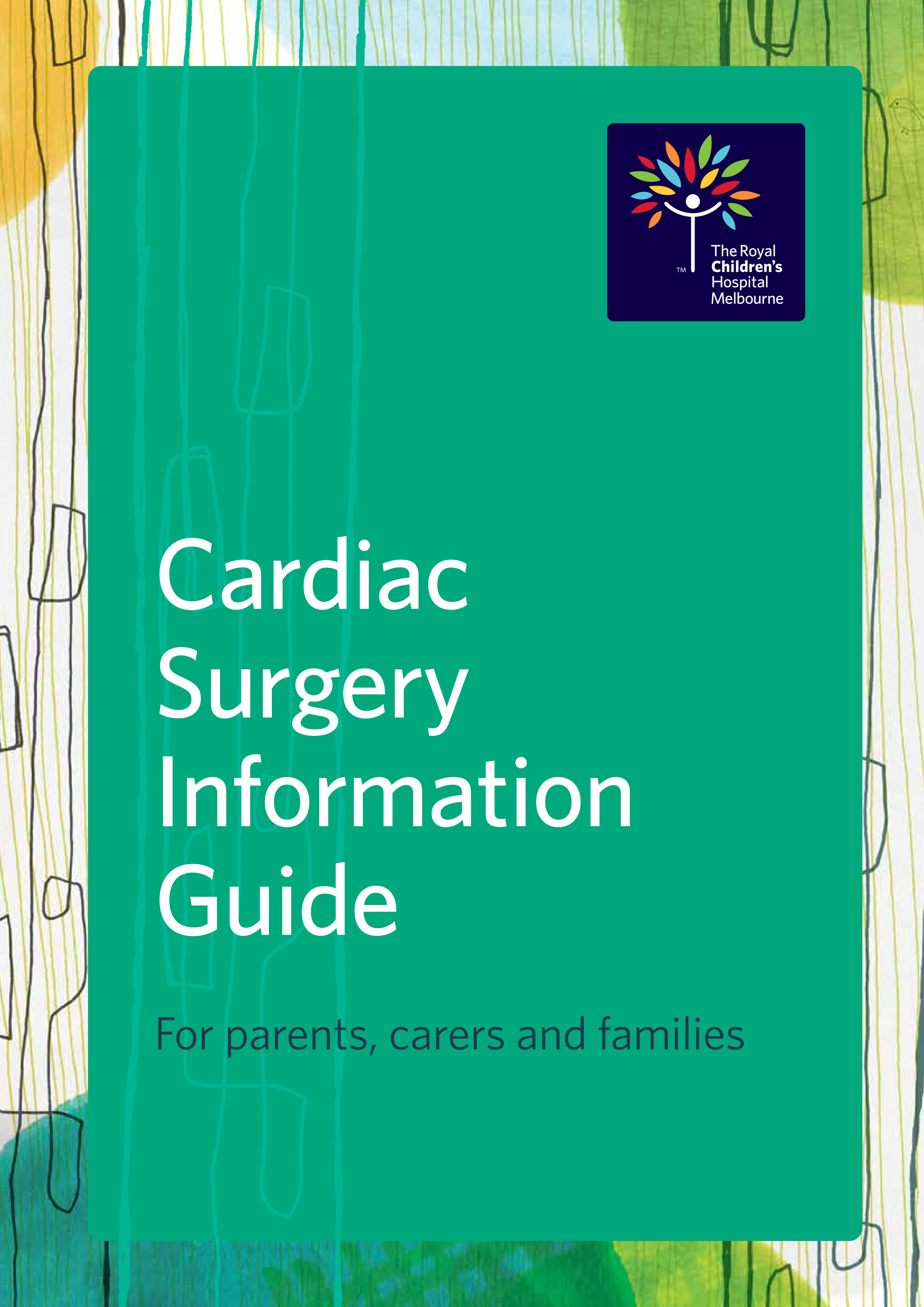


The Royal
Children's
Hospital
Melbourne

Cardiac Surgery Information Guide

For parents, carers and families

The Cardiac Surgery Information Guide is proudly supported by The Royal Children's Hospital Foundation.

Introduction

This guide has been developed to provide you with information about your child's care before, during and after cardiac surgery at The Royal Children's Hospital (RCH).

The information has been categorised into the different stages of your child's surgery, which allows you to read the information important to you at the time.

Some parts may appear repetitive. This is because some of the equipment, tests or processes are similar throughout the stages of your child's care: pre-admission clinic, Rosella (Paediatric Intensive Care Unit, or PICU) and Koala (Cardiac ward).

If you have questions about any of the information in this guide or about your child's care at the RCH, you can speak to your cardiac surgery nurse coordinator, nursing staff, medical staff or surgeon caring for your child.

Printed versions of this information guide are available for inpatient families to borrow. This RCH Cardiac Surgery manual is available online on the RCH website, under Cardiac Surgery:

www.rch.org.au/cardiacsurgeryguide

Contents

Before surgery

Cardiac Surgery Pre-Admission Clinic

Most children will attend an appointment at the RCH's cardiac surgery pre-admission clinic. Your child's appointment may be a few days or a few weeks before their scheduled operation date.

The purpose of the clinic is to assess your child's heart and general health before they have their surgery. There are many tests that need to be completed so you should allow for a full day (8.15am–4.30pm) at the hospital.

At this appointment, you will be provided with education and information about what to expect during your child's stay in hospital.

