

Information leaflet for parents/carers

# Sacrococcygeal Teratoma (SCT)



Your baby has been diagnosed with sacrococcygeal teratoma (SCT). This will have shown on an ultrasound as a lump near your baby's bottom. These are rarely malignant (i.e. cancerous).

This leaflet will give you more information on the condition and what you can expect during pregnancy, delivery and after the baby is born.

## Sacrococcygeal teratoma (SCT)

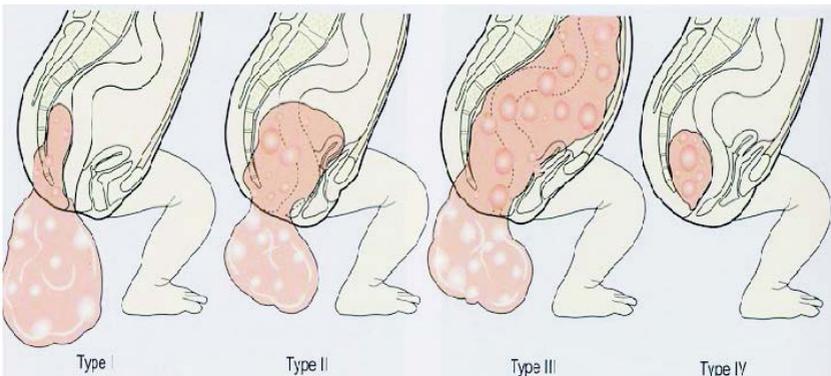
Sacrococcygeal teratoma (SCT) is divided into four types which depend on where the lump is.

Type I                      Nearly all the tumour is on the outside.

Type II                      The tumour is mostly outside but some is in the pelvis.

Type III                     Some tumour is outside but the biggest part is on the inside around the hips and tummy area.

Type IV                      Tumours are totally inside the tummy.



## During Pregnancy

Most SCTs are found on their own with no other problems, but in 1 in 5 pregnancies there can be other problems as well. A detailed ultrasound scan is done to check for this and any findings will be discussed with you.

SCT is a condition that can be treated by surgery after the baby is born. However, it can be a very serious problem and there can be the risk of losing the baby during pregnancy. These issues will be discussed with you in detail.

As explained above there are different types of SCTs, but the poorest outlook for survival are with SCTs where:

- The tumour is very large before 24 weeks.
- The tumour grows quickly during pregnancy
- Where the scan shows that the tumour has a large blood supply
- Where heart failure develops with the tumour.
- This happens in about 15% of babies with SCT.
- If there is a large increase in fluid around the baby.

If any of these problems occur they will be discussed with you by a specialist.

For this reason you will need regular ultrasound scans to measure the growth of the baby and the SCT. These scans will be at least every 4 weeks (sometimes much more frequently than this, again this will be discussed with you in person if needed).

## Delivery

Delivery will be planned for after 38 weeks but in some cases may have to be earlier. This will be discussed with you. The type of delivery will be different for each pregnancy. Where the SCT is very large, it may be necessary to deliver your baby by caesarean section and this will be discussed in detail with you in the later stage of your pregnancy.

## Treatment And Care After Delivery

At birth, your baby will need to go to the Neonatal Unit and will need to be assessed by the Neonatologists (doctors specialising in the care of newborn babies). It is likely that your baby will need to have a drip placed in his or her arm and then will need further radiological examinations (X-rays, ultrasound and possibly MRI). Your baby will then be reviewed by the Paediatric Surgeons who will arrange when the operation will take place to remove the tumour.

## Feeding

Breast milk is very important for every baby but especially sick babies and even more so for those with bowel/ stomach problems. Breast milk is far more than just food, it contains essential nutrients your baby needs to grow, develop, and recover from surgery or illness.

Although your baby cannot take milk at this time, in order to establish and/or maintain your breast milk supply for when they are well enough to feed, we encourage you to express your breast milk. It is important that you start expressing milk within 6 hours of birth and continue to do this at least 8-10 times a day, including at least once every night.

