



North Thames Cleft Centre at Great Ormond Street Hospital: Information for Families

Cleft palate repair

This leaflet explains about the operation to repair a cleft palate and what to expect when your child comes to the North Thames Cleft Service for the operation.

What is a cleft palate repair?

Cleft palate repair is an operation to repair defects of the hard and soft palate. In some babies born with clefts of the lip and palate, part of the palate (the front anterior part) is repaired at the time of the lip repair. An important part of the operation is joining up the soft palate muscles in a more normal position. The earliest we do the operation is when babies are approximately six months of age. Sometimes the operation involves leaving some raw areas at the side of the palate to allow the two halves to be brought together. Children usually stay in hospital for two nights, but can sometimes go home after one night.

Is there anything that I should do before the operation?

Where possible, we advise you to keep your child away from children or adults who have colds, 'flu' or other infections in the weeks running up to the operation. This will reduce the chances that your baby's operation will have to be postponed because he or she is not well. Babies feed better on solids rather than milk immediately after surgery, so it is helpful to wean your child before the operation, that is, between 17 weeks and six months. Please talk to the clinical nurse specialist about this.

Preparing brothers and sisters

If your baby has an older brother and/or sister it is important to remember that they too are likely to have some concerns about your baby's operation. It can be very helpful to explain simply to your other child(ren) what the doctors are going to do. You may want your other child(ren) to visit the hospital the day after the operation so that they can see the baby. As parents, you will then have had a chance to start to get used to the changes yourselves.



Great Ormond Street and St Andrew's
North Thames Cleft Centre
North London - Essex - South and West Hertfordshire



What happens before the operation?

You will receive basic information on coming into hospital with your admission letter. You will need to bring your baby for a pre-admission appointment before the operation. The purpose of this appointment is to meet the ward team who will be looking after your child.

The nurses will show you around the ward, explain about your stay and ask you some general questions. Your baby will need to have a medical check up and maybe a blood test to make sure he or she is well. Some photographs may be taken for medical records.

A doctor may also come to see you to explain the operation in more detail, discuss any worries you may have and to obtain your consent for surgery. If your baby has any medical problems, such as allergies, please tell the doctors. If your baby is taking any medicines, please bring these with you on the day of the operation. Another doctor (an anaesthetist) may visit you to explain about the general anaesthetic. Please bring your 'red book' with you to this appointment.

What does the operation involve?

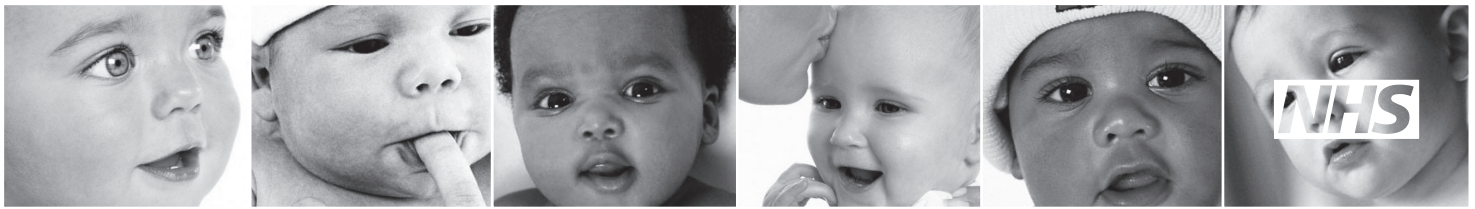
Your child may be admitted to GOSH on the day of the operation or the night before. We will explain which option is best for your child at the pre-admission appointment.

The operation is carried out by one of the plastic surgeons in the team. It involves joining the tissues that have not joined before birth. The surgeon uses an operating microscope to allow the small structures to be accurately joined. The operation usually takes from two to four hours, depending on the extent of the cleft.

What anaesthetic is used?

Your baby is given a general anaesthetic by an anaesthetist who specialises in giving anaesthetics to babies and children. One parent or carer may be able to go with your baby to the anaesthetic room and stay until he or she is asleep. This usually involves your baby breathing some anaesthetic gas. Later, a tube is passed into the airway (trachea) to safeguard breathing. A cannula (thin, plastic tube) is put in a vein and usually left in place for a short time after the operation. Fluids can be given to your baby through this tube during the operation and afterwards if necessary.





Are there any risks?

There is a small risk of infection following the operation, but your baby will be given an antibiotic following surgery. Every anaesthetic carries a risk of complications, but this is very small. There is a risk of bleeding during and after the operation, but your child will have an injection of tranexamic acid during the operation and an intravenous infusion afterwards to reduce this risk.

Your baby's mouth will be sore after the operations, partly due to the operation itself, but also because the surgeon will need to move it about to repair the palate. The nurses will give your baby pain relief medicine, so that he or she is not uncomfortable, particularly when feeding. If your baby's mouth swells internally a lot after the operation, he or she may have difficulty breathing for a while. If this happens, the doctors will put a temporary tube in your child's nostril to make breathing easier while the swelling goes down. We will monitor the amount of oxygen in your child's blood using a 'saturation' or 'sats' monitor for the first few days.

There is a small chance that the cleft could re-open or a small hole could develop. In some cases, this may close without further treatment but sometimes further surgery may be needed.

When can I see my baby after the operation?