A small number of children will not have a pre-admission appointment but will be admitted directly to Koala (our cardiac surgery ward) before their surgery. The cardiac surgery nurse coordinator will provide you with more details if this is the case for your child.

Before coming to the pre-admission clinic

Please complete the Health Questionnaire and Dentally Fit forms before your pre-admission appointment date and return these forms by scanning and emailing to: **cardiac.surgery@rch.org.au** or contact us for reply paid postal address.

You can find these forms and more information on our website **www.rch.org.au/cardiac_surg/Parent_Info/**

If your child is over 18 months old, please ensure they have had a dental check and received any dental work required to make them 'dentally fit' before surgery. The surgeon may delay the surgery until all the necessary dental work is completed.

A child who is not dentally fit before their surgery has an increased risk of endocarditis (an infection affecting the heart).

What to bring to the pre-admission clinic

On the day of your child's appointment, please bring:

- all medications that your child is currently taking (all prescribed and natural or complementary medicines, including vitamins, puffers and creams)
- information about any allergies
- your child's maternal and child health nurse book and immunisation record (e.g. My Health, Learning and Development Record in Victoria)
- the Dental check form (if not already returned)
- the Health Questionnaire (if not already returned)
- a favourite activity for distraction (e.g. book, toy or electronic device)
- any food and drinks you and your child will require for the day (e.g. snacks, formula). You will also need to bring a breast pump if you need to express
- a notebook and pen for recording information and questions.

Make sure your child is dressed suitably for their appointment.
They will need to take their clothes off a few times throughout the day for various tests, so dress them in loose clothing that allows easy access to the body (avoid tights or multiple layers where possible).

For babies choose clothing with buttons down the front, and pants and socks that allow easy access to the feet.

For older children choose a t-shirt and loose-fitting pants.

On the day of your appointment

At the pre-admission clinic you will meet with a cardiology nurse specialist who will organise the tests your child's doctor has requested and will discuss with you:

- your child's medical history, any previous surgeries and whether your child has had a blood transfusion or blood products given to them in the previous three months
- the assessment of your child (they will record some information, including temperature, blood pressure, oxygen saturations, height and weight)
- your child's recent health.

You will be given instructions on how to prepare your child for surgery (e.g. fasting, medicines information and pre-surgery hygiene instructions). The nurse will also talk to you about the care your child will receive at the RCH and talk you through what to expect with your child's day-to-day care following the surgery.

This appointment is a good opportunity to ask any questions, and please feel free to talk with the nurse if there is anything concerning you.

You will have the opportunity to meet with your surgeon for a surgical consultation and to sign consent for surgery.

What tests will be performed?

Blood tests: A blood test is needed to check all components of the blood and to determine your child's blood type. This is important so that the right blood type is made available for your child in case any needs to be given during surgery.

For most children, an anaesthetic cream that numbs the skin (e.g. EMLA or AnGel cream) can be applied to reduce pain. You can also help to distract your child with an activity, book or toy.

For babies, a sucrose (sugar) solution is given, which has a calming effect and triggers the body to release its own pain-relieving responses.

Chest X-ray: A chest X-ray allows doctors to look at the size and shape of your child's heart and to check your child's lungs before surgery.

Echocardiogram (echo): The echo will show the surgeons what the inside of your child's heart looks like before their surgery and may be repeated to give up to date information. The echo will show the surgeons what the inside of your child's heart looks like before their surgery.

An echo can take half an hour or more, especially if it is the first time your child has had an echo at the RCH. For the scan, your child will need to lie still in a darkened room.

For babies and toddlers, it can be useful to avoid feeding them in the two hours before to the scan, so they can feed just before or during the scan to help keep them settled. You can also try keeping them awake if you think this will help them fall asleep during the scan.

If your child is unable to keep still, sedation might be needed to make your child sleepy and relaxed. If your child needs sedation, it is likely another appointment will need to be made and you'll have to return for a second attempt at an echo.

If your child has previously had an echo with sedation, please let the cardiac surgery coordinator know in advance.

Electrocardiograph (ECG): An ECG is a test that records the electrical activity of the heart and prints it out on paper. Small sticky patches will be stuck to your child's arms, legs and chest, which are then connected via thin cords to the ECG machine.

An ECG test is painless but requires your child to lay down and be still for a few minutes.

Your child's care team

As your child moves through the cardiac surgery process, they will be in the care of the RCH Cardiac team. This team is made up of surgeons, doctors, nurses and other allied health staff from the RCH. All pre and post-operative care is provided by the RCH's Cardiac team, and referrals for allied health clinicians will be made for your child where needed.

Cardiac team

Your child will be cared for a team of cardiac specialists made up of a cardiac surgeon, cardiologist, intensive care specialists and cardiac nurses. The surgeon will perform the operation with the help of the team and specially trained nurses, doctors, perfusionists and anaesthetists.

Cardiac surgery nurse coordinator

The cardiac surgery nurse coordinator will schedule surgery, monitor outpatients on the cardiac surgery waitlist, organise pre-admission appointments, and liaise with the cardiac surgeons and cardiologists. The cardiac surgery nurse coordinator will be your main point of contact while you are on the waitlist.

Cardiology clinical nurse specialist

The cardiac nurses you meet during pre-admission have extensive cardiac knowledge and will guide you through your pre-admission day. They will provide education and ensure your child is fit and ready for surgery.

Anaesthetist

A cardiac anaesthetist will care for your child during the surgery. A small number of children may need to meet with an anaesthetist before surgery — it will be scheduled on the same day as the pre-admission clinic.

