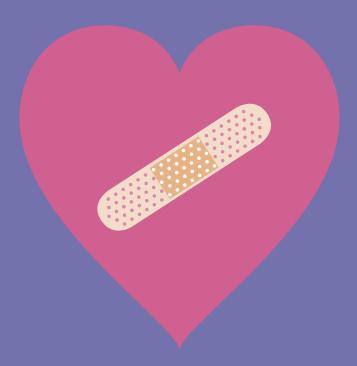
Care of children having cardiac surgery

Information manual for parents





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Care of children having cardiac surgery



This manual has been designed to provide information about your child's hospital stay when they have cardiac surgery. There is a large amount of information provided. You may find it difficult to take in all the information in one session.

The information is provided in sections and under specific headings to allow you to read the information important to you at the time.

Some aspects will appear repetitive. For example, central venous lines (CVC) will be discussed in both the Intensive Care Unit (ICU) section and the Cardiac Unit (7 West) section, as this line will remain in use for a few days.

We encourage you to read the information

several times.

Information manuals will be available in the outpatients department or the Cardiac Unit (7 West).

If you have any questions regarding any of the information, please ask the nursing staff, ward medical staff, cardiologist or the surgeon caring for your child.

We appreciate that having a child in hospital is a very difficult time for parents. We realise just how important it is for parents and their child to spend time together. Please feel free to visit any time.

Visiting times for visitors other than parents: 10.00am - 12.30pm and 2.30pm - 7.30pm.

The times given allow us to provide a rest period (quiet time) for the children in the unit. We feel this is essential to their healing process.

For both your child's benefit and for other children on the ward, we ask that only three visitors be allowed at the bedside at any time.

Admission day



Some children will be admitted through the pre-admission clinic, while others will be admitted straight to the Cardiac Unit (7 West).

Pre-admission clinic

- Admission will occur one to three days prior to your child's surgery.
- Children will attend the pre-admission clinic from 9.00am until approximately 5.00pm.
- If everything is satisfactory, your child will be discharged.
- Re-admission will occur on the morning of surgery (at 6.45am).
- On the morning of surgery, you will be required to begin fasting your child at home.
- Nursing staff will provide you with written instructions for fasting.
- Variation to the fasting instructions is not possible without permission from the cardiac anaesthetist responsible for cardiac surgery on that day.

Admission to Cardiac Unit (7 West)

Some children will be admitted to the ward one to two days before surgery and remain in hospital until their surgery. Nursing staff will assist parents with fasting their child.

Tests

On admission, routine tests will be required to assess your child before surgery. These tests include:

Chest X-ray (CXR)

 This is a special type of photo taken to assess your child's heart size and shape and the appearance of the lung fields. Even though your child may have had a CXR previously, a current CXR is required.



Chest X-ray



Blood test after anaesthetic cream has been applied

Blood tests

- The ward doctor will take some blood from your child's vein with a needle and syringe.
- Nursing staff can apply anaesthetic cream over the vein, which will make the skin numb, so your child should not feel any pain.
- It is often necessary for nursing staff to hold a child securely so that the procedure can take place safely.
 This will upset some children even though they don't experience pain.
- Parents can help to distract their child with books, toys etc. The blood test is necessary to check all components of the blood and for a cross-match.
 The cross-match allows blood to be available, should your child need it, either during the surgery or in the hours following.

Urine sample

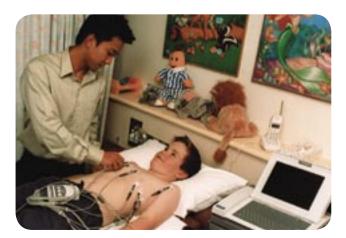
 A specimen of your child's urine will be collected and tested. For children who are not toilet trained, a small plastic bag is attached to the genital area to catch the urine.

Electrocardiogram (ECG)

- This is a recording, on a strip of paper, of the electrical activity in the heart.
- It is taken by placing small, sticky probes on the arms, legs and chest of your child.
- It is a painless procedure but requires the child to hold still for a few minutes.

Echocardiograph (echo)

- A cardiology fellow (doctor), or echo technologist will perform the echo.
- The echo machine uses sound waves to obtain a detailed picture of the inside of the heart and its structures. This is shown on a TV screen.
- The study may take up to an hour to complete.



Electrocardiogram (ECG)



Echocardiograph (echo) performed by the echo technologist

- The echo is performed in semi darkness. It is painless but requires your child to lie still. There is a TV over the bed and a video will be provided to entertain your child.
- If your child is uncooperative and all other measures fail, it may be necessary to give some sedation to enable the doctor or technician to complete the echo.
- The need for sedation will be discussed with you at the time.

Observations

The admitting nurse will take some observations.
 These include temperature, heart rate, breathing rate, blood pressures (usually right arm and leg), oxygen saturation and height and weight, plus a general assessment of your child.



