

Your child's cardiac surgery admission

Information manual for parents



heart
centre for children
the children's hospital at Westmead



This information booklet outlines the care your child will receive before and after their cardiac surgery at The Children's Hospital at Westmead. The aim of this booklet is to make you as prepared as possible for this challenging time in your family's life.



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Heart Centre for Children



Welcome to the Heart Centre for Children

The Heart Centre for Children (HCfC) is based at The Children's Hospital at Westmead and is part of the Sydney Children's Hospitals Network Cardiac Services. We perform over 550 surgeries and 200 catheterisations, and see over 3,500 children with heart conditions each year.

Your child may be booked in to have an operation, have already had one, or you may just be curious about what to expect should they need to come in to the Hospital. This guide is intended to give you as much information as possible and you can find even more on our website,

www.heartcentreforchildren.com.au

or by calling us on (02) 9845 2345.

How you can help

Did you know that most of the funding for the research that we do in to the causes for congenital heart disease and how to care for kids and families, as well as much of the equipment we need (like echo machines and cardiac monitors) comes from donations from the community? Every dollar goes a long way at the Heart Centre for Children – and always goes directly to where it is most needed. If you'd like to help us in some way, please let one of our staff know, email us hcfc.schn@health.nsw.gov.au or call the Heart Centre Manager on (02) 9845 2326.

Staff



Cardiology and Cardiothoracic Team

This team of doctors consists of Surgeons, Cardiologists, Cardiology Fellows, a Registrar and a Resident. In the Intensive Care Unit, the Intensive Care team will manage your child's care, working in partnership with the Cardiac team. On the ward, the Resident and Registrar are based on the ward and will be caring for your child in consultation with the Cardiologists and surgeons. Every morning in ward rounds, members of the cardiac team will review your child and plan their care for the day.

Your cardiologist will remain informed of your child's progress but may not be present on ward rounds.

Nursing Unit Manager

The role of the Nursing Unit Manager (NUM) is to support staff and patients and their families. If you have any problems that you are unable to discuss with the nurse looking after your child, the NUM is a good person to talk to.

Clinical Nurse Consultant

The Clinical Nurse Consultant (CNC) is a registered nurse who leads and consults in a particular area of care across the Hospital and is available to advise and support families, other nursing staff and medical staff. CNCs have a role in co-ordinating your child's care as well as coordinating discharge from hospital and referral to community supports.



Preadmission Clinic Nurse

The Preadmission Clinic Nurse will guide and support you through Preadmission Clinic, organising for consultations with medical and anaesthetic staff as well as providing direction to the various tests your child will have done. You will also have time to discuss with the nurse any concerns you have regarding your child's surgical admission.

Nursing Staff

The nursing team consists of Clinical Nurse Specialists (CNS), Registered Nurses (RN) and Enrolled Nurses (EN). Each shift you will be allocated an RN, and possibly an EN also, to manage the daily care needs of your child. A team leader is allocated for each shift and is also available if you have any questions or concerns.

Child Life Therapist

The Child Life Therapist's aim to minimise the stress associated with hospitalisation and support children and their families to cope more positively with their healthcare experience. The Child Life Therapist educates and prepares children for treatments and procedures, provides distraction during potentially stressful events and teaches coping strategies. They also provide a range of developmentally appropriate play experiences during hospitalisation to promote growth and development, encourage self-expression and build self-esteem. See page 22 for more information.

Aboriginal Health Education Officer

The Aboriginal Health Education Officer (AHEO) helps indigenous families access appropriate support services and resources at The Children's Hospital Westmead and in the community. The AHEO is available to talk with about problems, concerns and complaints. They can help with arranging a place for you to stay while your child is in hospital. They can also help organise transport for people who live in remote communities and in some cases for people who live locally.

If you would like to see the AHEO while you are in Hospital, just ask any hospital staff member to contact the AHEO for you. Alternatively, you can visit the Social Work Office and make an appointment. The AHEO is based in the Social Work department on level one, 8am – 5pm Monday to Friday (opposite the lift at the bottom of the walkway ramp).