Perfusionist

A perfusionist is a skilled scientist who will work closely with the surgeon and anaesthetist. The perfusionist is responsible for the operation of the heart-lung machine during surgery.

Physiotherapist

Most children will be visited by a physiotherapist after surgery. Physiotherapists help to get your child moving and walking again after surgery and provide deep breathing and coughing exercises.

Child life therapist

A child life therapist can provide your child with age appropriate activities to help your child cope during their hospital stay. Child life therapists are particularly helpful in preparing and supporting your child during procedures.

Dietician

A dietician may be contacted if your child requires a special diet or specialised feeding equipment.

Social worker

A social worker is available to provide support and counselling to families if needed. If you need to talk with the social worker during your child's hospital stay, you can ask the nurse caring for your child to contact them.

Lactation consultant

If you are breastfeeding or would like to breastfeed your baby after their surgery, a lactation consultant will be available to support you after your baby's surgery. Equipment to express, including pumps, are available on the ward. The hospital provides three meals per day for mothers who are breastfeeding.

How is cardiac surgery performed?

There are two ways to perform cardiac surgery — open-heart surgery and closed-heart surgery. Before your child's surgery, you will have a chance to meet with a surgeon who will explain what type of surgery is needed and the plan for your child's surgery.

Open-heart surgery

Open-heart surgery is when an incision (cut) is made through the middle of the chest, along the sternum. This type of incision is called a sternotomy.

If your child is having open-heart surgery, cardiopulmonary bypass is needed. Cardiopulmonary bypass is when the blood is diverted away from the heart and lungs and through a machine (commonly called a heart-lung machine). This machine will take over for the heart and lungs during the surgery.

This leaves the heart free of blood so that the surgeon can operate.

Closed-heart surgery

If the surgery is performed around the outside of the heart (e.g. on an artery), it is called closed-heart surgery.

Closed-heart surgery is often used to repair the major vessels (that carry blood to and from the heart) rather than the heart itself. Usually, cardiopulmonary bypass is not needed for closed-heart surgery.

Before surgery

The cardiac surgery coordinator will phone you the afternoon before your child's surgery to confirm:

- that the surgery is going ahead as originally scheduled
- the admission time (the time you need to bring your child into the hospital)
- fasting times for your child.

Fasting

Your child will need to fast before surgery. This is because their stomach needs to be empty for the anaesthetic to be safe. The cardiac surgery coordinator will contact you with specific fasting times once your surgery has been booked.

- Some children may need to be admitted to the ward the night before surgery so they can be fasted appropriately.
- In a very small number of cardiac children (very small, unwell babies or very cyanosed (blue) children), the surgeon, cardiologist or anaesthetist may ask that an intravenous line (IV) be inserted before surgery so your child can receive fluid directly into a vein through a drip (intravenous or IV therapy) — this will prevent dehydration while they fast.

Children less than 6 months of age:

- Please plan for the last breast feed to finish **no less than 3 hours** before anaesthesia.
- Please plan for a formula feed to finish **no less than 4 hours** before anaesthesia.

Should I continue giving my child's medicines before surgery?

You will be given instructions regarding your child's medications by the cardiac surgery coordinator or at your pre-admission appointment.

- If your child is on anticoagulation (blood thinning) medicines (e.g. Aspirin, Warfarin), you will be provided with a clear plan for the week before surgery.
- You should not stop giving any of your child's medicines unless you have been directed to do so.
- If you are still unsure or have any questions regarding your child's medications, please call the cardiac surgery coordinator on (03) 9345 5205

On the morning of surgery, you should bring all your child's current medications with you. This includes all prescribed and natural or complementary medicines, including vitamins, puffers and creams.

The morning of surgery

Anaesthetist

You will meet the anaesthetist when you arrive on the day of surgery. They will talk to you about their role in caring for your child. The anaesthetist will also confirm that your child has been fasted appropriately and may change your child's fasting times if there are any delays. Your child will only be allowed extra drinks of clear fluid if they are required to fast for longer than expected.

Admission

The nursing staff in theatre will ask questions about your child's health to gain a clear history — it may feel like you are repeating yourself, but it will ensure that the surgical team has all the relevant information to create a safe environment for your child.

Preparing your child for the operation

The anaesthetist will often prescribe a pre-medication to be given to your child before surgery to help children feel less anxious — most children feel relaxed and a little drowsy after it is given.

- You will be asked to clean your child with antiseptic wipes (to lower the chance of infection) and they will be given a hospital gown to wear.
- Nursing staff may put anaesthetic cream on the skin to help numb the area where an IV (drip) is needed.
- Your child will have an identification (ID) band attached around their wrist or ankle and these will stay on throughout their stay in hospital.

Pre-operative holding area

Two parents/caregivers will be able to go with your child to the area outside the operating theatres known as the pre-operative holding area and sit with them until the anaesthetist is ready.

- If you wish to be with your child when the anaesthetic is given, please ask the anaesthetist when you first meet them.
- Parents/caregivers are not allowed into the operating theatre during the operation.

During surgery

During surgery

Anaesthetic and operating theatre

The anaesthetist will give your child's anaesthetic in a smaller room, before taking them into the operating theatre. Children can be put to sleep in one of two ways.

- Most children will have anaesthetic given through a drip directly into a vein (IV) — there should be very little discomfort, as an anaesthetic numbing cream is put on to numb the skin beforehand.
- Some children will have a vapour (gas) medicine given to them with a mask that is placed over their mouth and nose.