Admitting nurse taking a blood pressure



Taking a temperature using a tympanic thermometer

Information required on admission

- · Medications your child is taking.
- Allergies that your child may have to medicines, foods, tapes or latex products.
- · Immunisations your child has received.
- Contact details of your local doctor.
- Dental visits. If your child is over two years old they should have their teeth checked by a dentist before the heart surgery.
- The feeding regime of your child. For example, breastfeeding, formulas, type of bottle and teats, how often they feed, foods that the child prefers, what their appetite is like and whether you have had difficulties with feeding your child.
- · Weight gain.
- Urine and bowel habits. How often your child passes urine or uses their bowels. Are they toilet trained day and night?
- Previous surgery your child has had (not just cardiac surgery.)
- Other health problems your child may have. (Asthma, eczema, hearing and eye problems etc.)
- The development level of your child. For example, are they sitting, walking, talking, attending school and how they are coping.
- Activity level of your child. Can they feed easily, if a baby? Do they play sport or how far can they walk if they are older? Do they tire easily?



The resident ward doctor will complete a medical assessment and be responsible for your child's general day-to-day care.

Resident ward doctor

- One of the resident ward doctors will complete a medical assessment and admission. The resident ward doctor will be responsible for your child's general day-to-day care during the hospital stay.
- It will be the ward doctor who will take the blood sample from your child.

Surgeon

- An appointment will be organised for you to see the surgeon.
- He will explain what the operation involves and allow you to ask questions.
- It may be useful to list any questions you have on a piece of paper so that you do not forget them during the interview. Consider leaving your child with a nurse, family member or friend during the interview so that you can concentrate on what is being said.
- Once you understand this explanation and discussion, the surgeon will request you to sign the 'consent form' saying that you agree to your child having the surgery.

Cardiologist

- Interstate and international patients will have an appointment with a cardiologist during the admission day.
- The cardiologist will review your child's information and take the opportunity to meet you before the surgery.
- Most Victorian and Tasmanian patients will have been reviewed by their cardiologist recently and may not need to be seen by the cardiologist on admission day.

Anaesthetist

- When possible, the anaesthetist who will care for your child during the operation will review your child. He will discuss the anaesthetic and any concerns you might have.
- If this is not possible on admission day, then the anaesthetist will see your child soon after arrival on the ward on the day of surgery (7.00am - 7.30am).

Cardiac physiotherapist

The cardiac physiotherapist will assess children over two years of age. The physiotherapist will discuss their role with you and your child and then he/she will teach your child some exercises that will help after the surgery. Young children find this session enjoyable as one of the exercises involves blowing bubbles.

Dietitian

A dietitian may be consulted, if there are any concerns with your child's weight gain, diet, or should you require advice. When a special diet other than a vegetarian diet is required, it is ordered through the dietitian.

Play therapist

- You may meet the play therapist, whose role is to provide outlets for any fears and anxieties that your child may have before and after surgery.
- He/she provides activities to help amuse the children.
- Play therapy sessions are held in the playroom. Ask the nursing staff about the times for these sessions.
- There are sessions where volunteers will be in attendance.

Social worker

- · The Cardiac Unit has a social worker.
- One of their roles is to provide emotional support and counselling to families, during a time that most find very stressful.
- The nurse caring for your child can arrange an appointment, if you have any issues you need to discuss with the social worker.
- The social worker is generally available Monday to Friday from 9.00am to 5.00pm.
- They attend the Intensive Care Unit and the Cardiac Unit each day.



'Blowing bubbles' with the cardiac physiotherapist

Tours

Tour of the Cardiac Unit (7 West) and the Intensive Care Unit (ICU)

- Nursing staff will provide a tour of the Cardiac Unit (7 West) and the Intensive Care Unit (ICU) to enable you to become familiar with these areas.
- Before visiting ICU, a 10-minute video and/or information manual are offered to parents to view in preparation.
- We recommend the visit to ICU as an important part of the preparation for the time when you first see your child after surgery.
- The Intensive Care Unit is situated on the 2nd floor.
- Parents have 24-hour access, except when medical rounds are in progress (early morning and late afternoon) or if sterile procedures are being carried out on a patient in the same room (to prevent the risk of infection). ICU staff will notify you when to leave.
- Visitors other than parents: ICU staff needs permission from the child's parents before allowing other visitors into the unit.
- There is a rest period and quiet time between
 3.00pm and 4.00pm. Only parents are allowed to visit during this time.

Breast milk expression

- Expression and storage of breast milk will be necessary for the period that your child is unable to feed at the breast (while fasting and in the first days after surgery).
- Education for mothers who will need to express their breast milk will be provided.
- All nursing staff will have some knowledge in this area and will be able to assist you.
- · A lactation consultant service is available.
- If you have any concerns about expressing breast milk or feeding your baby, please ask to see one of the lactation consultants.

Parent accommodation

- There is a limited amount of parent accommodation available in the hospital accommodation facilities.
- Your name can be placed on the waiting list.
 This will not guarantee that a room will be available when your child is admitted, as demand for parent accommodation is high.
- You should consider an alternative, in the event a room is not available.
- A list of motels and boarding houses in the area can be obtained from the parent accommodation office.