Psychologist

The Heart Centre for Children has two psychologists dedicated to providing emotional care and support to infants, children, young people and families affected by heart disease. Some of the ways we can help include:

- providing an opportunity to talk about your experiences, worries or concerns
- helping children and young people to cope with difficulties they may be having
- supporting siblings, grandparents and extended family members

Support is available to families at any stage and can be arranged by calling our Psychological Care Team directly on (02) 9845 0088.

Research Team

The Heart Centre for Children has a number of researchers who are interested in better understanding the causes of congenital heart disease and improving treatment and long term outcomes. A member of the research team may approach you to discuss research studies that may be relevant to your child.

Social Worker

The role of the Cardiac Social Worker is to provide emotional support, counselling and practical assistance to children, parents and families during diagnosis, treatment and hospitalisation. The Social Worker can help with a range of issues such as dealing with the stress associated with your child's illness or cardiac condition, accessing hospital and community services, family and relationship concerns, parenting and financial difficulties. Families are also supported during times of crisis related to their hospital stay.

It is important to identify your family and child's needs, strengths and resources (both psychological and external supports) during these times. Research has found that parental coping has a direct impact on the child's coping.

The Social Worker will meet with most Paediatric Intensive Care Unit (PICU) patients and families, patients with complex cardiac conditions and those who are in hospital for an extended period. Other families are seen on a referral basis or you can request to see a Social Worker anytime.

The role also involves education, advocacy, consultation and liaison with other organisations and support groups.

To contact the Social Work Department during normal business hours, phone (02) 9845 2641. After hours for urgent needs, you can contact the on-call Social Worker by calling the hospital switchboard on (02) 9845 0000.

Physiologist and Sonographer

During your stay, you will meet a Cardiac Physiologist. The Physiologist is responsible for doing some of the cardiac tests, including electrocardiograms, Holter monitoring and sometimes pacemaker checks. They will also help with vital signs monitoring during your child's surgery.

You will also meet a Sonographer. The Sonographer will perform the cardiac ultrasounds (echocardiogram), before, during and after your child's surgery.

Travel & Accommodation

Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)

If you live more than 100km from the Hospital, some of the costs incurred for accommodation and other travel expenses may be covered by this scheme. Check with your local IPTAAS office before your child's admission to hospital to find out if you are eligible.
www.health.nsw.gov.au/living/transport/iptaas.html

Accommodation at The Children's Hospital at Westmead

There is no bedside accommodation available in the PICU, however there is a Parent Hostel on level two, which is available if accommodation is required for parents only (unfortunately no children can stay here). As beds are subject to availability and cannot be guaranteed, it is important to organise this in advance wherever possible. Priority is given to parents of children in PICU. Please phone the Accommodation Coordinator on (02) 9845 2958 to discuss the accommodation options prior to admission.

A single, fold-out bed is available to one parent per child throughout your child's stay on the cardiac ward, Edgar Stephen Ward (ESW). The bed is positioned so that your child and emergency equipment can be easily accessed. There are also two parents' rooms located on the ward which you may be able to use, subject to availability.

Accommodation near the Hospital

Some of the accommodation options near The Children's Hospital at Westmead are:

Ronald McDonald House

The Children's Hospital at Westmead
(02) 9845 0600

Note that this is only available to families with children that need somewhere to stay and depends upon availability.

Wesley Lodge Motel

175 Hawkesbury Road
Westmead, NSW 2145
(02) 9635 1233

Wesley Apartments

30 Hainsworth Street
Westmead, NSW 2145
(02) 8094 1691

Chisholm Cottage

49 Alexandra Avenue
Westmead, NSW 2145
(02) 9633 4228

Motel Formula One

377 Great Western Highway
Wentworthville, NSW 2145
(02) 9769 0763

Parramatta Central Motel

32 Station Street
Parramatta, NSW 2150
(02) 9633 4311

Caulta@Parramatta

541 Church Street
Parramatta, NSW 2150
(02) 9654 0030

Absolute Waterfront Apartments

Various Locations
Parramatta, NSW 2150
(02) 8843 1300



Preparing your child for cardiac surgery

Admission to hospital for a surgical procedure can be a considerably stressful and often frightening time for families. The health care team have roles in preparing you and your family for your hospital experience, beginning at the initial consultation with the Cardiologist and Surgeon. The Preadmission Clinic and material like this booklet aim to better prepare you and your family. In addition to this, there are age-appropriate practices you can do at home to prepare your child for their hospital stay.

