



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

Cleft lip repair

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

What is a cleft lip repair?

Cleft lip repair is an operation to reconstruct the shape of the lip and nose. If there is a cleft palate as well, then the front half (anterior) of the palate is also repaired. The earliest we do the operation is when babies are approximately three months of age. Babies are usually in hospital for one or two nights after the operation.

Is there anything that I should do before the operation?

Where possible, we advise you to keep your baby 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 the operation will have to be postponed because he or she is not well.

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, perhaps by comparing the appearance of your baby's lip with theirs and then discussing how he or she will look after the operation. You may want your other child(ren) to visit the hospital the day after the operation so that they can see the baby with his or her new look. As parents, you will then have had a chance to start to get used to the changes yourselves.

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 in the month leading up to the operation. The purpose of this appointment is to meet the ward team who will be looking after your child.



Great Ormond Street and St Andrew's
North Thames Cleft Centre
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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.

Another doctor (an anaesthetist) may visit you on the day of the operation 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. Please do not put any moisturiser or petroleum jelly on your child's lips on the day of surgery.

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 may use an operating microscope to allow the small structures to be accurately joined.

The operation usually takes from one to two hours, depending on the extent of the cleft, but your baby will be away from the ward for two to four hours.

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 injection during the operation. 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.



Before and after
cleft lip repair



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 lip. The nurses will give 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. This complication is quite rare. If this happens, the doctors will put a temporary tube in your child's nose to make breathing easier.

There is a small chance that the repair may come apart or the lip may need further correction in which case another operation 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. Because local anaesthetic is used, your baby will probably not be feeling much pain directly after the operation but may be distressed, perhaps due to hunger. We expect there to be a little blood from the mouth and nose, and some swelling of the lip at this stage, but this is entirely normal and nothing to be concerned about. There may also be some swelling of the nose and cheeks.

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, partly because the lip is numb from the operation.



What happens afterwards?

When your baby has returned to the ward, he or she may be offered a bottle or the breast 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 or syringe. 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 to drink after each feed and medicine to keep the inside of the mouth clean.

Soon after the operation there may be some bleeding but this usually stops quickly. Only very rarely will any further measures be necessary to stop the bleeding. Your child's lip may look swollen and bruised for the first few days after the operation, but this will soon go down. The corners of your baby's mouth may be sore for a few days after the operation, but this will improve within a few days. There may also be some crusts on the lip but these will soon separate.

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. Sometimes it can take a while for parents to get used to the 'new look' of their baby and they can miss the old smile. It is not unusual for parents to feel a bit sad for a while after the operation.

When you get home...

By the time your child goes home he or she should be getting back to a normal feeding pattern of milk from his or her usual bottle and teat. It is important to make sure your child is drinking enough. His or her lip may be swollen after the operation and the shape of his or her mouth may be different, but your child will soon adapt.

Please remember to rinse your child's mouth with cooled, boiled water after all milk and medicine for at least two weeks after the operation. This helps cleanse the lip and stops milk 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).



Looking after the operation site

It is important to keep the lip clean and free from scabs to make removing the stitches easier and ensure better long-term appearance. Your nurse will make sure that your child's lip is clean before you go home and teach you how to keep it clean until the stitches are removed.

We recommend that your child should not use a dummy for at least two weeks, unless advised otherwise by your consultant. Try to stop your child putting fingers or toys into his or her mouth as this could be harmful.

Your child's lip may appear slightly red, swollen and/or bruised after the operation. The swelling can take a few weeks to settle down. The scar initially becomes thick, lumpy and short over the first few months. This is part of the healing process and it can take two years or longer for the scar to fully settle down.

Stitch removal

Stitches used in the operation may either be dissolvable or require removal after the operation.

Before you leave hospital, we will teach you how to massage the area to help the stitches breakdown. If your child has dissolvable stitches, they will need to come back to GOSH for a wound check around a week after the operation.

The non-dissolvable type of lip stitches are removed between five and seven days after the operation. The stitches are taken out under mild sedation or a short general anaesthetic. We will give you information about this appointment before you go home. This will include fasting times, that is, the time after which your child should have nothing to eat or

drink. Please follow these instructions exactly otherwise the appointment may have to be delayed or even cancelled.

Infection

Infection after cleft lip repair is rare, but signs of infection at the wound include:

- Inflammation or redness
- Irritability
- Raised temperature
- Loss of appetite

If your child develops any of these signs, please call the ward, as a course of antibiotics may be needed.

If the operation site oozes or breaks apart, please contact the ward for advice and review.

Follow up

If your child has a cleft palate, he or she may be reviewed before the palate repair operation. If your child does not have a cleft palate, we will send you an appointment for around three months after the operation.

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



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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