

WHEN A CHILD IS ADMITTED TO HOSPITAL CLEFT LIP AND/OR PALATE SURGERY

This information is provided to help you prepare for your child's surgery. It is important to remember that each child is an individual. The information provided is as accurate as possible if you have further questions you should consult with your Surgeon or the staff on the Kidz First Surgical Unit.

At Kidz First we believe in a team approach that includes the patient and family. A multi-disciplinary team will care for your child and therefore you will meet many different staff. All staff will wear identity badges. We want your family's stay with us to be as pleasant as possible so we encourage you to ask questions or raise any concerns that you may have.

If your child has a runny nose, a cough, is generally unwell prior to their surgery, or has been in contact with any infectious disease e.g. chickenpox, please notify the nurse co-ordinator for Plastic Surgery on 021 286 4550 or (09) 276 0000 and ask for locator 93 8022.

TO HELP PREPARE YOUR CHILD FOR SURGERY

It is important to make your family and your child feel as comfortable as possible during your time in hospital. Other parents have found that these ideas have helped prepare for the time of surgery.

After infants with cleft palate have had surgery, they will need to be fed from specialised feeding equipment such as the 'pigeon' teat. It is less stressful for them if they are familiar with the bottle, cup or spoon before coming for surgery. Information regarding feeding devices is available from your Speech – Language Therapist.

Your child will be required to use this method for several weeks post surgery.

*Whether your child can continue to breastfeed post surgery, should be discussed with your Surgeon.

Nursing staff and Hospital play specialists can assist you with information and advice on ways to support other children in the family.

To ensure your child is well for surgery a pre admission clinic appointment at Manukau SuperClinic or admission into Kidz First the day before surgery will be arranged.

The theatre booking clerk will notify you of your appointment time or admission date and time. It is usual to be admitted the night before surgery, due to the distance most families have to travel.

Pre admission appointment: Please put aside a minimum of 2 hours to get this completed.

- A house surgeon will check your child's general health. Checking ears, listening to the chest etc. Your surgeon will NOT be present at this time.
- Admission forms will usually be completed during this time.
- You will have an opportunity to ask questions. It pays to write them down before you go.

ADMISSION DAY

On arrival to the unit you will be met by a nurse, who will show you to your room and then orientate you to the unit. There is a parent bed at each patient bedside.

The day of admission can be a busy day for young children and you may find it helpful to have a support person if you have other young children.

Nursing staff will complete a standard admission/patient history form and record your child's temperature, pulse, weight, your child's normal routines, etc. We welcome your knowledge of your child's daily routines.

Nursing staff and play specialists will work with you to develop a care plan for your stay at Kidz first and will assist you with understanding the procedures for the next day.

The morning of surgery, your child will be assessed by the Surgeon and Anaesthetist to ensure they are well for surgery. It is a time when they will answer your questions.

Your baby will be fitted for arm splints before going for surgery. The arm splints have been designed and made by parents from the Cleft support group. These are necessary to prevent injury to their mouth.

Arm splints are to be worn 24 hours per day, and must be kept on for three weeks post surgery. Some parents give their children a break from the arm splints allowing them to exercise their shoulders, but only if they can provide intensive supervision during this time. Never leave your child unattended without arm splints on.

Bring your baby's feeding equipment.

If you would like to make your own arm splints, please take a look at the Cleft Lip & Palate Support Group website. www.cleft.org.nz There is a pattern and instructions.

DAY OF SURGERY

It is important for children's safety that before surgery there is time when they have not been having food and drink.

The nurses will let you know what time your child will have their last feed before surgery. This will depend on the time of surgery and whether they have breastmilk, formula or milk. It is important that your child is woken for this feed.

Some parents wish to accompany their child into theatre. This must be discussed and agreed with by your child's anaesthetist. Generally one parent may accompany their child into theatre until their child is anaesthetised.

Cleft surgery usually takes between 1.5 to 3.5 hours, therefore it can be a good idea to use this time to have a break – visit friends, go for a coffee, or a walk. This is only an approximate time as the surgical procedure and recovery time differs with each child.

Please let the ward staff know where you may be and leave a contact telephone number if possible.

A ward staff member will let you know when you can return to the theatre recovery area. On some occasions theatre recovery staff may request for parents to sit with their child in Recovery Room until they are stable and comfortable enough to return to the ward.

On return to the ward parents are able to nurse their baby on pillows while resting in the Lazy-Boy chair provided. The nurse looking after your child will be regularly assessing and recording your child's well being.

Regular pain relief and fluids will be given through an intravenous line (often called an IV) until they are comfortable and eating/drinking well. If you are concerned about anything, immediately talk about this with your nurse. Your understanding of your child will help staff understand and care for your child. The nurses are there to help you, so don't be afraid to ask for anything that will help you care for your child.

After surgery, your child's food needs to be very soft and smooth with no lumps; adding their milk to solids makes it sloppy and is a good way of giving extra fluid to your child. Do not give your child toast, crackers or any other hard food. Small regular portions are best. There are some great ideas on the Cleft support group website and handouts are available from staff.

While nursing staff and play specialists work with families to provide a care plan to support children during their time in hospital and reduce the negative effects of stress it can sometimes be difficult to maintain normal routines while in hospital. Parents often say that the first 24 hours are the hardest for families. It is important for parents to have regular breaks and get some rest. Other adults familiar to your child may stay to give the parent staying in hospital a break.