If your child is of pre-school age, a brief explanation the day before admission is appropriate, eg. "We're going to stay at the hospital for the next few days. The doctor will do an operation to help your heart work better".

Your child may have a more developed understanding that they have a heart problem, allowing for a more in-depth conversation of why they need the procedure. For these children, this preparation is most effective if commenced a week before hospitalisation. Medical play can be very beneficial for these age groups. Staying at the bedside overnight and during the day with your child is very beneficial to your child and is highly encouraged by the ward. (See the accommodation section on page seven).

Older children and adolescents may request more in-depth information and a longer preparation period. However, as with children of all ages, their personality will play a role in the depth of preparation they need. Some older children will request tours of the Paediatric Intensive Care Unit and the ward and want to know every detail of what will happen to them. For others, this experience might actually increase anxiety levels. Your child will often tell you what they want to know.

It is very important to involve children of this age in decision-making regarding their treatment. This gives them a sense of control over the situation. For certain procedures, staff will often allow for reasonable negotiation with your child as to when the procedure occurs. The Heart Centre team have a great deal of experience with children of all ages, so feel free to involve them at any point you feel necessary.

As a parent you must also cope with your own anxieties whilst keeping calm for your child. Please call on the Cardiac Clinical Nurse Consultant before the operation or hospital staff to answer any questions you have during your stay. Children pick up on your anxiety levels and the more prepared you are, the calmer they will be.

For more information

The Kids Health Bookshop is located on level two and has books that may help prepare your child for their hospital stay.

There are also guides for all ages in the FAQ section of our website, www.heartcentreforchildren.com.au.



Preadmission clinic



Your child will need to attend the Cardiac Preadmission clinic on the Friday prior to their operation. The Cardiac Preadmission Clinic is held in the Heart Centre for Children, located on level three. This clinic provides an opportunity for the team to collect information about your child that will be needed for his/her surgery and use this as a baseline for your child's progress. The clinic also gives families a chance to ask questions about the planned surgery, and become familiar with the hospital environment.

Preadmission Clinic Nurse

The preadmission clinic nurse will guide you through the clinic, organising for consultations with medical and anaesthetic staff as well as directing you to the various tests your child will have done. You will also have time to discuss with the nurse any concerns you have regarding your child's surgical admission and be shown the ward and intensive care unit. The availability of these tours will depend on how busy the clinic and units are on the day.

The Preadmission Clinic begins at 9am on Fridays. You can phone the Preadmission Nurse on (02) 9845 2345

Tests

At the clinic, routine baseline tests will be required to assess your child before surgery.

Echocardiogram (echo) – performed in the Heart Centre for Children clinic

Commonly known as a cardiac ultrasound, an echo uses sound waves to obtain a detailed picture of the inside of the heart and its structures, displayed on a screen.



Electrocardiogram (ECG) – performed in the Heart Centre for Children clinic

This is a non-invasive recording of the heart's electrical activity taken using numerous leads stuck on the skin. It is a quick, painless procedure that requires the child to hold still for a few minutes.

Chest x-ray – performed in Medical Imaging, level two

X-rays assess your child's heart size and shape and how clear the lungs are. A current x-ray is required.

Blood tests – performed in Pathology, level two

It is necessary to check the basic components of the blood and to process a cross match. This enables blood products to be readily available should your child require blood during or after their surgery.

Preadmission clinic

Observations

Basic vital signs include temperature, heart rate, respiration rate, blood pressure and oxygen saturation. Your child's circulation and neurological status will also be assessed. This is achieved by feeling your child's pulses in their arms and legs and by determining if their limbs are equal in movement and strength.

Weight and height

This is needed to correctly calculate medication and anaesthetic drug doses for your child.