Your baby will go to the recovery room after the operation and one parent or carer will be able to go there with a nurse as your baby is waking up. We give

painkillers before your child wakes up, but he or she may still have some discomfort. Children are often distressed perhaps due to hunger. Usually there is a little bit of bleeding in the first few hours after the operation. This is often more from the nose than the mouth.

When can my baby feed?

We are happy for your baby to feed as soon as he or she is awake after the anaesthetic. The first feed may be difficult. If your baby is struggling to feed, we may suggest using a naso-gastric tube, passed into one nostril and down into the stomach, for the first few feeds.

What happens afterwards?

At first there may be some bleeding from the nose or mouth but this usually stops quickly. Only very rarely will any further measures be necessary to stop the bleeding. The corners of your baby's mouth may become sore after the operation but applying petroleum jelly (Vaseline®) will improve within a few days. Raising the head of the cot and cuddling your child over your shoulder helps to keep them more upright, reducing any swelling and making them more comfortable.

When your baby has returned to the ward, milk and puree food may be offered in the normal manner as soon as he or she is awake. If your baby is not happy to drink from the bottle, fluids may be taken more easily from a spoon, syringe or beaker. If your baby is reluctant to drink it may be necessary to give extra fluid through the drip. The drip will be removed once he or she is drinking well again. It is important to give your baby



some cooled, boiled water after each feed and medicine to keep the wound clean. Your baby will have a sore mouth after the operation and so may not feel like eating or drinking much. Various medicines can be given at regular intervals to help ease the pain and make feeding more comfortable.

When you get home...

Sleeping

It can help to raise the head of the cot to reduce any swelling. If your child breathes noisily when asleep, please contact the Cleft Team.

Feeding

By the time your baby goes home he or she should be getting back to a normal feeding pattern of milk and puree food. Often babies prefer the consistency of puree food to milk to start with, but they will take fluids better once they get used to their new palate. A useful tip is to encourage your child to eat cereal and packet foods that need mixing with milk. This will keep up fluid levels and make sure that he or she is getting enough nourishment.

Keep using your child's usual bottle as he or she is used to it. It may take time for your child to adjust to the new palate and feeding. You may want to try a harder bottle or teacher beaker in the future, but please ask us for further advice before making any changes to your child's feeding.

We recommend that your child avoid hard foods for two weeks after the operation and should not use a dummy for this period either, unless agreed otherwise by your consultant. Try to stop your child putting fingers or toys into his or her mouth as this could damage it.

Please remember to rinse your child's mouth with cooled, boiled water after all milk, medicines and food for at least two weeks after the operation. This helps cleanse the palate and stops food collecting in the operation site, which could lead to infection or wound breakdown.

Medicines

You can give pain relief medicines, such as paracetamol syrup or ibuprofen syrup, at home following the dosage instructions on the bottle.

We advise that you give regular pain relief medicine for at least two weeks after the operation, making sure that you give your child a dose about 30 minutes before feeding.

Your child's last dose of _____ medicine was given on the ward at _____ (time). You can give the next dose at _____ (time).



Infection

Infection after cleft palate repair is rare, but signs of infection include:

- Swelling or redness of the palate
- Irritability
- Raised temperature
- Loss of appetite

If your child develops any of these signs, please call the ward or your family doctor (GP), as a repeat course of antibiotics may be needed.

Stitches

These are dissolvable, and will gradually disappear by two to three weeks, but for as long as they are still there you should continue to clean your baby's mouth with cooled, boiled water each time after eating, drinking or taking medicine. Sometimes when the stitches fall away, a small hole might be left in the palate, which may close without more surgery. This will be checked when your child comes for a follow up appointment.

Follow up

After your baby has had a cleft palate operation, he or she may need to come back to GOSH for a wound check five days after the operation. This appointment should be made before you leave hospital. Your child will need to come back three to four months later for an outpatient appointment. This appointment will either be sent to you in the post.

If you have any questions in the meantime, please telephone us on the numbers overleaf.

The North Thames Cleft Centre supports a number of charities as detailed below:

SD03 fund

This fund is used to support team members in attending valuable training courses, meetings and other educational events. Contributions to this fund are made via GOSH and then directed to the appropriate fund. Please ask a member of the team for details.

CLEFT – bridging the gap

This is a charity set up to research the unanswered problems in improving care for children born with cleft lip and palate. We also support cleft lip and palate teams in the developing world by working with them to improve surgery and facilities. Visit www.cleft.org.uk for further details.

Great Ormond Street Hospital Charity

This supports the work of GOSH so that it can help more children who needs its specialist expertise. Visit www.gosh.org for further details.

CLAPA

This is the representative organisation for all people with and affected by cleft lip and/or palate in the UK. Branches, such as CLAPA-GOS focus on supporting parents and maintaining the the information flow between specialists and parents. Visit www.clapagos.org.uk for further details.



Notes

If you have any questions, please call:

**Great Ormond Street
Children's Hospital**

Peter Pan Ward

020 7829 8825

Clinical Nurse Specialist

020 7813 8439

**St Andrew's Centre,
Broomfield Hospital**

Phoenix Ward

01245 513 256 or 01245 513 258

Clinical Nurse Specialist

01245 516 029

Compiled by the North Thames Cleft Centre at Great Ormond Street Hospital and St Andrew's Centre, Broomfield Hospital in collaboration with the Child and Family Information Group at GOSH

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www.gosh.nhs.uk