There is a quiet, private area on the ward that you can use to breast feed your baby or express breast milk. Expressing milk can be done by hand, which is useful in the first few days after birth when you can expect to express small amounts of sticky clear or yellow fluid called 'colostrum'.

Electric breast pumps are available for use on the ward. Your expressed breast milk will be stored safely until your baby is well enough to feed. The nursing staff will be able to show you how to express and store your milk and arrange for you to have access to a breast pump.

## Surgery

The operation to remove the tumour might be complicated. It is possible that the operation can cause blood loss and carries the small risk of the baby not surviving the operation. Also, the tumour itself or the operation to remove it may cause some damage to the nerves to the bowel or bladder. This is more common when a tumour is mostly intra-abdominal (Types III and IV)

Risks are different for each baby and the Paediatric Surgeons will discuss your baby's specific circumstances with you prior to the operation.

All surgery carries a small risk of bleeding during or after the operation. Every anaesthetic carries a risk of complications, but this is very small. Your child's anaesthetist is a very experienced doctor who is trained to deal with any complications. All the doctors who perform this operation have had lots of experience and will minimise the chance of problems occurring.

Almost all of these SCTs are 'benign' tumours. In a small number (less than 1%), there may be more uncontrolled

growth of the tumour and this would need to be monitored carefully in your baby.

## After Surgery

Your baby will come back to the ward to recover, and you will be able to visit as soon as he or she is settled back on the ward. All babies are closely monitored after the operation, and so your baby will be connected to monitors to check his or her breathing, heart rate and oxygen levels. He or she will also be given pain relief through the intravenous infusion (drip). Over time, the drips and monitors will be removed one by one.

The nurses on the ward will encourage you to look after your baby as much as you feel able while he or she is recovering. You may feel anxious, especially while your baby is connected to drips and monitors, but it will become easier with time. If you are worried about caring for your baby, please talk to the nurses.

You will be able to go home or be transferred back to your local hospital once your baby is feeding properly and gaining weight. Your local health visitor or community paediatric nurse will visit you regularly. Your baby will need to be seen again by the surgeon after discharge to check that everything is okay, and we will send you a letter in the post to tell you when the clinic appointment will be.

## What is the outlook for children with SCT?

For most babies who have had surgery the outlook is good. Children are usually able to control their bladders and bowel as normal, though a small number can have problems.

The cosmetic appearance of the bottom is often abnormal in children who have had large SCTs. However rarely does this cause significant problems. There is a small risk of this happening again and close surgical follow up will be needed, sometimes with Imaging.

## Is there a support group?

### **BLISS**

BLISS is a support group which is able to offer support and advice to families with babies with a range of conditions.

68 South Lambeth Road  
London SW8 1RL

Helpline: [0870 7700 337](tel:08707700337)

Email: [Information@bliss.org.uk](mailto:Information@bliss.org.uk)

Website: [www.bliss.org.uk](http://www.bliss.org.uk)

A UK wide charity offering support, advice and information regardless of a child's condition or disability. Through their Making Contact serve they may also be able to put you in touch with other families who are affected by the same disability / medical condition as your child.

### **Contact a Family**

209-211 City Road  
London EC1 1JN

Freephone Helpline: [0808 808 3555](tel:08088083555)

Email: [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)

## Further Information

We hope this information leaflet has been useful and will help you to understand all about your child's condition. However some medical information can be difficult to understand. If you need more information or have any concerns please speak to a member of the medical team caring for you or your baby.

## Looking after and sharing information about your child

We have a duty of care to help patients and families understand how information about them is kept and shared and we include the following information in all our patient leaflets:

Information is collected about patients relevant to their diagnosis, treatment and care. We store it in written records and electronically on computer. As a necessary part of that care and treatment we may have to share some patient information with other people and organisations who are either responsible or directly involved in the patient's care. This may involve taking the patient's information off site. We may also have to share some information for other purposes; such as research etc. Any information that is shared in this way will not identify the patient unless we have the patient's and parent's/carer's consent. If you have any questions and/or do not want us to share that information with others, please talk to the people looking after your child or contact PALS (Patient Advice and Liaison Service) on 0121 333 8403.



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