Infection checks

A sample is obtained from the nose, throat and possibly groin region to detect the presence of bacteria naturally occurring on the skin. These swabs are obtained three weeks prior to surgery in order to identify and treat if any organisms are present. You will be given a request form when you meet with your child's surgeon. The swabs need to be taken at your local pathology service. The results will be followed up by the Preadmission Nurse and you will be contacted if treatment is required.

Nursing admission

This helps the nursing staff get to know you and your child a little better. The nurse will ask you information about:

- allergies – including food, medicines, tapes or latex products
- immunisation status
- regular medications
- your child's feeding routine – breastfed, formula, type of bottles/teats, how often they feed, normal appetite etc.
- toileting habits – toilet trained or nappies, regular bowel motions
- history – including previous surgeries, other health problems such as asthma, eczema, hearing or sight problems
- child's developmental and activity level
 - interaction, walking, tiredness etc.

Medical assessment

The Cardiac Registrar or Resident will complete a medical assessment of your child. These doctors will be responsible for your child's general day-to-day care during their ward stay.

Anesthetist Review

The Anesthetist will manage your child's anaesthetic during the operation and will meet with you and your child during Preadmission Clinic. It may be useful to list any questions you have.

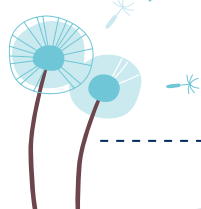
Research

One in 100 children are born with Congenital Heart Disease (CHD). CHD accounts for a high proportion of infants and children requiring hospitalisation, surgery and treatment in intensive care units. Research is an essential component of the Heart Centre for Children and enables us to develop a better understanding of CHD to continue improving the treatment available to these children.

Various research studies take place within the Heart Centre. At the Preadmission Clinic prior to your child's procedure, or when admitted to the Hospital, you will be approached by members of our research team about specific research studies. You will be provided with information and have the opportunity to ask questions. Participation in a study is completely voluntary. Your decision not to participate in research will not affect your child's care in any way. It is simply an opportunity to assist us in better understanding CHD and to provide the best possible treatment for children born with heart problems now and in the future.

Tours of the PICU and ESW

We aim to provide tours of the PICU and the ESW to children and families during their Preadmission Clinic visit to prepare them for their stay, however at times this is not possible due to clinic staff availability and how busy the units are on the day.



The days before surgery

Middleton Day Surgery Ward

Middleton Ward nursing staff will call you three days before your child's surgery date. Middleton Day Surgery is the ward through which you will be admitted on the day of your child's surgery.

During this phone call the nurse will ask you questions related to how well your child is. You will also be given estimated arrival times.

The day before surgery, Middleton Ward nursing staff will call you between 2pm and 7pm with finalised arrival and fasting times.

Where is Middleton Day Surgery Ward?

Middleton Day Surgery Ward is on level three. A glass lift is on the left hand side of the main entrance, opposite the Emergency Department. Take this lift up to level three, cross the bridge and follow the signs.

What do I need to bring with me?

- Medicare Card
- Any x-rays/scans that are relevant to the procedure
- Your child's usual medication (if taking any)
- Clean pyjamas
- Nappies, bottles, formula, sterile water, a favourite toy, dummy
- Activities for your child and for yourself

Please remove all of your child's jewellery and nail polish prior to arriving. We suggest that you leave any valuables at home.

Cancellations

Whilst all possible planning has been undertaken for your child's surgery to proceed, you should be aware that it may be necessary to reschedule the date of surgery. The reasons for this may be that unexpected, urgent cases may need to be fitted into the surgery schedule, there may be a lack of beds in the Hospital or your child may be unwell due to a cold or infection.

The Cardiac Surgeon will make the decision to reschedule surgery if one of these situations occurs. They will nominate a new date for surgery and inform you within a day or so. If your child's surgical date is changed before admission, you will be contacted by the Hospital's Booking Office who may also be able to inform you of the new date for surgery. If you wish to discuss the deferment of your child's surgery further, please contact your surgeon's office directly.

Who can accompany my child?

- No more than two adults may accompany your child to the Day Surgery Ward.
- No other children are allowed in Middleton Ward. If you have other children, please make alternative arrangements for their care (exceptions are made for mothers with breastfeeding babies). Sibling Care is available at the Hospital from 9am – 3pm. There is a small fee for this service. Please phone the Volunteer Service on (02) 9845 3840 to check availability and make a booking.