When your child is asleep, the anaesthetist will insert a breathing tube, intravenous line, arterial line and a urinary catheter. They will also attach some monitoring equipment. This may take up to an hour and a half or more to complete.

The surgeon will not be required while the anaesthetist is preparing your child, so don't be worried if you see the surgeon once your child has gone into the operating theatre. The surgeon will be called to theatre when the anaesthetist is ready for the operation to start.

Where should I wait while my child is in surgery?

The cardiac surgery coordinator will give you a guide for the length of time your child's surgery will take, however it is not unusual for the surgery to take longer.

We suggest you leave the hospital for some of the time that your child is expected to be in surgery — leaving the hospital can make waiting a little easier. Some parents and carers choose to go home or return to their accommodation. Other parents decide to go for a walk, visit the zoo or take a trip into the city. If you choose to stay within the hospital, you can spend time waiting in the cafes, the Family Hub or the gardens.

Wherever you decide to spend the time waiting, make sure your mobile phone is charged, remains switched on and that it has a signal.

The surgeon will contact you when the operation is finished.

Please allow another one and a half to two hours before you see your child. This extra time allows the anaesthetist to stabilise and prepare your child to be transferred out of the operating theatre.

After surgery in Rosella

After surgery: Rosella

Most children who have cardiac surgery will be moved to Rosella, the RCH's Paediatric Intensive Care Unit (PICU) after the surgery is finished. While your child is in Rosella, doctors, nurses and technicians will monitor your child closely and provide specialist care.

The length of time your child needs to stay in Rosella will depend on the type of surgery they had and how quickly they recover — this can be from one night to a few days. Try not to compare your child's recovery with other children, doctors will let you know if they are happy with your child's recovery and how they are improving.

Visitors and visiting hours

The doors to Rosella stay locked to protect patient confidentiality, so you will need to use the doorbell and intercom system every time you wish to enter the ward. Even if the doors to Rosella are open when you arrive, please use the intercom and wait until you are invited in.

Parents/caregivers can visit their child in Rosella at any time, although you may be asked to leave the ward during ward rounds or during procedures. You cannot sleep in the patient rooms while your child is in Rosella so please arrange alternate accommodation during this time.

Visitors may only visit with your permission.

No more than two people are able to be at the bedside at any time.

All visitors must adhere to hospital visiting hours — between 8am-12pm and 2pm-8pm.

Family and friends should not visit if they are unwell.

Please use antiseptic hand gel when you enter and leave Rosella, and before and after touching your child. Hand gel is available throughout the ward for staff, families and visitors to use.

Medicines given in Rosella

When your child is first transferred to Rosella they will be supported by a ventilator (breathing tube and machine).

For the first few hours after surgery, your child will remain sedated and some children will also be given a muscle relaxant medicine to stop them breathing against the ventilator (at this stage they won't be able to open their eyes).

These medicines are given to reduce movement, keep your child comfortable and reduce the amount of work the heart needs to do, giving the heart some time to recover after surgery.

It is a good idea to get some sleep during the time that your child is sedated. This may help you to prepare for when they are awake and needing your attention. You are welcome to phone or return to Rosella at any time.

If you are away from the ward, make sure the nurse looking after your child has the appropriate contact numbers to reach you. The nurse will call you if there are any changes in your child's condition.

Many parents are worried about their child waking up while they are not there — you can ask the nurse to update you daily about the plans for your child. When your child is ready to be weaned (removed) off the ventilator, the doses of sedative will be lowered or stopped to allow your child to 'wake up'.

Pain relief

Different types of pain relief are given to treat pain. Doctors and nurses will control doses to make sure your child is getting the right amount of relief for their pain level.

Monitoring and equipment

Not all children who have cardiac surgery will need all the tubes and equipment described. The type of cardiac surgery and your child's individual needs will influence the type of equipment and the length of time they are needed.

Arm splints

Arm splints may be used to stop your child from pulling out some of the lines and wires. The splints do not stop all movement but can help by keeping the elbows straight and makes it more difficult for hands to reach or pull at equipment.

Monitors

All children who have cardiac surgery will need monitoring during their stay in both Rosella and Koala. Your child will have stickers and leads attached to them, which collect data to display on a hospital monitor. Tracings of your child's heartbeat, breathing and oxygen levels will be displayed on a screen at your child's bedside and at other work areas in the ward.

The nurse uses the monitor to check your child's vital signs and will set alarms based on your child's age and condition. When the monitor alarms it does not necessarily mean there is a problem. Slight movement or a loose lead can interrupt the signal and cause the machine to alarm.

If you are worried about your child for any reason, speak to your child's nurse who can explain why the monitor has alarmed.

Ventilator (breathing machine)

Nearly all children who have cardiac surgery will be ventilated in Rosella. The ventilator is a machine that can breathe for your child and reduces the amount of work their body has to do. The breathing tube will be inserted through the nose (sometimes through the mouth for older children) into the trachea (windpipe). This tube allows air to pass from the ventilator into the lungs. There will be tape around the tube and over your child's face to keep the tube in place.

To stop the tube from getting blocked, nursing staff will sometimes need to pass another small tube through the ventilator tube to clear mucus (fluids) by suctioning.

Your child will not be able to speak or make noise until the breathing tube is removed. Some children will need to stay on the ventilator for a few days, while some will only need a few hours. Doctors will monitor your child and decide when they are ready to have the ventilator weaned (removed).