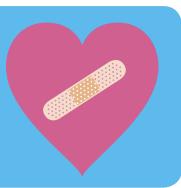


- In 7 West, parents wishing to stay by their child's bed at night should discuss this with the nurse in charge of the shift.
- We are restricted by the 'nature' of our patients and the fact that we have very little space available on the ward.
- The only facility we can offer is an armchair that reclines a small degree. The armchair is only available to one parent per child.
- When staying by the bedside, it is important that you position the chair so that nursing staff will have easy access to other patients, your child and their essential equipment.
- Please be reassured that, if you leave the ward at any time, we will not hesitate to call you, if there is a change in your child's condition or they need you.
- Always make sure that you provide up-to-date contact numbers to the nurse caring for your child before you leave.

Participation in your child's care

- Parents are welcome to participate in their child's care.
- We recognise that children feel more secure if mum and dad are assisting with some of their care (for example, feeding, washing).
- If there are some things you would prefer to do for your child, please discuss this with the nurse caring for them.
- On most occasions you will be able to stay with your child during procedures.
- The nurses and doctor will discuss the procedure with you.
- If you feel that you are uncomfortable or do not wish to stay, then please tell the nurse.
- In some circumstances, the doctor or nurse may suggest that you do not attend.

The morning of surgery



Fasting

- Children will begin fasting in the early hours
 of the morning on the day of surgery. It is
 necessary for the child's stomach to be empty
 before an anaesthetic, to help prevent
 any complications.
- Nursing staff will advise parents of the fasting times. Written instructions will be provided to assist parents of children admitted on the morning of surgery.
- All children on the cardiac surgery list will be given the same fasting times, regardless of their order on the surgery list for the day. This provides the ability to rearrange the theatre schedule, in the event of emergencies or cancellations.
- · Parents must follow the fasting times strictly.
- The anaesthetist will review your child shortly after arrival on the morning of surgery (7.00am – 7.30am).
- If your child is not the first case for surgery, the anaesthetist can discuss the possibility of another drink (clear fluids).
- The anaesthetist is the only person who can give permission for another drink on the morning of surgery. Nursing staff are able to contact him for further orders.
- In a small number of cardiac children (very small ill babies or very cyanosed, 'blue' children) the surgeon, cardiologist or anaesthetist may prefer that an intravenous line (IV) be inserted to give fluid. This will prevent dehydration while the child is fasting.



Patient waiting for surgery (pre-operative holding area)

Pre-medication

- Children are often given a pre-medication a half to one hour before transfer to the operating theatre.
- This is usually in the form of a small volume of syrup medicine or tablet.
- It generally makes the child feel relaxed and a little drowsy so that they feel less anxious about the surgery and leaving their parents.
- Nursing staff may also place anaesthetic cream over a vein chosen by the anaesthetist.
- When a child has taken a pre-medication they should remain in bed or on their parent's knee, to prevent any injury occurring while they are drowsy.
- A hospital gown will be provided to wear to surgery.
- Two identification labels will be attached to either legs or arms to ensure correct identification.

Accompanying children to theatre

- Parents will be able to accompany their child to the waiting area outside the operating rooms (known as the pre-operative holding area) and sit with them until the anaesthetist is ready.
- Most cardiac anaesthetists will require parents to say goodbye to their child in this waiting area.

In the anaesthetics room

Your child will be asleep within a few minutes of leaving you.

- For some children the anaesthetist will gently place a mask over the mouth and nose. A vapour medicine is given via this mask to make your child fall asleep.
- Most children will have a small plastic canula inserted into a vein for the anaesthetic medicine to be administered through. Anaesthetic cream will be applied to the site to make insertion of the canula painless.
- Both methods will be rapid and ensure that your child will remain asleep during the operation.

When your child is asleep

- The anaesthetist will insert the ventilator (breathing) tube, intravenous lines/central venous line, arterial line, urinary catheter and attach the monitoring equipment.
- This may take up to an hour or more to complete.
 The surgeon will not be required until then.
- Please do not be concerned if you know your child is in the operating theatre but see the surgeon on ward rounds. The surgeon will be called to theatre when the anaesthetist has completed the necessary preparation for surgery.
- The surgeon then performs the operation with the assistance of a team of highly qualified nurses, doctors, perfusionists and anaesthetists.

Open-heart surgery

- If your child is having 'open-heart surgery'
 a cardiopulmonary bypass (CPB) machine
 is necessary. During CPB, the blood that normally
 circulates through the heart and lungs is diverted
 through the heart-lung machine. The heart-lung
 machine maintains circulation and oxygenation.
 This leaves the heart free of blood and allows the
 surgeon to complete the surgery.
- Most children requiring open-heart surgery will be transferred to the intensive care unit (ICU) when surgery is completed. A small number of children may not require care in ICU after open heart surgery. Their breathing tube will be removed in theatre. They will be transferred through to recovery and remain under the supervision of the anaesthetist for approximately two hours. From recovery the child will be transferred to the Cardiac Unit (7 West). Medical and nursing staff will refer to this as the 'fast track policy'. The surgeon will discuss the possibility of 'fast tracking' your child if he/she fits the criteria for this care.

Closed-heart surgery

- 'Closed-heart surgery' refers to cardiac surgery outside the heart and mostly without the assistance of cardiopulmonary bypass.
- Not all children having closed-heart surgery will need to be transferred to ICU when their surgery is complete. There are some children who will be transferred straight to the recovery room. When sufficiently recovered from the anaesthetic they are then transferred to the Cardiac Unit (7 West).

