

Heart Surgery for Children – Information for families whose child is waiting for heart surgery

Your child has been placed on the waiting list for heart surgery at Starship Children's Hospital.

What does this mean?

Every week the children's heart specialists hold a conference where they discuss each child's case and decide who needs to have heart surgery. Once this decision has been made, they are placed on the waiting list. All the children on the heart surgery waiting list are prioritised depending on when it is best for them to have surgery and how urgently they need their operation.

Closer to the time, when a date has been decided for your child's surgery, you will be notified by phone. The surgical booking administrator will call to notify you of your child's operation date. They will want to know your child's current weight, so it is a good idea to know this.

Why do we have to wait?

Sometimes, it is better for your child to grow before he/she has surgery. Surgery must also be prioritised depending on how urgently surgery is needed – children who are stable and safe wait for a routine booking date. The cardiac service would like to give families plenty of notice of their child's operation date, unfortunately, due to a variety of reasons, last minute changes are often necessary. If the date you are given is not convenient (e.g. childcare issues, exams) please tell us as soon as possible.

While you are waiting, if your child's condition changes it is very important that we are contacted as soon as possible. You can talk directly to the cardiac nurse specialists on (09) 630 9972 or email Paedcard.ns@adhb.govt.nz or via your GP, paediatrician or paediatric community nurse.

Expected length of stay

This can range from a few days to a few weeks. A rough estimate can be given depending on your child's age and condition; you can ask the nurse specialist for this information. However this is only a guideline and will be dependent on your child's progress. Your child's progress will be reviewed daily while in hospital and you will be kept updated.

If your child requires other procedures (e.g. cardiac catheter, cardiac MRI) prior to surgery, be aware that your stay will be a few days longer. We try to allow for several days between procedures. You and your child may need to stay in [Ronald McDonald House](#) between procedures if you come from out of Auckland.

After you have received a date for surgery

It is important to tell us if your child has a cold and/or fever when he/she is called to come into hospital, especially if you are from out of Auckland, as this may affect whether or not surgery can go ahead. If your child becomes sick, go to your paediatrician or GP and they will help to decide if your child is too sick for surgery. After your visit call the surgical booking administrator on (09) 630 9946 (mob: 021 915 743) or the heart nurse specialists on (09) 630 9972 or email Paedcard.ns@adhb.govt.nz to let them know about the illness. Be sure to tell us if your child has been started on any medications such as antibiotics. The surgeon may decide to wait until your child gets better before going ahead with surgery.

If you need more information about dates for surgery, contact the surgical booking administrator on (09) 630 9946 (mob: 021 915 743). To confirm your admission, call **0800 PATIENT (0800 728 436)**. For information about the operation your child is having or any other clinical queries contact the cardiac nurse specialists on (09) 630 9972 or email Paedcard.ns@adhb.govt.nz.

For general information about your child's admission to Starship hospital, including how to get there and what to bring, visit the [Starship website](#). Please remember to bring your child's car seat with you for your return home, and any medicines or special formula your child might be taking.

Stopping medicines before surgery

If your child is taking any medicines it may be important for them to stop these prior to coming to Starship. Please check with your doctor, or ask the nurse specialists, as this could delay surgery, and inform the surgical booking administrator on (09) 630 9946 (mob: 021 915 743). In particular, this is important if your child is taking medicines that interfere with blood clotting such as aspirin or warfarin. The surgical booking administrator will call and tell you on what date your child must stop his/her medicines before coming in.

How do we get to Auckland?

The Ministry of Health have a national travel and accommodation policy for people who live significant distances away from specialist services. See the [Starship website](#) for more information.

If you come from out of Auckland, your local hospital is responsible for paying transport costs to get you here. When you are given a date to bring your child in for his/her operation, contact your local hospital and ask to speak to the travel coordinator who will organise transport to Auckland for you. If you experience difficulties organising this, please contact the surgical booking administrator on (09) 630 9946 (mob: 021 915 743).

Accommodation

There is accommodation for one parent/ caregiver on ward 23B. For safety reasons, overnight accommodation is not available in your child's room in the PICU or Intensive observation areas – parent rooms are provided within the hospital for one parent over this time. For families from outside Auckland, accommodation is available at [Ronald McDonald House](#) and should be prearranged by the travel coordinator.

The day before cardiac surgery

This is a day with many interruptions. You and your child should be prepared for a busy day, with periods of waiting. Please arrive on time, expect to stay on the ward with your child for the whole day as several important tests and meetings need to occur before surgery can go ahead.

Tests and investigations

These will include blood tests, a chest x-ray, electrocardiogram (ECG), and sometimes an echocardiogram. A family member will need to be with the child to provide support for all of these tests. For information about how to help your child cope with their procedure, see the [Kidshealth website](#).

Meeting with the Surgeon and Anaesthetist (signing consent forms)

The meeting with the Surgeon and Anaesthetist is when you will have the details of the operation and anaesthetic explained to you. At this time you will need to sign the consents for surgery and the anaesthetic. This is a time to ask questions - some parents may like to make a list to refer to.

