Oxford University Hospitals
NHS Trust

Oxford Craniofacial Unit

Preparing for your child’s operation
The news that your child is going to have an operation can be very scary and upsetting. This booklet has been written to help prepare you for what will happen over the next few weeks and months before the operation. We have written it with help from parents who have already experienced surgical care for their children with the Oxford Craniofacial Unit.

Please remember that this booklet is a guide only and may not cover all your child’s specific needs and treatment – every child is an individual. If you are unsure please check with the specialist nurses; contact details are on the back of this leaflet.

**Next steps**

The timing of your child’s operation will depend on the diagnosis and their age. You will be given a guide of when the operation is likely to be and the date will be confirmed in writing about a month before the operation. Your child’s specialist nurses will give you and your child support during this process. You will be able to call them at any time if you are worried or want to talk.

**Coming into hospital**

Your child will need to come and stay in hospital for two days before their operation day to have a full assessment. This will be on a:

- Tuesday and Wednesday for Thursday operations
- Thursday and Friday for Monday operations.

At this assessment they will meet the surgical team who will be operating and will have eye, hearing, development and speech and language assessments.

During your child’s stay we may be able to offer you accommodation in Oxford’s Ronald McDonald House. This is on level 2 of the Children’s hospital. Your child can stay with you in-between tests and assessments.
In very rare case you may have to stay in a local hotel with your child whilst they are having the assessments carried out.

On the day of surgery, children less than 12 years old will be admitted to Robin’s ward. If they are older they will be admitted to Melanie’s ward. Each bed space on these wards has a parent’s sofa bed next to it so that you can sleep near them if you want to.

This facility is not available in the Children’s high dependency unit. This is because of a limited amount of space in the unit. Alternative accommodation will be provided for you in Ronald McDonald House whilst your child is in the Children’s high dependency unit.

Getting ready

Closer to the time of the operation there will be a few practical things that you can do to get ready.

These include:

• **Clothing**
  Once your child has had their operation, you will find it quite difficult to pull any tight fitting clothing over the top of their head. Babygros and button-down-the-front pyjamas are the most suitable. Most children wear very little clothing during the first few days after the operation.

• **Special toy/comforter**
  A hospital is a very strange environment for your child; please bring any special toys or comforters that they may have.

If your child has a dummy please also bring this, as well as spares.

These items will give your child a greater sense of security.
• **Arrangements for the care and support of your other children**

Please spend a little time think about who are the best people to look after any other children and any pets you may have whilst you are with your child in hospital.

During the early days of your child’s hospital stay, you may be very anxious. Your other children may be much happier staying with relatives. Brothers and sisters are more than welcome to visit or stay once the operation is over and your child is back on Robins/Melanie’s ward.

Your child’s specialist nurse will be more than happy to advise you on how to prepare siblings for your child’s operation using special toys and story books. Our play specialists will also give you support during the preparation process.

**Please do not forget to organise care for your pets whilst you are in hospital!**

• **Toiletries for you and your child**

Please bring along everyday things you would normally use such as shampoo, toothpaste/brush and soap, dummies, nappies, etc. Towels are provided for your child on the ward and for you in Ronald McDonald House.

• **Food and special dietary needs**

For bottle-fed babies – please bring feeding bottles and an unopened tin of baby formula for use while they are on the ward. Sterilising facilities are available, both on the ward and in Ronald McDonald House.

If you are still breast feeding and you wish to continue feeding your baby when they are admitted to hospital, we will support you and provide a quiet area if required. After the operation the nursing staff will show you how to position your baby using a pillow to support their head. You can start feeding
your baby again as soon as they are awake enough to feed safely.

If your child has a special diet, either for religious reasons or medical needs, then we can provide for them. Please let their specialist nurse know before they come in for the operation.

Ronald MacDonald House has a fully equipped kitchen so we suggest bringing a few ready meals and treats for yourselves whilst you are here.

• **Things to do!**

It is worth having something with you to do or keep you occupied whilst your child is in hospital. There will be quiet periods of time when your child is sleeping or you are waiting for results and having something such as a book or an iPod can be a good distraction from worrying.

The hospital does have a Wi-Fi connection (which you will need to pay to access) if you want to use your laptop or iPad.

**Don’t forget your chargers!**

**Common fears and anxieties**

It is very understandable to be anxious about your child’s operation. The specialist nurses and our clinical psychologists are available to support you throughout this period. Please do not hesitate to ring and speak to them – no question is too trivial.

Remember, if you are searching for information on the internet, the information may not be correct or relevant to the care that your child will receive in Oxford. Results found on the internet can cause you to worry unnecessarily.

For example, we shave off just a very narrow strip of your child’s hair for the operation. We would only shave your children’s hair off completely in very exceptional circumstances; we also don’t use head bandages!
You may find that the Headlines Craniofacial Support Group are able to support you and link you up with other families with children who have undergone similar experiences.

www.headlines.org.uk

Living in the hospital

When you receive your child’s operation date through the post you will need to contact the specialist nurses to confirm that you wish to stay in Ronald McDonald House. We try very hard to make sure every family is offered a room but in rare circumstances this may not be possible. In this situation alternative accommodation will be offered and one parent can stay on the ward.

**It is very important that you remember to ring the specialist nurses to confirm your details.**

You will be offered a car parking permit for the duration of your child’s stay. There is a weekly fee for this permit but it is much cheaper than paying the hourly rate. When you arrive, please park in one of the ‘Pay and Display’ car parks while you bring your child to the ward. Once you have the permit you can move your car to one of the staff car parks.

Day of the operation

While your child is in theatre, it is very important that you go out for a while, have a meal and go for a walk; the nursing staff will telephone you when the operation is over.

When the nurses call you will be given an idea of how long it will be before you will be able to see your child in the Children’s high dependency unit.

You will have been given an opportunity to visit the unit and meet the nursing staff during the preoperative assessment days.
Looking after yourself

Living in the hospital and supporting the care of your child can be very tiring; it is really important that you take breaks for meals and drinks. Your child needs you to be feeling positive and healthy.

Going home

When the doctors feel that your child is ready to go home they will let you know. This is likely to be during the daily ward round. There are various pieces of paperwork and letters which need to be completed before you will be able to take your child home. The nurses will also go through a special discharge booklet with you so that you have an idea of what to look out for.

Your child will still need regular pain relief in the early days after discharge. It is worth buying a bottle of age appropriate paracetamol from your local chemist before they come in to hospital.

For a few weeks after their operation your child may prefer to have a soft pillow under their head when they are lying down.

If your child is a toddler, a set of reins are extremely useful for the early post-operation weeks. They hopefully may prevent too many trips and falls and bumps to their head. You may want to get your child used to walking with reins before they come in for their operation.

Once at home if you are worried at all or have any questions please call the specialist nurses for advice and support – that’s what they are there for!

Follow up

You will normally be given an appointment to bring your child back to clinic in three months’ time for a post operation check.
Occasionally they may be given an appointment sooner if there have been any concerns whilst they are in hospital. If you do not receive an appointment and you are coming up to three months after your child’s operation please call the Craniofacial office on **01865 231 085**.

**If you have any further questions**

Please ring the **Craniofacial Advanced Nurse Practitioners**

Tel. **01865 231 003 or 07919 387 482**

You can leave a message and we will get back to you as soon as possible; usually by the end of the next working day.

For any urgent advice outside of normal working hours please call Robin’s Ward.

Tel. **01865 231 254/5**

If you need an interpreter or need a document in another language, large print, Braille or audio version, please call **01865 221473** or email **PALSJR@ouh.nhs.uk**

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