Waiting period

The hours when your child is in theatre will seem very long.

We recognise that parents will cope with this waiting period in individual ways:

- Some will return home or to their accommodation to wait.
- Some will go for a walk in the park or take a trip to the city or zoo and carry a mobile phone.
- We suggest that you leave the hospital for some of the time your child is expected to be in surgery.
 It makes the waiting a little easier. If you do not have a mobile phone, the Cardiac Unit can provide a 'parent pager' for you to carry while your child is in surgery. The surgeon can contact you via the pager.
- If you return to the hospital to wait, please use the
 7 West waiting room or the Family Resource Centre.

It is not unusual for the operation to take a little longer than the first prediction.

- Please do not be concerned. It rarely indicates that there is a problem.
- If you are anxious, please speak to the nursing staff.

The surgeon will phone towards the end of the operation.

- At the time that he/she calls you, your child may still be in the operating theatre while the anaesthetist concludes his procedures and prepares for the transfer to the intensive care unit (ICU) or the recovery room.
- The surgeon will indicate when you can visit your child.
- It takes quite some time to complete the transfer to ICU or the recovery room and settle your child. Please do not be concerned if there appears to be a delay.

Intensive Care Unit (ICU)



Immediately after the completion of the surgery, most children will be transferred to the Intensive Care Unit (ICU).

Experienced doctors, nurses and technicians will monitor your child closely and provide the specialist care needed.

To enter the Intensive Care Unit (ICU)

Please use the doorbell and intercom system to ask permission to enter the unit.

This allows the unit staff to:

- Maintain patient confidentiality if medical rounds are in progress.
- Prevent you entering the room if a sterile procedure is in progress (lowers the risk of infection to that child).

You must wash your hands or use antiseptic hand gel each time you enter. There is a hand basin in the main corridor just inside the entrance. Hand washing or antiseptic hand gel is necessary to help prevent the spread of any infection to your child.

Visitors to the Intensive Care Unit (ICU)

Parents have almost unlimited access.

- There is a medical round early morning and late afternoon when all visitors are asked to leave to maintain patient confidentiality.
- You may be asked to leave if a patient in the room requires a sterile procedure to be performed.
 This helps to lower the risk of infection.
- ICU staff will notify you when any of these events are about to occur.

Visitors other than parents:

- ICU staff will not allow any visitor access to your child unless they have your permission to do so.
- It may be necessary to limit the number of visitors at any one time.

First visit

- When you first see your child, he or she will appear quite still.
- This will be due to sedation/pain relief given to them via the intravenous line.
- Some children will also be given medication known as a muscle relaxant to prevent them breathing against the ventilator or becoming too active.
 - If your child is given muscle relaxants they will not be able to open their eyes while the medication has its effect on them.
- The sedation/pain relief and muscle relaxants encourage your child to rest and minimise the amount of work the heart needs to do, in the first hours after the operation.
- Children will often appear 'puffy' or swollen.
 This will be most noticeable around the face.
 This is due to fluid retention and will disappear over the next day or two. Fluid retention is common after cardiac surgery and cardio pulmonary bypass.



When you first see your child he or she will appear quite still

Ventilator (breathing machine)

- Nearly all children who have cardiac surgery will be 'ventilated'.
- · The ventilator machine will breathe for them.
- The ventilator tube will be inserted through the nose or mouth into the windpipe (trachea). This tube allows air to pass from the ventilator into the lungs.
- The tape you will see around the tube and over the face prevents the tube from being dislodged.
- Nursing staff may need to clear secretions from the breathing tube to prevent it from blocking. It involves passing a thin tube down the breathing tube that removes the secretions by suction. This is referred to as 'suctioning'.
- Your child will not be able to speak or make a noise until the ventilator tube is removed.
- The ventilator will be required throughout the operation and for some time while in ICU.
- Some children may require as little as a few hours ventilation, while the average time is about 12-24 hours. Other children may require ventilation for a few days.
- The doctors will monitor your child and decide when the time is right to wean the ventilator.
- When your child is breathing without the help of the ventilator, the tube passing through the nose or mouth into the windpipe (trachea) will be removed.

Oxygen is then given to assist breathing

- This can be given via a facemask, nasal prongs (most common) or a clear plastic box with oxygen circulating in it (known as a head box).
- · All the techniques are painless.
- Oxygen may be required for as little as a few hours for some children, up to several days or more for others.

Naso-gastric tube

- A tube known as a naso-gastric tube passes through the nostril, the oesophagus (food pipe) and down into the stomach.
- It allows stomach fluids and gas to drain out into a container and prevents vomiting.
- Older children generally have this tube removed before they leave ICU.



Left: Ventilator (breathing) tube Below: Ventilator (breathing machine)





Naso-gastric tube with collection container

- Small babies may retain the naso-gastric tube so that breast milk or formula can be given through it, until they are strong enough to suck.
- Removing the tape securing the tube to the face is the most uncomfortable part of removing the naso-gastric tube.

Cooling blanket

 In some circumstances, your child may be nursed on a cold blanket. If required, the cooling blanket helps to lower the heart rate by reducing body temperature.

