

Your Child in Hospital (*Headlines factsheet*)

Most children who are diagnosed as being affected by craniosynostosis are likely to have surgery recommended and the child and family will be facing what may be a new experience – a stay in hospital. For those children with syndromes involving craniosynostosis, this will be the start of a series of visits and operations over the early years of the child's life, during which hospital will become a familiar environment – for some, even home from home! Whichever the case, those first stays can be a particularly worrying and disruptive time for the whole family. This leaflet aims to answer some of your questions and help make things easier:

Getting Ready

Many of the initial investigations and surgical procedures for craniofacial conditions take place when your child is still a baby. In these circumstances there is little you can do to prepare the child itself for hospital, except take reasonable precautions to avoid infections in the few weeks prior to your visit. You yourself are likely to feel anxious about what will happen. Correct information about the forthcoming treatment will help reduce worry – so don't hesitate to contact your hospital specialist or the ward staff with any queries, or the Craniofacial Support Group, especially if you would like to talk to another parent who has been through the same experience. Don't sit and worry in silence!

As children get older, they will of course become much more aware of what is going on around them. Even if they are not old enough to fully understand their condition, it is important to talk about the approaching visit to hospital and explain as much as you think they can appreciate. Nothing is more stressful for a child than the unexpected, or to worry about the unknown, and things are easily misunderstood. Although it's understandable not to want to upset your child more than necessary, it is far better to prepare him or her by explaining the truth about what is going to happen, as clearly and simply as you can, including any older siblings in the discussion – and to answer questions truthfully.

Children need time and warning about such a dramatic new experience, though for young, pre-school age this need be only a few days. It may help to play "doctors and nurses" games, or with older children, to talk a little about "how bodies work", for example.

On the home front, make practical arrangements well in advance. Inform the child's school where necessary, giving them an idea of what the visit will involve and how long an absence it may entail. Obviously any children who will be staying at home, plus pets, will need to be looked after, so if it isn't possible for the parent not travelling to hospital to do this, other plans will have to be made for them – preferably with someone familiar such as a close relative or friend. A good supply of clean clothes and food to keep the family going while you are away will help things run smoothly. Under special circumstances, your Health Visitor may be able to arrange home help. Low income families may also be eligible for help with transport costs to hospital – ask the hospital or ward social worker about this.

What to Take

For your child, you will need:

- * Night-time clothes, including slippers, dressing gown, hairbrush, toothbrush and toiletries.
- * Day-time clothes, which should be loose-fitting and cool, as the ward tends to get hot. For babies, ask if the ward provides disposable nappies.
- * Your child's favourite teddy or toy, however old and worn, and anything else he is especially attached to, such as a special dummy or drinking cup.
- * Any medicines currently being taken, though these must be handed over to the ward staff on arrival to be kept securely.

For yourself you **will** need:

- * Cool, comfy clothes for on the ward, with a cardigan or jumper and coat for going outside.
- * A dressing gown or track-suit and slippers or soft shoes in case you are up during the night.
- * Toiletries and towel.
- * An alarm clock, if you may be sleeping away from the ward.
- * Something to do, whether it's knitting, crosswords or writing that best-seller – time can go very slowly in hospital.
- * Tea bags and coffee are usually available on the ward, but you might like to take some supplies to make your own light snacks, etc., (though remember fridge space will be limited, and you won't be able to store any raw meats or dairy products there).
- * Change for the phone or a Chargecard.
- * Electrical equipment isn't encouraged and if you bring a hairdryer, for example, it will need to be checked for safety before it can be used.

Don't forget storage space will be limited, so avoid the temptation to bring everything but the kitchen sink. One thing worth doing before you leave home though is to get together a list of questions you might want to ask the doctors or therapists – minds are notorious for going blank during those vital few minutes of the ward round!

On the Ward

Procedure will vary between hospitals and depending on whether your child is in for assessment, minor surgery or for a major operation, when you might be admitted a day or so before so that vital up-to-the-minute tests like X-rays and blood tests can be made. Whichever the case, a nurse will greet you and together you will fill in a care plan for your child, designed to make life in hospital as "normal" as possible. She will also do routine checks such as temperature, blood pressure and nose and throat swabs, and will show you around the ward.