Oxygen

Once the ventilator has been weaned, oxygen may be given to help keep oxygen levels stable until your child's breathing returns to normal. Giving oxygen is painless and it can be delivered through nasal prongs or a face mask for as long as necessary

Nasogastric tube

The nasogastric tube is a thin soft tube that is passed through your child's nostril, down the back of the throat. The tube is used to drain stomach fluids and gas into a container, which prevents the stomach becoming full of air and reduces the chance of vomiting.

Older children usually have their nasogastric tube removed before they leave Rosella. Babies may keep the nasogastric tube so that breast milk or formula can be given through it until they are strong enough to feed normally (e.g. breastfeed or bottle feed).

Pressure lines

Pressure lines may be inserted into the heart or pulmonary artery during surgery. While your child is in Rosella, the lines can help to measure and monitor the pressure inside the vessels and the heart if needed.

When the pressure lines are no longer needed, they will be disconnected and have a cap placed over the end. The lines may stay in place for a few days and the surgeon will decide when it can be removed.

Arterial line

An arterial line will be inserted into an artery (often in the wrist) during surgery. It has a connector called a 'three-way tap' which allows blood samples to be taken for blood tests, without the need for needles.

These bloods tests are used to help the doctors monitor your child's progress. Blood pressure can also be measured using the arterial line, and medical and nursing staff will be able to see this measurement as tracing on the monitors.

Central venous catheter (CVC)

A central venous catheter (CVC), also called a central venous line, is an IV line that is usually placed into a large vein on one side of the neck (a vein in the groin may also be used). It has multiple connectors so many different fluids and medications can be given at once. A CVC can also be used to monitor pressures inside the vessels while your child is in Rosella.

A CVC is usually needed for a few days as most of the medicines your child needs will need to be given directly into a vein. Once your child is transferred to Koala, doctors may prefer to replace the CVC with a peripheral intravenous line (IV, or drip). Usually a peripheral IV is put in the hand or arm and in babies a foot is also sometimes used.

The CVC and any IVs that have been inserted will be removed as your child's condition improves.

Urinary catheter

The urinary catheter (inserted by the anaesthetist during surgery) will usually be removed before your child leaves Rosella, although a small number of children may be transferred to Koala with the catheter in place. The purpose of the catheter is to prevent urine retention and also allows nurses to accurately measure your child's urine in the first few days after surgery.

Peritoneal dialysis tube

A small number of children may have a peritoneal dialysis (PD) tube put in during surgery. The PD tube is used to help manage fluid and electrolyte (body salts) balance. If a child has a PD tube, it can also be used to help cool the body if they have a high temperature (fever).

Chest drains

The surgeon inserts tubes into the chest during surgery. Each tube is connected to a collecting chamber and these are called chest drains. Chest drains allow any fluid that remains in the chest cavity to drain out of the body after surgery. The chest drains usually remain in for two to three days and may be connected to suction, which can help to gently pull fluids out. Some children may need the chest drains to stay in for a longer period (sometimes several days or weeks).

Pacing wires

Pacing wires are routinely inserted in most children having open-heart surgery. Having cardiac surgery can sometimes interrupt the beating of the heart. If affected, the pacing wires can be connected to an external pacemaker to help keep the heartbeat in a normal rhythm until the heart recovers.

Cooling blanket

In the first few hours after surgery your child may be nursed on a cold blanket. The cooling blanket helps to lower your child's body temperature and lowers the heart rate, helping the heart to recover after surgery.

Fluid balance

Fluid balance (the amount of fluid your child has in and out of their body) is an important part of your child's care after cardiac surgery.

Until your child is able to eat and drink normally, your child's fluid and nutrition will be given directly into a vein through a drip. It is unlikely that your child will be able to eat and drink normally while they are in Rosella. Doctors will let you know when your child is able to start eating and drinking.

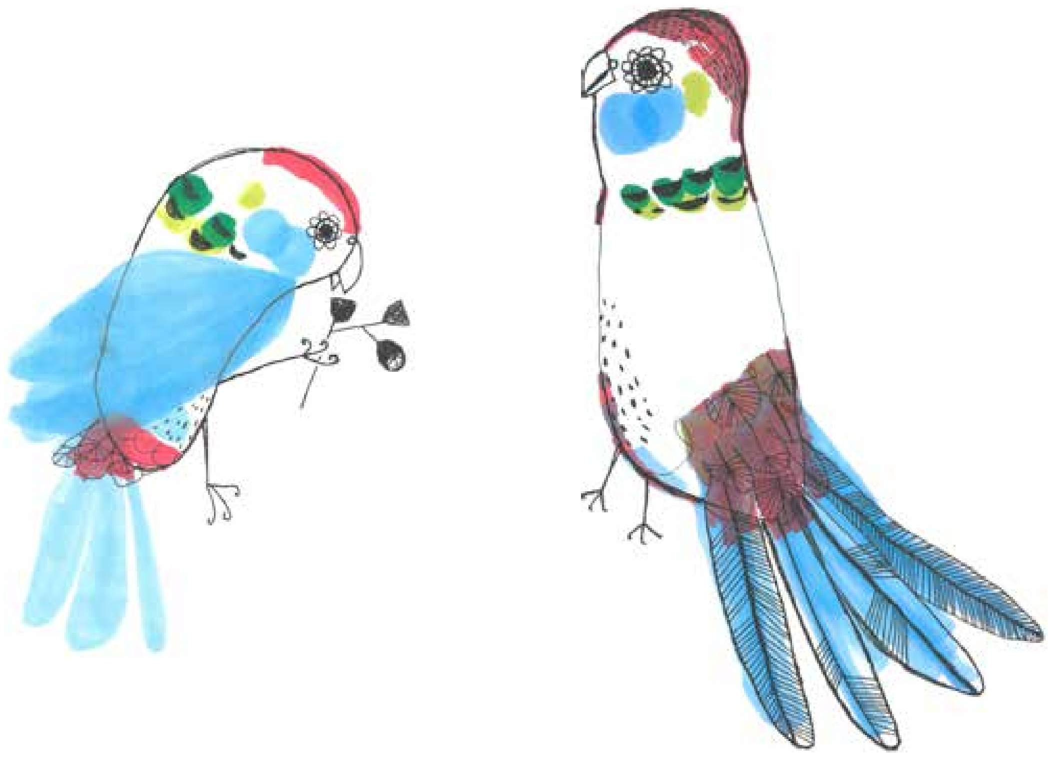
After your child's urinary catheter is removed, the nurses will weigh nappies and older children will be asked to use a bottle or pan when they go to the toilet so their urine can continue to be measured and recorded.