Central venous line (CVC)

- Most children will have an intravenous line known as a central venous line (CVC) to give fluids and medications. This is usually positioned into a large vein in one side of the neck. A vein in the groin may be used in some circumstances.
- The line is secured with a small stitch to the skin as well as tape.
- The CVC will remain in place for two to three days.
- When your child's condition is stable and they are tolerating fluids and not requiring drugs through the line, doctors will ask for the line to be removed.
- This is quite a quick procedure. Removing the securing tape can be the most uncomfortable part of the process. The site will require a band-aid for a day.



Central Venous Line

Arterial line

- Most children will have an arterial line inserted into an artery (usually in the wrist). The arterial line appears similar to the intravenous line.
- Blood samples can be taken from this line via a 3-way tap. The use of this tube means that there is no need to have needle pricks for the blood tests.
- Medical and nursing staff are able to monitor the blood pressure via the arterial line.
- The arterial line will be removed before your child leaves ICU. It involves removing some tape and applying pressure to the site. A small pressure dressing will be applied.



Arterial line

Monitoring or pressure lines

- Towards the end of surgery, the surgeon may insert monitoring or 'pressure' lines into the heart or pulmonary artery.
- 'Pressures' can be continuously monitored from these lines.
- The monitoring/pressure lines will only be in use while your child is in ICU.
- When the line is no longer required for monitoring, nursing staff disconnect the line and place a cap on the end. The lines will remain in place for several more days, and then the surgeon will ask for them to be removed.
- There are some stitches securing the line to the skin that need to be cut. By pulling gently, the line is easily and quickly removed and a band-aid is placed over the site for a day.
- Older children describe the sensation as 'weird' rather than painful, with a quick tingling or slight stinging sensation as the final portion comes through the skin.

The scar/incision from the operation

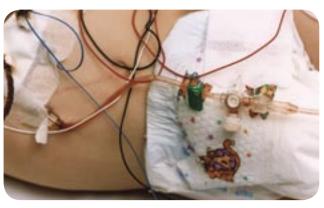
- Most cardiac surgery is performed via an incision (cut) through the middle of the chest. However, some children will have their surgery performed via an incision under the arm.
- The incision will be covered in a white dressing that is removed on day 4 (day of surgery = day 0).
- After removal of the dressing, the incision is cleaned with saline solution when required.
- The stitches that hold the incision together are generally under the skin and will dissolve over the next few weeks.



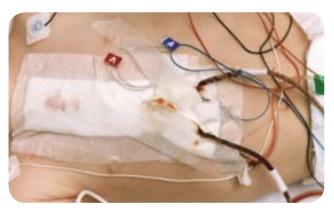
- The surgeon will insert tubes into the chest during the surgery. The tubes allow any fluid that accumulates in the chest cavity after the operation to drain into a collection chamber. The tubes and collecting chambers are known as chest drains.
- The chest drain will remain in for one to three days on average.
- Some children will require a chest drain for a longer period. (For example, children who have the Fontan procedure may have their drains in for several days, even weeks.)
- Sedation or pain relief is required to remove the chest drain. This procedure can be a little uncomfortable and requires the child to remain still.
- During removal of the chest drain, the nurses will tie stitches the surgeon has left in place to close the small incision the drainage tubes passed through.
- These stitches will need to be removed five to seven days after the drain is removed.

Pacing wires

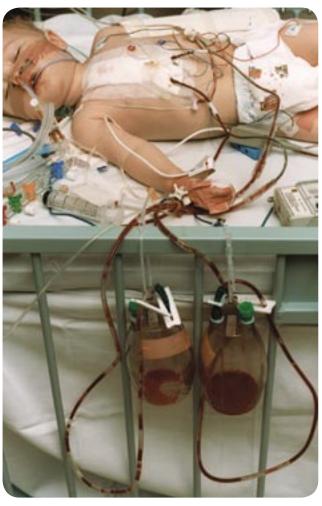
- Often wires referred to as 'pacing wires' are routinely inserted towards the end of the operation.
- The pacing wires are a precaution, in case the natural conduction and beating of the heart is interrupted or affected by the surgery.
- Sometimes the heart needs some help to maintain a normal heartbeat.



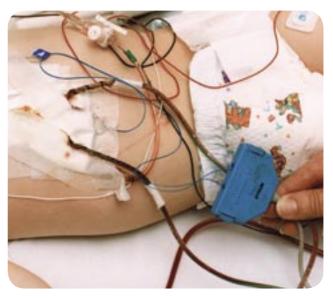
Monitoring or pressure line in use



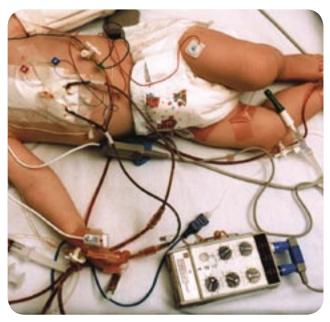
The scar/incision from surgery with the dressing still in place



Chest drains



Pacing wires attached to a temporary pacemaker



Temporary pacemaker

- In this situation, the pacing wires (which are usually rolled up and secured onto your child's chest) can be connected to a battery-driven 'pacemaker'.
- This external pacemaker regulates the heartbeat.
- Only a small number of children having open heart surgery will need the help of an external pacemaker.
- The pacing wires are removed when no longer required (usually the day before discharge).
- This is a quick procedure that involves cutting a stitch that secures the wires to the skin. The wires are gently pulled to remove them and a band-aid placed over the site for a day.