Fasting

Fasting times (when your child cannot eat or drink anything) must be followed strictly. It is very important that your child's stomach is empty before an anaesthetic, to help prevent any complications. Please make sure you write down these times and follow them exactly.



The day of surgery

Admission

You will be admitted through Middleton Day Surgery Ward by the receptionists and admission paperwork will be finalised. You will then be directed to the waiting room.

A nurse will complete your admission. This includes taking some observations such as weight, temperature, heart rate, breathing rate, blood pressure, oxygen saturation and a general assessment of your child.

The nurse will confirm fasting times and consent. Identification bands are checked and put on your child's arm and leg to ensure correct identification.

The process of 'going to sleep' and options will be discussed with you and your child. Your child can go to sleep with a vapour anaesthetic via a mask, or your child can have a small plastic cannula inserted into a vein for the anaesthetic to be administered through. If your child chooses to have a cannula, nursing staff will apply cream that will numb the area.

Premedication

Some patients will be given a premedication. This is usually in the form of a small dose of syrup medicine or tablets. It generally makes the child feel relaxed and a little drowsy so that they feel less anxious about the surgery.

If your child is given a premedication, it is important that they remain in bed to prevent injury while they are drowsy. A 'purple egg' (television) is usually set up for your child to watch and act as a distraction.

The Anaesthetist will review the child and discuss any anaesthetic issues and post operative pain medication with parents.

Accompanying children to theatre

One parent can accompany their child into the anaesthetic bay until the child has gone to sleep. A volunteer will accompany you into and out of theatre.

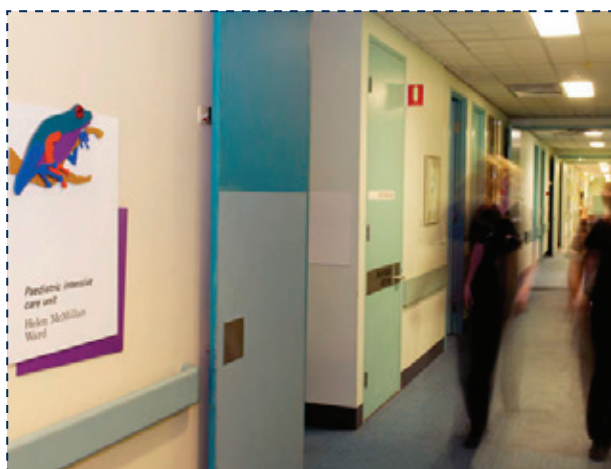
While your child is in theatre

Depending on where your child is intended to go after his/her operation (Usually NICU, PICU or ESW), you may be asked to leave your mobile phone number or be given a pager so that the theatre staff can contact you when your child's operation is over.

The surgeon or anaesthetist is generally able to give you an idea of how long surgery is likely to take. It is a good opportunity to go for a walk or get something to eat and drink. If you are given a pager, these have a range of over 50km so you can quite safely leave the Hospital if you wish to and you will still receive the message.



Paediatric Intensive Care Unit (PICU)



It is strongly recommended that you come to visit the PICU prior to your child's surgery so you and your child can familiarise yourselves with the environment. Please request this during your visit to the Preadmission Clinic.

You must wash your hands or use the antiseptic liquid which is supplied at the door of the room before entering and when leaving your child's room both in PICU and the ward.

The day of the surgery

Prior to your child's arrival into the PICU you will be paged and shown to a room where you will have a chance to speak to your child's Surgeon immediately after their surgery.

There will be a delay before you can visit your child in PICU. This is to help stabilise your child after returning from the operating theatre. One of the nursing staff will show you to your child's bed.

Parents / Guardians

- Parents/guardians are able to visit at any time, however, there may be times where access to your child is restricted during an emergency or a procedure.
- There are no facilities for parents to sleep at the bedside as it is important for the staff to have full access to your child. It is also important for you to get some rest overnight so you can be there for your child during the day.