Fluid retention is common after cardiac surgery. Your child may appear swollen or puffy, which you will most likely notice around their face and hands. This swelling will usually go down over a few days.

Photographs and video

You may take photos and video of your child while they are in Rosella and Koala, but please do not take photos or video of the nursing staff, unless you ask their permission first.

Please make sure that you avoid taking photos and video of other patients.



After surgery in Koala

After surgery: Koala

When your child is breathing without the ventilator and is stable, they will be transferred out of Rosella and most likely to Koala, the RCH's cardiac ward. Patients of all ages are cared for in Koala and staff range from cardiac specialists to trainee medical staff and specialist nursing staff. They are all involved in your child's care and recovery.

Particularly complex or long-term patients may also be supported by nursing care managers to help assist and co-ordinate their care during their stay in hospital.

Nurses on Koala ward are allocated to look after your child as well as one or two other patients.

Visitors and visitor hours

Parents/caregivers can visit their child in Koala at any time.

Visitors may only visit with your permission.

No more than three people are able to be at the bedside at any time. If too many visitors arrive at once, please ask them to take turns visiting your child.

All visitors must adhere to hospital visiting hours — between 8am-12pm and 2pm-8pm.

Family and friends should not visit if they are unwell.

Koala has quiet time between 12pm and 2pm, when procedures, visitors (including siblings) and noise is limited. Quiet time is enforced, as it helps your child and other patients to rest and recover.

Please use antiseptic hand gel when you enter and leave Koala, and before and after touching your child. Using antiseptic hand gel reduces the chance of spreading an infection to your child. Hand gel is available as you enter Koala and Rosella ward.

Staying overnight in your child's room

Parents/caregivers are welcome and encouraged to stay overnight with their child. For safety reasons, only allow one parent/caregiver can sleep over each night, and siblings are not permitted to stay. The daybed in your child's room becomes a bed at night with sheets, blankets and pillows provided.

You are welcome to put your name on the parent accommodation (Ronald McDonald House) waiting list (preference will be given to regional, rural or interstate families). You may need to look at other accommodation options as a room is not always available. You will have received an accommodation list in your pre-admission pack please refer to this for other options.

Medicines given in Koala

Once your child is transferred to Koala, they will begin taking liquid or tablet medicines, rather than having these through a drip.

Your child may have a range of different medicines prescribed to help them recover from surgery. The more common medications are frusemide (Lasix) and spironolactone (Aldactone), which work together to remove extra fluid from the body and reduces the amount of work the heart needs to do.

If your child needs to have a procedure that is likely to cause some discomfort (e.g. removal of lines or drains), they may be given sedation and pain relief. You will be given information about the type of sedation being used before the procedure. Distraction (e.g. reading a book, blowing bubbles, singing songs, watching a movie or playing a game on a phone or tablet) can also be helpful during procedures to help children feel less anxious.

Pain relief

Pain relief is an important part of your child's care. Pain relief aims to keep your child comfortable enough to sleep, move around and take deep breaths, which will help to prevent complications and improve recovery.

The Children's Pain Management Service (CPMS) may review your child's pain medications and provide support and guidance to the medical and nursing team so that the best pain management is provided while your child is recovering.

Pain relief will initially be given through your child's IV (drip). As they recover, they will require less pain relief and will be given oral pain relief medicines (liquid or tablets).

If your child is capable enough, their pain relief may be switched over to a machine called a Patient Controlled Analgesia (PCA). Your child can control the PCA by pressing a button to have dose of pain relief. The PCA is set with safeguards, so don't worry about your child getting too much medicine. Children who use the PCA have effective pain relief with less side effects as they only get what they need.

If your child can use a PCA, they will be shown how to use it at their preadmission appointment.

Monitoring and equipment

While some of the tubes will be removed before your child leaves Rosella, your child will usually be transferred to Koala with some lines, wires and drain tubes. Some children may still need oxygen and will keep their facemask or nasal prongs on until it is no longer required.

Tubes and lines are removed once your child's doctors or surgeons decide it's safe to do so.

When chest drains are taken out, nurses will tie a knot with the suture (thread), forming a stitch to close the skin where the tube has been. The puncture site left after removing a drain is a little bigger than other lines and so the stitch helps to keep the wound closed and allows it to heal. The stitch will need to stay in place for five days and can be then be removed by the nursing staff if your child is still in hospital, or by your GP (local doctor) if you have been discharged home.

Care after surgery

Wound care

After surgery, the surgeon will use stitches to close your child's wound.