Monitoring

- · Your child will be continuously monitored while in ICU.
- The readings will be displayed on a monitor screen by the bed.
- The staff can check at a glance whether the tracings and readings are satisfactory.
- When the monitor alarm rings, it does not always indicate a problem with your child.
- Sometimes slight movement will interrupt the signal and the regular patterns on the screen are upset, causing the alarm to sound.
- If you are concerned, please talk to the nurse who is caring for your child.

Urinary catheter

- The urinary catheter inserted by the anaesthetist is generally removed before leaving ICU, although some children may return to the Cardiac Unit with it in place.
- The purpose of the urinary catheter is to prevent retention of urine and to allow accurate measurement of urine. Fluid balance is important immediately after cardiac surgery.
- After the urinary catheter is removed, nursing staff may weigh nappies or collect urine in a bottle or pan to measure urine.



Urinary catheter

Peritoneal dialysis (PD) tube/drain

- Only a small number of children requiring cardiac surgery will have a peritoneal dialysis (PD) tube inserted during surgery.
- Peritoneal dialysis (PD) is used to assist in fluid and electrolyte balance in some circumstances.
- If a child has a very high temperature, the PD tube may assist with a cooling method in some circumstances.
- Most children who require the PD tube will have it removed before leaving ICU.

Not all children who require cardiac surgery will need all the tubes and equipment mentioned for their care after surgery. The tubes and equipment required for each child will depend on the type of cardiac surgery they are undergoing. For example: children undergoing closed-heart surgery and expected to be transferred to the recovery room and then to the Cardiac Unit (7 West) may only require nasal prong oxygen, a peripheral intravenous line, naso-gastric tube and chest drains immediately post surgery.

While a general view of how long various tubes and equipment are required has been given, the length of time required is dependent on individual patients needs. Please do not be concerned if some variations occur. Talk to the doctor or nurse caring for your child.

Pain relief

- Pain relief consists of morphine via an infusion pump into an intravenous line in the first day or so.
- In the early hours after surgery while the ventilator is still breathing for your child, the dose of morphine given will keep them heavily sedated.
- The morphine dose will be reduced before the ventilator is weaned.
- The reduced dose will be adequate for pain relief at this time.
- For older children who understand the concept, patient controlled analgesia (PCA) may be introduced when they wake.
- Morphine is provided via a special infusion pump that allows the patient to request the pump to give a flush (by pressing a button) when they are in pain or anticipate pain.
- The PCA pump is programmed with safeguards to prevent overdose.
- Patients who are able to use this method tend to have good pain relief, with few side effects, as it is tailored to their own needs.
- If your child is able to use patient controlled analgesia, nursing staff will provide education to you and your child, on the pre-admission/admission day.



Arm splints prevent children from pulling out their lines



Care of your child continues throughout the night

Arm splints

- To prevent children from pulling out their lines and wires, arm splints may be required.
- The splints assist by keeping the elbow straight.
- The splints do not restrict all movement but do prevent the child from reaching their lines and wires.

Through the night

- · Care of your child continues throughout the night.
- · Your child will still be sedated.
- You will be feeling physically and mentally drained.
 Take advantage of this time to take some rest.
- Should your child's condition change or they wake and need you, the nursing staff will phone you.
- If you wish to enquire about your child, phone ICU at any time. (Contact numbers for ICU will be given to you.)

Length of stay in ICU

- On average, children stay in ICU for one to two nights following surgery before being transferred to the Cardiac Unit (7 West).
- Transfer is dependent on the type of surgery your child has had and how quickly they recover.
- Don't be disappointed if your child seems to be taking longer than other children. Recovery is an individual process and it is difficult to predict exactly how long it will take.
- Your child will be transferred to the Cardiac Unit (7 West) as soon as their condition is stable.

After transfer to the Cardiac Unit (7 West)



The days following surgery will involve various tests and procedures.

These include blood sampling, chest X-rays, echos, ECG, physiotherapy; removal of drain tubes, monitoring lines and pacing wires and general wound care.

Oxygen

- Some children may still require oxygen to assist their breathing.
- The oxygen will be delivered through nasal prongs.
 Sometimes a facemask may be used or a head box for small babies.
- Gradual weaning of the oxygen will occur as their condition improves.

Central Venous Line (CVC)

- The CVC will remain in for another day or two.
- The CVC will be removed when your child is tolerating oral fluids and no longer requires any medicines through the line.
- Under some circumstances the doctors will request the CVC to be removed and a peripheral intravenous line to be inserted.
- The most uncomfortable thing about the removal of the CVC is removing the tape.
- A band-aid will be placed over the site for another day.