- There is a Parents' Hostel available at a nominal cost for parents to sleep in within the Hospital during the child's admission. This room has a phone so that you can ring your child's bedside directly. The nursing staff will phone you in the hostel if your child needs you. Please refer to the accommodation section for further information.

Visitors

- Other visitors can visit between 10am and 12pm, or 3pm and 8pm. Please keep visitors to a minimum in PICU to reduce the risk of infection.
- Your child's siblings can visit as long as they do not have an infectious illness and have not been in contact with other infectious people.
- Visiting by children other than siblings is discouraged.
- Only three visitors (including parents/guardians) are allowed at the child's bedside.
- Visitors should be accompanied by parents/guardians unless prior arrangements are made by the parents/guardians with PICU staff.
- For confidentiality reasons, information about your child is only given to the parents/guardian. Please ask other relatives/ friends to call you for information rather than the PICU staff.
- Please ask visitors to use the phone outside PICU to ask for access to the unit.

Facilities

- Parent's Lounge with microwave and tea making facilities.
- Waiting area for other visitors outside PICU.
- If you are breastfeeding, there is a facility for expressing and the storage of your breast milk. Your bedside nurse can organise for someone to show you where this is. A Lactation Consultant is available if required. Speak to your PICU nurse for more information.

Paediatric Intensive Care Unit



After Surgery

When you first see your child after their heart surgery they will be connected to many pieces of equipment. This can be very overwhelming and the bedside nurse will explain the things connected to your child. Most of these things are listed below.

PLEASE NOTE that your child may not have ALL of these things.

The machines connected to your child make a variety of noises and have a number of different alarms. The nursing staff may seem to ignore the alarms, however they are very experienced and know which ones require urgent attention and which ones are normal.

The breathing machine (ventilator)

- The ventilator is attached to a breathing tube in your child's nose or mouth.
- The ventilator assists your child's breathing.

- Your child will need to have their breathing assisted by the ventilator until they are stable and are able to fully support their own breathing again.
- The breathing tube will need to be cleared of secretions periodically with suctioning by the bedside nurse.

Nasal prongs and face mask

After the breathing tube and ventilator is removed, your child will usually require oxygen. Oxygen is delivered through nasal prongs or a face mask.

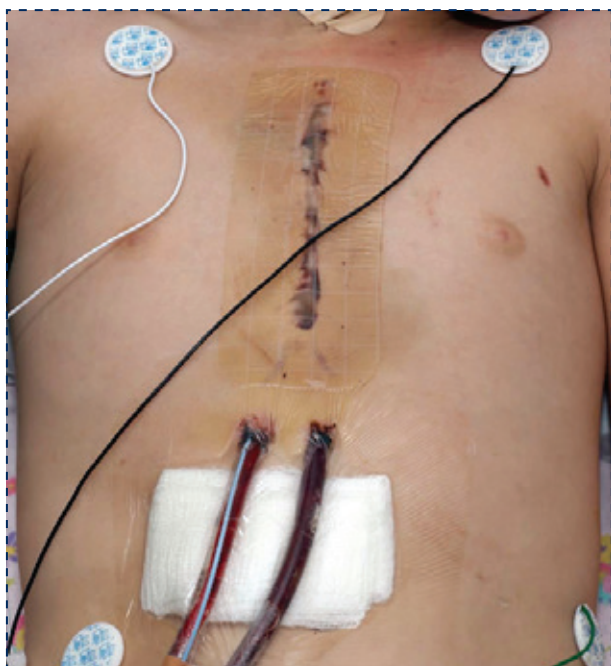
Gastric tube

- This tube is inserted into the nose/mouth and goes into the stomach so that stomach juices and air can be removed from your child's stomach to help prevent vomiting.
- Medications can also be given to your child through the gastric tube.
- Your child can also be fed through the tube, if necessary.

Paediatric Intensive Care Unit

Chest drains

- Between one and four chest drains will be placed in your child's chest during surgery.
- They are used to drain blood and fluid from around the heart and lungs.
- These chest drains are removed when there is minimal drainage. This can be as early as the first day after operation but may take longer.
- Some chest drains are used to remove unwanted air from around the lungs. These are removed when there is no more air draining.