For most children, the stitches will be under the skin. These stitches do not need to be removed as they dissolve slowly over a few weeks.

Some children will have stitches that can be seen on the surface of the skin. These will need to be removed 10 days after surgery.

Your child will have a dressing over their wound and stitches to keep the area clean and dry. This dressing is usually removed four days after surgery. At this stage, the wound will be cleaned with saline solution (a sterile salt water mixture).

Once all of your child's lines, wires and drains are removed, you will be able to give them a shallow bath (or brief shower for older children) and wipe the wound with a clean, damp cloth.

You will need to keep the wound dry for at least two to three weeks. Your child should only have a 'soak' in a bath or shower once the wound is healed and all scabs are gone.

Thoracotomy

Sternotomy

Physiotherapy

Movement soon after surgery helps to prevent chest infections or circulation problems. It may seem quite soon, but within the first 24 hours, your child will be encouraged to move around in bed and do deep-breathing exercises. They may also be asked to sit out of bed and take a walk.

A physiotherapist who specialises in working with children after cardiac surgery will visit all children who have open heart surgery and help them as needed:

- For children over two years of age, physiotherapists mostly assist with getting out of bed in the first few days after surgery. They can provide extra support to children with mobility issues or chest concerns.
- For children under two years of age, a physiotherapist will usually only visit once they are moved to Koala. Physiotherapists will do a developmental screen, provide parents/caregivers with education and exercises they can do with their child and provide referral to a community physiotherapist where needed.

Physiotherapy

Post-op blues

In the first few days after surgery, you may notice that your child seems more tired and miserable. This is a normal reaction in children who have had surgery and is referred to as 'post-op blues'. Post-op blues can continue for up to a week.

To help your child recover and improve their mood, let them rest as much as possible between hospital activities (e.g. physiotherapy). If your child doesn't seem to be improving or you have any worries about your child, please talk to the nursing or medical staff.

Eating and drinking

It may be a day or two after the surgery before your child will be given drinks or food. Some children may not feel like drinking or eating in the first few days after surgery.

Fluid restrictions

After cardiac surgery, most children will need to have their fluid intake restricted (limited). Fluid restrictions in the first few days after surgery reduces the amount of fluid the heart needs to pump, this helps reduce the workload on the heart and in turn this will help the heart to recover. Limiting the amount of fluids also reduces fluid retention (swelling).

Fluid restriction includes:

- fluid and medications given through your child's IVs (drips)
- all drinks (e.g. water, milk, juice, breastmilk)
- fluid foods (e.g. custard, jelly, yoghurt, ice cream, soups, watermelon, oranges and milk or formula added to cereals).

You and your child's nurses will develop a plan that allows your child to have small drinks throughout the day and a small amount for an overnight drink. Over a few days, doctors will slowly increase the amount of fluid your child can drink. It is important to ask the nurses before giving your child a drink or fluid foods. All drinks and fluid foods need to be measured carefully and recorded. Most children will be back to normal fluids before they are discharged from hospital.

Fluid restrictions for babies

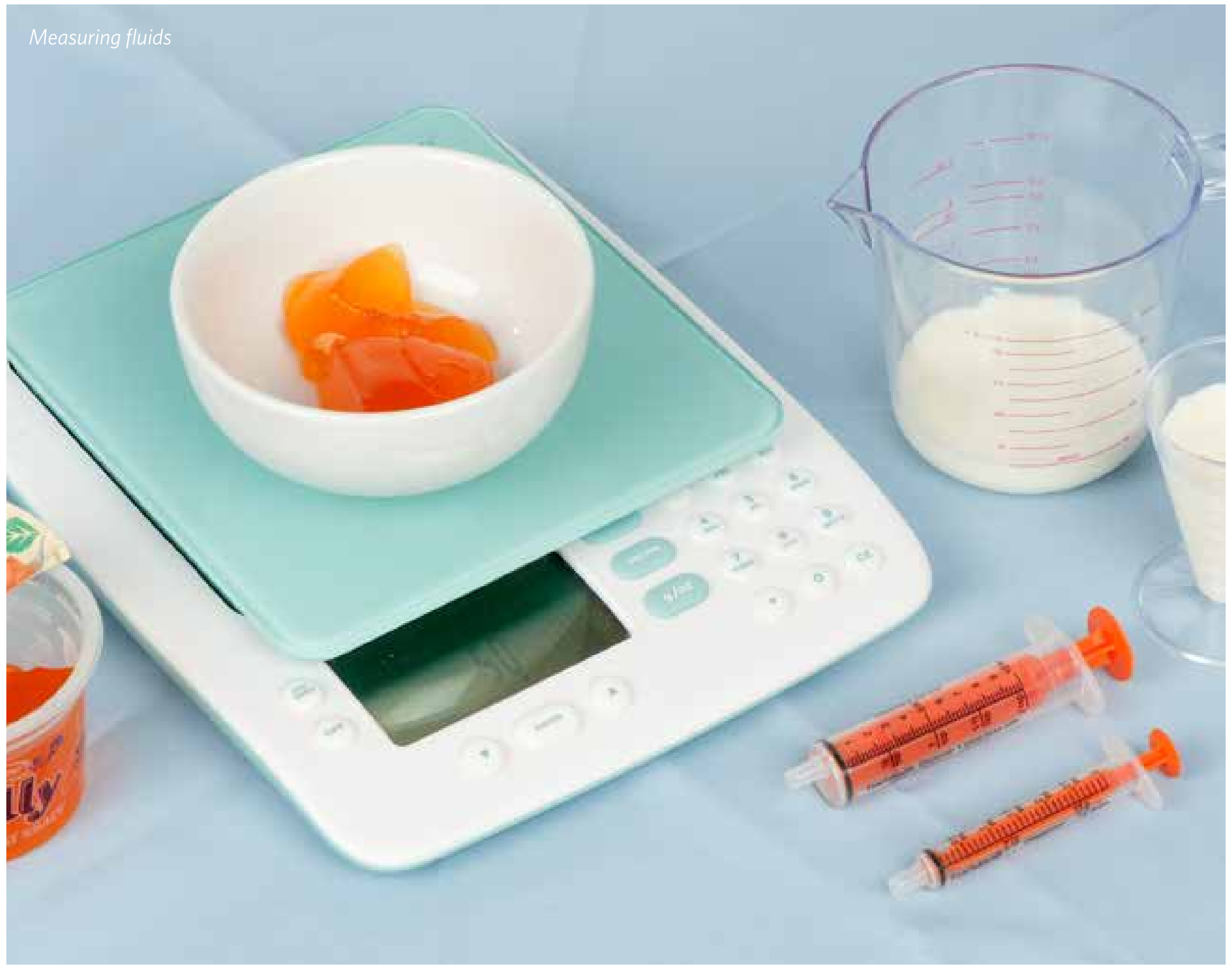
Nurses will work out how often your baby needs to feed and what volume of milk they can have at each feed while they are on a fluid restriction.