If you still have concerns several weeks after returning home, contact the Cleft co-ordinator on 021 574 434 or speak to your GP.

QUESTIONS OFTEN ASKED BY FAMILIES

How old will my child be when they have surgery?

The lip and hard palate are repaired at approximately 5 months of age.

The soft palate is repaired at approximately 10 - 12 months of age.

Surgery may be delayed if your child is unwell.

How long will my child be in hospital?

Usually the length of stay is approximately 1-3 days on the surgical unit at Kidz First.

What is provided in the hospital?

Please also refer to the A-Z guide available on the Kidz First website and on the Kidz First surgical ward.

- A bed and linen is provided for the parent in your child's room.
- Meals for your child and free meals for the parent/caregiver staying in the hospital. You may bring in food for your child. Please remember that your child should have only soft food after surgery.
- Baby baths, shower facilities, towels etc are provided for baby and parent/caregiver.
- Microwave, fridge, coffee/tea facilities are provided in the unit kitchens.
- Sterilising units and Milton tablets are available or you may bring your own. If you use a microwave steam steriliser, you may bring it with you.
- Playroom – there is a playroom where your child and other children in the family are welcome. Parental supervision is required at the weekend for children under 5 years old.
- Telephone calls can be received in your bedroom. Outside local calls can be made from the parent lounge.
- For information regarding Visiting, Parking and Security see the Parent handout or the staff. NOTE: visiting hours are strictly adhered to. They are between 2pm and 8pm.
- Due to the infection control policy, we are unable to provide laundry services.
- Please be aware the hospital has a smoke free policy and smoking is not permitted on site.

What should I take into hospital?

- Own specialised feeding equipment.
- Baby formula - It is best to bring in a formula that baby is familiar with as they are more likely to drink what they are used to. This also decreases the risk of an upset tummy.
- Favourite toys, blankets etc
- Extra clothes for you and your child e.g. bibs for babies. It is common for your child to dribble a lot after surgery.
- Disposable nappies – there are some available but you may find it helpful to bring your own supply.
- Phone card / \$2.00 coins for parking. (where possible a limited parking area for parents is provided free of charge)
- You are welcome to bring in extra food (very soft food for baby) that your child particularly enjoys.
- Toiletries for personal use.
- Stroller or pram - some babies feel more secure in their own pram.
- Bring any medication your child is having. Pain relief is provided.
- We prefer you leave your valuables at home. We are unable to take responsibility for such items as laptops, mobile phones etc.

What will my baby feel?

Pain management begins during surgery and for the first 8 hours after **cleft palate** surgery children have a nurse 'special'. This nurse stays with your child and will be checking your child's comfort and physical wellbeing and minimising the pain felt by your child by providing appropriate pain relief. Children having cleft lip surgery do not require a nurse special. Your nurse will ensure adequate pain relief will be given regularly.

After the 'special', a nurse will be assigned to you each shift. It is important to ask the nurses about any concerns or questions you may have.

In the following days post surgery, your child may require regular oral pain relief. If you are concerned about your child's pain, let your nurse know.

When will my child be able to eat and drink?

After surgery, children are able to eat and drink as soon as they are awake and feeling up to it. Most children slowly increase the amount they take over a day or two. It is important to encourage small amounts regularly.

Most children find it easier to have smooth sloppy solids initially. Your child may find drinking liquids difficult at times as they adjust to the changes in their mouth. Small regular drinks and sloppy solids will help them adjust to swallowing again. Your speech language therapist will continue to visit you at home to provide ongoing information and support. Please contact your speech language therapist or the cleft coordinator if feeding is an ongoing difficulty.

FOLLOW UP APPOINTMENTS

At 6-8 weeks after surgery, you will be seen by the Cleft Team for a follow up appointment.

Then appointments are at 1-2 yearly intervals as needed.

Further surgery will be discussed as required.

Once your child is old enough to require ongoing dental treatment, your cleft clinic appointments will be suspended until dental treatment is finished. If during this time you need to see one of our specialists, please contact the coordinator to arrange an appointment.

CONTACTS

Cleft Co-ordinator: 021 574 434 or (09) 276 0044 ext 8922

Plastic Co-ordinator: 021 286 4550 or (09) 276 0000 locator 938022

Kidz First Surgical Unit: (09) 270 7091

NEED FURTHER INFORMATION? WANT TO TALK TO SOMEONE WHO HAS EXPERIENCED WHAT YOUR FAMILY IS GOING THROUGH?

Contact the Cleft Lip & Palate Support Group.

We are a group of parents and professionals drawn together because of our beautiful cleft children. We want to support your family through the cleft journey, supplying information and a listening ear to assist you to make informed choices for your family and child.

You can ring us on 0800 4 CLEFT (0800 425 338)

Look at our website: www.cleft.org.nz or e-mail us on info@cleft.org.nz

Support Groups such as the Cleft Lip and Palate Society and Plunket have excellent resources for information and support.

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Acknowledgements: Kidz First
Carol Bolton
Cleft Palate Society

Document Name	When a child is admitted to hospital for cleft...doc	Version:	1.0 May 2009
Document Owner:	CMDHB Cleft Co-ordinator	Next Review Date:	May 2011
Counties Manukau District Health Board			