Monitoring or pressure lines

- Arterial line: This is usually in the wrist and is used for monitoring your child's blood pressure and is a source for taking blood for tests. This is removed before going to the ward.
- Central venous catheter: This is usually placed in the neck into a big vein so that medications and fluids can be given through it. This is usually removed before going to the ward.

In many cases, the Surgeon places pressure lines directly through the chest wall into the heart. These lines may be in the left atrium, right atrium or the pulmonary artery. The purpose of these lines is to monitor pressures in different areas of the heart. These lines will be removed before your child is transferred to the ward.

Peritoneal Drain (PD)

- Often a drain is placed into the abdomen to drain fluid that may collect there.
- Some children can have reduced kidney function after heart surgery. If this occurs, the peritoneal drain can also be used temporarily to clear unwanted fluid and chemicals.

Urinary catheter

- This is a tube that is inserted into your child's bladder. The purpose of this is to accurately measure and monitor your child's fluid needs.

Pacing wires

- Some children have a change from normal heart rhythm after surgery.
- Many children having open heart surgery will have small wires placed on the surface of the heart during the operation.
- If the pacing wires are required they will be attached to a pacemaker box which will help coordinate your child's heart rhythm.
- Pacing wires are temporary and if not required will be removed prior to leaving PICU.

Other equipment

- Bedside monitor: This is the screen at the top of the bedspace and is used to continuously monitor body functions such as heart rate, blood pressure etc.
- Syringe pumps: These are at the bedside and are used to administer medications continually.

Paediatric Intensive Care Unit

Fluid restriction

It is very important that you do not allow your child to have any more than the nominated amount of fluid as this may slow their recovery.

After their surgery your child will only be able to have small amounts to drink. This is to prevent extra workload for the heart. This amount will increase gradually over the days following surgery until they are allowed to have as much as they want. The staff will tell you as these changes happen.

If your baby is breastfed you will be unable to do so for the first few days after the operation. You will need to express milk which can be given to your baby in measured amounts either through a bottle or through the gastric tube. Breast pumps are available in private rooms on both ESW and Grace Neonatal Intensive Care Unit (NICU) to allow you to express milk until your child is able to breastfeed.

It is very important for staff to monitor your child's fluid balance.

Please keep the nurses updated about how much fluid your child drinks as well as when you change a nappy or they pass urine.

Pain relief

Your child's pain will be managed using a combination of drugs and techniques.

Initially they will be on a continuous infusion of opioid, such as morphine, through a line into their vein, with additional oral medicines to keep them comfortable. They may also have a button for either the nurse or your child (depending on their age) to give them additional medicine through the intravenous line when they need it. This infusion pump has programmed limits so your child cannot receive too much medicine.

A pain management team exists specifically to assist with the management of your child's pain and will see your child on a regular basis while they are on the infusion.

As their condition improves, the infusion will be turned down until they are comfortable only on oral medicines, such as paracetamol and oxycodone.

Other measures can also be taken to ensure your child's comfort, such as holding a pillow/folded towel to their chest when they cough, distraction etc.

The nursing staff will assess your child's pain regularly, however if you feel your child is in pain please tell the staff and they will do their best to make your child comfortable.



Physiotherapy



Children often need physiotherapy following chest surgery to help prevent and decrease lung complications.

Following an anaesthetic and surgery it is common for children to have increased secretions in their lungs. After the surgery, children will be less active than normal. This results in the child being unable to take a deep breath or cough effectively to clear the secretions.

The Physiotherapist may use several techniques to help clear secretions, depending on the age of the child. Children usually find these activities easy and fun, such as blowing bubbles!

Sometimes it can hurt a little to cough or to take deep breaths after chest surgery. This is why the Physiotherapist will often call ahead to arrange a time for treatment. That way we can fit in with optimal pain relief and feeding. If your child was walking prior to the surgery, the Physiotherapist will also help to increase your child's mobility.

Edgar Stephen Ward



Edgar Stephen Ward (ESW) is a 18-bed unit dedicated to the care of babies, children and adolescents with cardiac defects and diseases.