Babies may be too tired to feed when they are first transferred to Koala, and may be given feeds through a nasogastric tube until they can feed normally. Usually babies will start with just one or two bottle or breast feeds each day, alternating with their nasogastric feeds. As they recover, you will be able to gradually increase the number of feeds.

Breastfed babies may need to be weighed before and after each feed to make sure they are not getting too much milk. Nurses will help you with this process and record the amount of milk your baby is drinking.

Fluid restrictions for children who have a Fontan procedure

Children who have a Fontan procedure will need to stay on their fluid restriction when they go home and may be continued for several months. You will be provided with an education pack containing information if your child is required to continue their fluid restriction at home.



Measuring fluids

Monitoring your child's weight after surgery

Once they leave Rosella, your child will be weighed daily to help monitor their fluid retention. 'Real' weight gain will improve as your child recovers.

Your child may lose weight after their surgery. Weight loss can happen for a number of reasons:

- a result of the period of fasting before surgery
- intravenous fluids given after surgery (these keep your child hydrated but have less calories than milk or food)
- your child's fluids are restricted after surgery
- use of diuretics after cardiac surgery to help to get rid of extra fluid.

A dietician may be involved in your child's care if they require a special diet or specialised feeding equipment.

Medicines

Your child will need to continue taking some medications after leaving the hospital. After your child is discharged, they will have a follow-up appointment with their cardiologist, who will let you know when the medicines can be stopped

Discharge planning

How long will my child stay in hospital?

Most children will stay for about five to seven days. Children who have more complex surgery or who have other health problems that might impact on their recovery will need to stay for longer.

Plans for discharge are started as soon as your child is admitted to Koala to ensure you and your child have a smooth discharge and have everything you need before you leave hospital. Despite the planning efforts of staff on the ward, it can be difficult to predict the exact day of discharge, so it is best to take each day as it comes.

On the day you leave the hospital, you will be asked to leave before 10am. Doctors may discharge rural/interstate patients from the hospital but will ask that these children remain in Melbourne for a few more days. An appointment will be scheduled so that your child can be reviewed before they are given the 'all clear' to leave Melbourne.

Children living in Victoria will have an appointment scheduled to see their cardiologist a few weeks after their surgery.

Children living interstate will need to see their cardiologist soon after arriving home. An appointment will be made with your cardiologist soon after your arrival back in your home state.

Your child's behaviour at home

A stay in hospital causes disruption for children and it may take some time for your child to return to their normal routine. Once you leave hospital, you may notice a regression in your child's behaviour (e.g. recently toilet trained children may begin to wet or soil again).

Your child may cling to you and refuse to let you out of their sight or wish to be held all the time. This behaviour can happen even if you have stayed with them throughout their time in hospital.

The routine for siblings can also be affected, so you may notice that their behaviour changes as well. Some siblings may show jealousy towards the child that stayed in hospital as they may feel that they are not receiving equal levels of attention.

Providing reassurance to all children and returning to your normal family routines should help to re-establish normal behaviours. If you have any concerns about your child or their siblings, discuss this with your child's doctors.

Caring for yourself during your child's stay

We recommend that you take care of your own health so that you are not too anxious or tired when the time comes to take your child home. After their surgery, caring for your child and any siblings can become quite demanding.

To stay healthy, you should try to make a plan that works for your child's and family's needs. When you can, take the opportunity to sleep, eat well and exercise.

Some suggestions for looking after yourself include:

- alternate hospital stays by parents and carers so one can sleep while the other stays with the child in hospital
- take time out when a relative or friend can sit with your child
- limit the number of visitors (particularly those you feel you need to entertain)
- take up offers of help from family and friends (e.g. cooking meals, doing laundry, looking after your other children)
- take a walk away from the hospital (e.g. walk down to the gardens or to the park).

It may also be less stressful to limit the number of phone calls you need to answer while in hospital. Try sending a group message instead to update family and friends about your child. The social work department and other allied health professionals are available throughout your stay at RCH if you need support. Please ask the beside nurse to place a referral for you.

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