Family-centred care - Most hospitals now encourage "family-based care", where at least one parent is resident with the child throughout their stay. So parents are not treated as "visitors", but essential members of the care team, looking after the child's needs as if they were at home. Always tell the ward staff if you need to leave the ward at any time – and never go off the ward without explaining where you are going and for how long to your child, as the sudden disappearance of Mum or Dad can be very distressing.

Although only one parent can generally be accommodated, other family members are usually welcome to visit at any time (though bringing a noisy gang of young siblings just before bed-time isn't such a good idea). Resident parents are usually put up on a sofa bed on the ward or in parents' accommodation close by. Ask the ward staff about arrangements for meals, laundry, washing facilities, etc.

Who's who Throughout your stay at various times of the day a stream of medical people will appear for short chats. Prior to any general anaesthetic, these will always include the anaesthetist and doctor. Before an op or during assessment periods the day will be filled with visits to other departments like X-ray, scans, photographic, and perhaps ENT (ear, nose and throat) or ophthalmics. Post-op, ward rounds usually take place first thing in the morning and/or around tea-time after the day's "list" has finished.

Passing the time Most children's wards have stacks of toys that will hopefully keep your child busy in the play room or on the ward whether he is up and about or confined to bed. There is often a play leader assigned to the ward. Though she may not be there at all times she will be able to give you a welcome break,

and is trained to help reassure a child anxious about their operation through play. Breakfast is usually prepared in the ward kitchen, and the children's lunch and tea brought up to the ward at regular times each day.

The Operation

You will have been told the approximate time your child is likely to go to theatre, though this is extremely flexible! Try to be patient if delays occur. He will need to have had nothing to eat or drink ("nil by mouth") for a certain number of hours beforehand, which the nurses will explain. This could be an ideal time for a bath, to divert everyone's attention from breakfast or lunch! Your child will also receive a "pre-med", either orally or by injection, about an hour before he is due in theatre. This dries up secretions in the nose and mouth and helps to sedate him.

A porter will appear when it is time to go and, together with a nurse, will accompany you to the anaesthetic room. Most hospitals usually allow one parent to go too, to comfort and reassure the child.

Once back on the ward, there is *nothing you can do!* Try not to sit around lost in your own thoughts. Major ops can take many hours, so then it is best to get yourself right away from the hospital for a long walk, shopping trip or visit somewhere to take your mind off things.

After the operation is completed, the child spends a short period in the recovery room before being returned either to a quiet part of the ward or, in the case of a major cranial procedure, to intensive care. Be prepared for some distress, especially after a cranial op, because he is likely to be surrounded by a jungle of drips, tubes and beeping technology. Perhaps he will still have smears of blood and antiseptic, and clips or stitches will be visible on the head. There will be swelling and bruising, which is sure to get worse over the next few days before it starts to look better.

Your child may come around a bit, but is more likely to go on sleeping for several more hours. Take this chance to have a meal or catch some sleep if you can. Don't neglect yourself – you're not going to be much comfort to your child if you are over-tired or stressed out.

This is the hardest time for parent and child and it is easy for spirits to reach rock-bottom and everyone to get very emotional. The good news is that children recover *incredibly* quickly even from the most intensive surgery. Barring complications, within a week the difference to your child will be truly amazing and the improvement will continue day by day as the facial swelling settles. It is fun for your child to have visitors during the day-time during the recuperation period. but remember he will tire quickly.

Going Home

When you have been given the okay to go home by the consultant, an outpatient appointment will probably be arranged and a letter sent to your family doctor to keep him in the picture. There may also be advice on how to care for your child at home following the operation. If you have any concerns at all once you are back home, phone the ward and discuss them without delay.

Expect it to take a little while for old routines to become settled into once again. Children often become difficult or more "baby-ish" for a while following a hospital stay, and siblings can be awkward too. This phase should pass in time. You have survived!

Acknowledgments

– All About Your Hospital, Welcome to Great Ormond street, & Tiger Ward Parents' Guide, Great Ormond Street Hospital for Children NHS Trust

– Apert's Syndrome, A Parent's Guide by Pam Walker