



Great Ormond Street Hospital for Children NHS Foundation Trust

## Assessment for craniofacial surgery: information for families

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You may already have seen members of the craniofacial team but often we ask for a more detailed assessment to plan treatment now and in the future. This craniofacial assessment takes place over two to three days and involves other members of the multidisciplinary craniofacial team. This information sheet from Great Ormond Street Hospital (GOSH) explains the series of appointments that make up the craniofacial assessment process..

The craniofacial team consists of many different specialists, all of whom have expertise in looking after children with complex craniofacial conditions. These specialists include:

- Craniofacial/Plastic Surgeons
- Neurosurgeons
- Ear Nose and Throat (ENT) Surgeons
- Orthodontist
- Ophthalmologist
- Audiologist
- Speech, Language and Feeding Specialist
- Psychologist
- Geneticist
- Clinical Nurse Specialists

When you meet each member of the team – either during the craniofacial assessment or later when your child comes for treatment – we will introduce ourselves and tell you about our role in your child’s care.

### What will the assessment involve?

The assessment usually starts at 9am on a Wednesday and we hope to have everything completed by 5pm on the Thursday. Sometimes, we need to schedule additional tests and scans at

another time but we will always aim to arrange them for the same week. If you live outside of London, we may be able to book you into the Patient Hotel overnight – please contact us as soon as possible to arrange this.

We try very hard to keep the appointments running to time but sometimes delays occur if other patients need longer or there is an emergency. The clinics are often busy so please try to get there on time or if you are delayed, tell a clinic assistant or call the Clinical Nurse Specialists.

In case of delays, we advise bringing a favourite toy or book to distract your child as well as snacks and drinks. We also operate a buzzer system in Outpatients – this means you can leave the department for a break and some fresh air without worrying you will miss your child’s appointment.

We try to schedule a lunch break for you and your child each day – our Lagoon Restaurant serves hot and cold drinks and snacks as well as full meals.

## **Sleep study**

Many children with craniofacial problems have disturbed sleep or snore heavily, so a sleep study is usually needed as part of the assessment. A sleep study takes place overnight and we usually try to arrange this for the Tuesday night before the assessment starts or on the Wednesday night during the assessment process. Further information about sleep studies is available at [www.gosh.nhs.uk/medical-information/procedures-and-treatments/sleep-study](http://www.gosh.nhs.uk/medical-information/procedures-and-treatments/sleep-study)

## **Imaging scans**

Most children will require an imaging scan so that we have a detailed view of their head and face. This helps us plan treatment and monitor how successful it is afterwards. Usually a CT or MRI scan is needed as these give us much more detailed information. Depending on your child's age, they may need to have sedation or a general anaesthetic for the scan. More information about CT scans is available at [www.gosh.nhs.uk/medical-information/proceduresand-treatments/your-child-having-ct-scan](http://www.gosh.nhs.uk/medical-information/proceduresand-treatments/your-child-having-ct-scan) and MRI scans at [www.gosh.nhs.uk/medicalinformation/procedure-s-and-treatments/mri-scans](http://www.gosh.nhs.uk/medicalinformation/procedure-s-and-treatments/mri-scans). Separate information sheets are available explaining these scans under sedation or general anaesthetic.

## **Clinical photographs**

This is another important stage of the assessment process which helps us to plan treatment and monitor its effects afterwards and as your child grows older. Our professional photographers will take a series of views of your child which will be added to your child's medical record. We may ask you to give consent (agreement) for us to use your child's photographs in teaching and publications. Further information about clinical photography is available at [www.gosh.nhs.uk/medical-information/procedures-and-treatments/clinical-photography](http://www.gosh.nhs.uk/medical-information/procedures-and-treatments/clinical-photography)

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## **Eye tests**

Children with craniofacial conditions often have problems with their eyes so we include a series of eye tests in the assessment process. Usually you will see a number of specialists who will carry out different tests to get as full a view of your child's eyesight as possible. Some tests will need eye drops beforehand which may sting and make your child's vision blurry, but this improves within an hour or so.

## **Anaesthetic assessment**

All children and young people having a general anaesthetic for their planned procedure have a separate assessment for the anaesthetic. We need to make sure that we have all the information we need to look after them safely. Further information about this assessment is available at [www.gosh.nhs.uk/wards-and-departments/departments/clinical-specialties/anaesthetic-pre-operative-assessment-information-parents-and-visitors/key-guidance-parents-and-carers](http://www.gosh.nhs.uk/wards-and-departments/departments/clinical-specialties/anaesthetic-pre-operative-assessment-information-parents-and-visitors/key-guidance-parents-and-carers).

## **Consultations with members of the team**

During the assessment process, you will also meet other members of the team depending on your child's needs. We realise that seeing a number of people during the assessment process can be tiring and confusing. Many families have found that making a list of questions to ask beforehand can be helpful, as can taking a notebook and pen to write down the answers you are given.

## **How do we know what will happen and in what order?**

The assessment process starts on Starfish Ward on Level 4 Southwood Building so please go straight there when you arrive at GOSH.

Volunteers are available to take you there or give you directions.

The ward staff on Starfish will explain the plan for the assessment to you and give you a folder, timetable and map of the hospital. In order to record each specialist assessment, the folder will contain a voice recorder. Each member of the team you see will record their results which will then be typed up into a full report within a week or so of the appointment. We will send a copy of this report to you, your family doctor (GP), paediatrician and any other health professionals involved in your child's care.

## Useful numbers

For queries about the appointment and Patient Hotel, please telephone our Craniofacial Secretary on 020 7829 8658.

You can call our Craniofacial Clinical Nurse Specialists on 07768 526 449 Monday to Friday from 9am to 5pm. You can also email them at [andrea.white@gosh.nhs.uk](mailto:andrea.white@gosh.nhs.uk) or [kathy.truscott@gosh.nhs.uk](mailto:kathy.truscott@gosh.nhs.uk)

## Further information and support

Headlines – the Craniofacial Support Group – is the main support organisation in the UK for families of children and young people affected by a craniofacial disorder. Visit their website at [www.headlines.org.uk](http://www.headlines.org.uk).

Changing Faces is another organisation that will be able to offer help and support to anyone living with a condition that affects their appearance. Visit their website at [www.changingfaces.org.uk](http://www.changingfaces.org.uk) or telephone their helpline on 0845 4500 275.

## What happens after the assessment?

At the end of the assessment process, usually on a Thursday afternoon, you and your child will meet the Craniofacial Consultant in clinic to discuss the initial results and findings available.

The following Tuesday, the entire Craniofacial team have a meeting to discuss the full results and plan treatment. The Clinical Nurse Specialists will telephone you after this meeting to talk to you about the treatment plan and on-going care needed.