Chest X-ray



Oxygen given through nasal prongs

Pain relief

- Pain relief consists of morphine via an infusion pump into an intravenous line in the first day or so. When transfer to the ward occurs, the morphine dose will not be as high as in the first hours after surgery. The dose given will still provide adequate pain relief but the child will be more aware of his surroundings.
- For older children who understand the concept, patient controlled analgesia (PCA) may be introduced when they wake.
- With this method, morphine is provided via a special infusion pump. This PCA pump allows the patient to request a flush (by pressing a button) when they are in pain or anticipate pain.
- The PCA pump is programmed with safeguards to prevent overdose.
- Patients who are able to use this method have good pain relief, with few side effects, as it is tailored to their own needs.
- If your child is able to use patient controlled analgesia, nursing staff will provide education to you and your child on the pre-admission/ admission day.
- When the morphine infusion ceases, Panadol and Codeine will be given (by mouth or rectally) for pain relief. Eventually only Panadol will be required.
- It is not possible to promise 100% pain relief; however, a good level of comfort should be possible for all children.
- There is a pain management service available in the hospital to assist when necessary.

Monitoring/pressure lines

- Monitoring/pressure lines are only required for monitoring while your child is in ICU.
- Before transfer from ICU to the ward, the lines will be disconnected and have a cap placed over the end.
- The monitoring/pressure lines will remain in place for three to five days.
- · The surgeon will ask for them to be removed.
- The procedure is quick and involves cutting a stitch and gently pulling the line.
- A band-aid will be placed over the site for another day.
- Older children describe the removal as a 'weird' sensation rather than painful. There is a tingling sensation as the final portion comes through the skin.



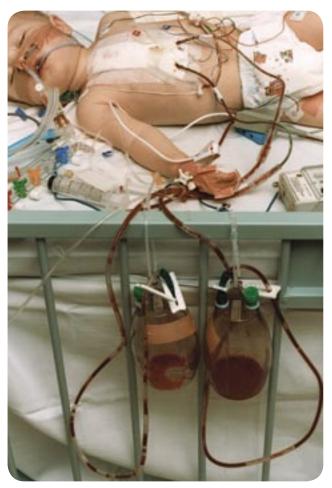
Monitoring/pressure lines disconnected and capped before transfer from ICU

Chest drains

- The surgeon will insert tubes into the chest during the surgery. The tubes allow any fluid that accumulates in the chest cavity after the operation to drain into a collection chamber. The tubes and collection chambers are known as chest drains.
- The chest drain will remain for one to three days on average.
- On return to the Cardiac Unit, the chest drain may still be in place.
- Some children will require the chest drain for a longer period. (For example, children who have the Fontan procedure may have their drains in for some time.)
- Sedation or pain relief is required to remove the chest drain. This procedure can be a little uncomfortable and requires the child to remain still.
- During removal of the chest drain, the nurses will tie stitches the surgeon has left in place, to close the skin.
- These stitches will need to be removed five to seven days after the drain is removed.

The scar/incision from the operation

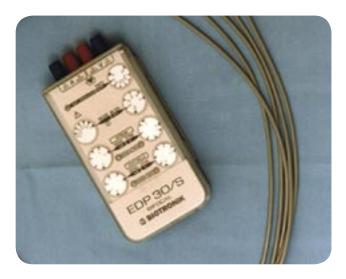
- Most cardiac surgery is performed via an incision (cut) through the middle of the chest. However, some children will have their surgery performed via an incision under the arm.
- The incision will be covered in a white dressing that is removed on day 4 (day of surgery = day 0).
- After removal of the dressing, the incision is cleaned with saline solution when required.
- The stitches that hold the incision together are generally under the skin and will dissolve over the next few weeks.
- Once the lines and wires are removed, your child may have a short 'splash' bath after day 5 and a longer 'soak' bath after day 10.



Chest drains



Scar / incision after removal of the dressing



Temporary pacemaker



Pacing wires rolled up and secured to the chest

Pacing wires

- Often wires referred to as 'pacing wires' are routinely inserted towards the end of the operation.
- The pacing wires are a precaution, in case the natural conduction and beating of the heart is interrupted or affected by the surgery.
- Sometimes the heart needs some help to maintain a normal heartbeat. In this situation the pacing wires (which are usually rolled up and secured onto your child's chest) can be connected to a batterydriven 'pacemaker'.
- This external pacemaker regulates the heartbeat.
 Only a small number of children having open-heart surgery will need the help of an external pacemaker.
- The pacing wires are removed when no longer required (usually the day before discharge).
- This is quick procedure that involves cutting a stitch that secures the wires to the skin. The wires are gently pulled to remove them and a band-aid placed over the site for a day.
- Older children describe the removal as a 'weird' sensation rather than painful. There is a tingling sensation as the final portion comes through the skin.

Monitoring

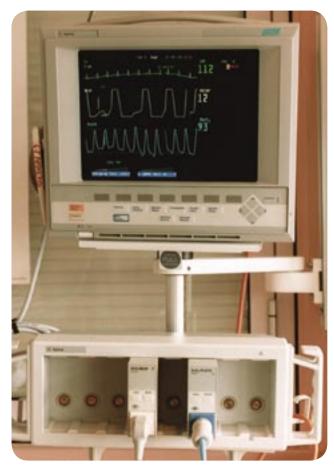
- Your child will be continuously monitored on the ward until the pacing wires are removed.
- The readings will be displayed on a monitor screen by the bed and at the central station.
- Some children may be attached to a telemetry monitor enabling them to walk around the ward while being monitored.
- The staff can check at a glance whether the tracings and readings are satisfactory.
- When the monitor alarm rings it does not always indicate a problem with your child. Sometimes slight movement will interrupt the signal and the regular patterns on the screen are upset, causing the alarm to sound.
- · If you are concerned, please talk to the nurse.