There are two parts to the consent form that must be signed by the legal guardian: a part where you consent for your child to have the operation and another part where you consent for your child to have an anaesthetic.

The operation cannot go ahead without these two consents! Please do not leave the ward until both consents are signed. If you must leave, ensure you have informed the ward staff, and have left a contact phone number.

Visit to the Intensive Care Unit

Your child's nurse can take you to the Paediatric Intensive Care Unit (PICU) for a visit. This is so you can see the PICU before your child has surgery, and know what to expect after the operation. Older children may wish to go on this visit so they know where they will wake up after their operation. Please ask if this is not offered.

The Play Specialists

On the ward, there is a playroom run by the play specialists. As well as providing somewhere to play, play specialists can help prepare your child for his/her operation and any procedures he/she may undergo. Children must be supervised by an adult in the play room at all times.

On the day of surgery

We need your help to prepare your child for theatre. Your co-operation at this stressful time is vital for surgery to be as co-ordinated as possible:

It is very important that we can find you—please do not leave the ward without first talking to your child's nurse and make sure we have your phone number.

Nothing to eat or drink: For their safety, your child must not have anything to eat or drink after a certain time. This is at least 4-6 hours before surgery for food and milk drinks and 2 hours for clear fluids: the anaesthetist will tell you the final time that your child needs to stop eating and drinking when you sign the consent form.

Bath / Shower: Every child needs to use a special soap and have 2 baths/showers before their operation.

The pre-medication and final preparation

Approximately 30 – 60 minutes before the operation, your child may be given medication to help him/her to relax and stay calm. After taking this, your child needs to stay in his/her bed. Try to make this a quiet time for your child.

Escorting your child to theatre

Two adult family members can go with your child for the theatre check-in. Please wear shoes for your own safety, as this is a clinical area. No food or drink to be brought into this area.

Keeping in contact

Your child's surgery can be a lengthy procedure and may take anywhere between 2 and 8 hours or more depending on your child's age and type of surgery. There are waiting areas within the hospital but it is often a good idea to plan something to occupy your time. This can also be a time for you to get some rest as it is a stressful time for the parents as well as the child.

You will be given a phone call towards the end of the surgery by one of the theatre nursing staff. This will be a brief call to update you on your child's surgery. When your child reaches the intensive care unit approximately an hour or two later, there is a second call, when you can visit your child.

Please ensure we have accurate phone numbers you can be contacted on.

In the Paediatric Intensive Care Unit (PICU)

When your child's operation is finished, they are moved to intensive care. The staff try to allow parents to see their child within forty-five minutes of admission to the PICU. Except for this settling in time, parents can visit at any time. However, whilst your child is in PICU we recommend that you use the opportunity to ensure you also get adequate rest and sleep.

Family Information

Factsheet

The nurses will encourage you to participate in your child's care if you feel comfortable to do so. Some important information:

- There are only two visitors allowed in the PICU and 23B high dependency area per patient at any one time. If you have large numbers of visitors, please ask where an appropriate meeting place is located.
- The nursing and medical handover rounds happen between 7.00 and 8.30am. This is a busy time for PICU staff when they need to be focussed on your child. Later on in the morning, when ward rounds are completed, staff will be more available to explain details of progress to parents and answer questions.
- Please wash your hands when you enter your child's room, and wear shoes at all times.
- Do not use cell phones in PICU, as these can interfere with some of the equipment.
- Even in PICU, your child will enjoy being talked to and touched. Parents are welcome to help with basic cares.
- Once your child is well enough, he/she will transfer to ward 23B for the rest of their recovery.

Recovery

Once your child is stable they will be transferred to the children's heart ward (23B). See the [Starship website](#) for more information about ward 23B. Parents and caregivers are expected to be involved and share in the care of their child.

Fluids

After surgery the amount of fluid (milk, water, juice etc) is restricted and closely monitored. How long a child is fluid restricted will be different for each child. It can be just a few days to a couple of weeks. Nursing and medical staff will make sure that you are aware of any fluid restrictions.

Breast feeding and expressing

For mothers who are breast feeding it is essential that you express regularly (i.e. as often as your baby would normally feed) to ensure you develop and maintain a good milk supply. The nursing staff will set you up with expressing equipment and contact the lactation consultant if extra help is needed.

Infection Risk

Cardiac babies and children can be vulnerable to infection. If you or any of your family / friends are slightly unwell or have had contact with chicken pox or measles, please discuss with the nurse before visiting. If anyone is unwell they should not visit the hospital. This is important for your own child as well as for the other children in PICU and the ward. Please ensure you wash your hands or use the antiseptic handgel provided whenever you enter the cardiac ward and prior to entering or exiting your child's room. For more information about hand hygiene see the [Starship website](#).

Going Home

When the cardiac team are happy with your child's recovery you will either be able to discharge directly to home, or you and your child may transfer to your local hospital first.

We provide education for you about your child's care (e.g. medicines) and what to do if your child should become unwell before you leave. You will be given a pamphlet "Going Home after Cardiac Surgery" which will provide you with information about follow up and people to contact if you have concerns about your child. It is important that that you attend follow up appointments to monitor your child's heart and their recovery following surgery.