for your baby
- Babies with spina bifida often have a latex allergy and they will need to avoid contact with latex.

Foot stretches (continued)



Uncurl toes over your fingers as in the picture - apply gentle pressure down on the top of the toes. Then apply gentle pressure upwards with your bottom finger.

Hip stretches



With baby on their side, support the back of the uppermost hip to prevent rocking backwards, and gently stretch the leg backwards to bring the hip joint as straight as possible. Repeat with both hips.



Support the back of the uppermost hip with one hand to prevent it rocking backwards and gently stretch the hip outwards away from the other leg. Repeat with both hips.

Knee stretches



With the hip as straight as possible (see hip stretch), gently bend the knee to get a nice stretch down the front of the thigh (this is a big stretch so it should be done very gently). The stretching hand should put gentle pressure below the knee to produce a bend at the knee.



With the hip slightly bent, hold the front of the leg above the knee (thigh) and, with your other hand, hold the leg below the knee from behind. Gently straighten the knee.

Foot stretches



Support the little bones at the ankle with one hand and hold the foot between the fingers of your other hand, as close to the ankle joint as possible. Gently push the foot upwards using pressure under the foot.



As with the above exercise but gently stretch the foot downwards using pressure on the top of the foot.