Physiotherapy

- Children are encouraged to move around in bed and to do deep breathing exercises.
- As soon as they are well enough we will encourage them to sit out of bed and then to walk.
- Physiotherapy assists in preventing complications after surgery, such as the development of lung consolidation.
- Children over two years of age will have a
 physiotherapy review before surgery. In this
 session, the physiotherapist will demonstrate
 the exercises the child will need to do and discuss
 her role in his care.

Fluid restrictions

- Fluid restrictions are necessary after most cardiac surgery. The fluid restriction prevents further fluid retention and extra work for the heart.
- The volume of fluid your child can have will include fluids from the intravenous line (IV) as well as oral fluids.
- On the first day back on the ward, most children under 12 years will be allowed 60% of the volume of fluid required for their weight and age.
- For children over 12 years, the fluid restriction will start with one litre.
- Doctors will increase the fluid volume each day, if the child's condition is improving.
- Most children will be back to normal fluid volumes prior to discharge.
- It is important that you consult the nurses before giving your child a drink. All fluids should be measured accurately by using a mixture cup or syringe.
- Some foods will need to be measured as well.
 Custards, jelly, yoghurt, ice cream, soups, watermelon and oranges are considered to have a high fluid content.
- Nurses are able to estimate a fluid value by weighing these foods.



Monitor in use on the Cardiac Unit



Blowing bubbles with the cardiac pyhsiotherapist



Fluid restriction after cardiac surgery



Medications

Fluid restrictions following the Fontan procedure

- Children having the Fontan procedure are placed on a 50% fluid restriction.
- The 50% fluid restriction will remain throughout the hospital stay and for several weeks after discharge.
 It may be a period of months before your child will be off all fluid restrictions.
- The cardiologist will supervise a gradual increase in the fluid volume.
- You should not alter the fluid restriction without consulting your cardiologist first.

Fluid restrictions and the breast-fed baby

- While on a fluid restriction, breast-fed babies will need to be test weighed to measure the volume of fluid they take.
- Test weighing involves weighing your baby prior to a feed and then again following the feed. The breast milk taken at the breastfeed is calculated by the difference in the two weights. At this time, we are concerned that your baby may be receiving too much breast milk.
- Generally, most babies will start breast feeds when the restriction is 70% – 80% fluids and when they are considered ready to feed at the breast.
- At first it may only be one or two feeds a day, increasing gradually as your baby's condition improves.

Daily weight

- All children will be weighed daily following their surgery. This is to monitor fluid retention. Fluid retention is indicated by a large weight gain in 24 hours.
- Real weight gain will be monitored over a period of days or weeks.

Medications

- Doctors may order medicines to help your child's recovery.
- Some of these medicines may have to be taken when your child is discharged to go home.
- The more common medicines are Lasix and Aldactone.
- These drugs work in combination to remove excess fluid in the body and therefore reduce the workload on the heart.
- Your cardiologist or paediatrician will decide when your child will finish taking the medicines.
- You should not stop giving the medicines to your child unless the cardiologist or paediatrician instructs you to do so.
- If you run out of medicine, please contact your cardiologist or paediatrician immediately for advice.

Post-op blues

- You will notice that your child may seem tired and miserable during the first few days. This may continue for up to a week for some children.
- This is a normal reaction and is commonly referred to as the 'post-op blues'.
- Let your child rest as much as possible between the routine hospital activities.
- Eventually your child will return to normal.

Discharge

- If your child has progressed well after surgery they may be discharged home three to seven days after the operation.
- However, this will depend on the type of cardiac surgery performed, plus the individual child's own ability to heal.
- Children having more complex surgery may need to stay longer.
- Doctors may discharge interstate or country patients from the ward but will request that they stay in Melbourne for a few more days.
- These children will return to the outpatient clinic or ward to be reviewed by the cardiologist, before the final decision is made to send them interstate.
- Interstate patients may be required to return to the referring hospital so that their own cardiologist can review them prior to final discharge to home.
- This will be discussed with you when your flights are confirmed.
- Before leaving hospital, Victorian patients should be given an appointment to see their cardiologist for a review.
- It is difficult to guarantee the day of discharge home so it is best just to take each day as it comes.



Post-op blues

Expected behaviour of children after discharge

- Hospitalisation causes disruption to a child's normal routine and it may take some time for them to settle.
- Some children experience a regression in their behaviour. For example, recently toilet trained children may begin to wet or soil again.
- Children may cling to their parents and refuse to let them out of their sight or wish to be continually held. This behaviour will occur despite the constant presence of their parents during their hospitalisation.
- Siblings may also exhibit some of the above characteristics as their routine is also disrupted. They are aware of their parent's anxiety for the cardiac child and may display jealousy towards them.

The intention of this information manual is to help parents understand the care of their child while hospitalised for cardiac surgery.

We hope this manual has been useful to you.

Care of children having cardiac surgery, Information manual for parents

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