We believe our role on ESW is to deliver holistic care and act as an advocate for children and their families. The first thing you will notice is that ESW has a very different set-up to PICU. The main reason for this is that your child will be more stable and require less intensive monitoring. The staff on ESW encourage positive staff-patient interaction to help the child feel more comfortable about their stay.

Visiting hours and Conditions

Visiting Hours:

Parents and guardians may visit their child anytime.

General visitors are welcome:
10.30am – 12 noon and 2pm – 7.30pm

ESW does have specific visiting hours. The children on the ward may be very unwell and the families are going through a stressful period. Specific visiting hours are enforced to give patients adequate rest to aid in their recovery.

We ask that these visiting hours are strictly followed for the consideration of ALL patients on the ward.

The transfer from PICU to ESW

Usually the day of transfer to the ward is a busy one. Many lines and drains will be removed before the transfer to the ward but not necessarily all of them. It all depends on your child's own unique recovery.

Your nurse on the ward usually has three or four other patients to care for. This is because your child is now stable enough to have less intensive care. If you need a nurse for anything at all you can just use the buzzer and they will attend to you as soon as they can.

Now that your child requires less intensive nursing, we will support you in resuming normal care of your child. You will be able to cuddle your child and take over activities like changing nappies and feeding as you feel comfortable to do so. One parent is encouraged to stay by the bedside overnight on a fold-out single bed. No more than one person is allowed to stay at the bedside overnight to make sure the nurse can access your child easily.

A Dietitian, Social Worker, Physiotherapist, Speech Pathologist and also Child Life Therapist regularly visit the ward. The Cardiology Resident and Registrar also base themselves on the ward as well as taking care of children on other wards.

Your child may be in minimal clothing whilst in PICU so that they can be adequately assessed and cared for. However once on the ward, you are encouraged to dress your child in their own clothes so they can start feeling more comfortable. Clothes that open over the chest are essential and also clothes that don't cover the feet so that saturation probes can be changed regularly.

If your baby settles with wrapping, the ward has a supply of wraps. You are also encouraged to bring your own. If your baby drinks from a bottle it is suggested that you bring your own familiar bottles as this helps your child with feeding after their operation. Please also bring teats etc for bottles. Milton sterilising is available on the ward and Milton containers are changed by the nursing staff each night.

Edgar Stephen Ward

You may need to bring nappies for admission, however ESW has a stock of nappies so you are not required to use your own nappies during your stay on the ward.

Holding your child for the first time after the operation can be a little daunting for some parents. The nurses will help you with this as it is important and comforting for both the child and family. Please make sure when you lift them that you do not pick them up under the arms as this may cause pain. It is best to cradle them like a baby.

Observations

Observations are necessary to see how your child is progressing and the frequency of these is determined by your child's condition. Blood pressures, heart rates and temperatures may need to be taken hourly at first, becoming less frequent as your child's condition stabilises. Saturation probes need to be moved every two hours.

Staff try to disturb children as little as possible. Sometimes we leave observations until your child is awake, however at times we may need to perform tests/observations when they are asleep. We all have the best interests of your child in mind at all times.

Fluid restriction

Please page 16 for more information about fluid restriction.

Daily Weighs

Your child will need to be weighed every day so that staff can assess their progress. It is important this is done at the same time everyday with as little clothing on them as possible, preferably first thing in the morning before a feed. This is to make sure the measures are accurate.



The incision/scar from the operation

- If your child is having open heart surgery, they will have an incision (cut) either down the front, middle of their chest (sternotomy) or around the left side of their chest (thoracotomy).
- The stitches that hold these incisions together are dissolvable.
- This incision will be covered with a dressing that will be removed and the site cleaned before discharge or seven days after the operation.
- Your child will also have small incisions from where the drains were removed. These will have smaller dressings on them that will be changed daily. There may be a stitch at this site which will be removed about five days after the drain is removed.

Edgar Stephen Ward



Night time on the ward

Three nurses usually work the night shift on ESW. If you cannot find them, they may be attending to another patient. Please press the buzzer once and they will come as soon as they can.

The nurses still need to do observations on your child during the night time. Every effort is made to not to disturb your child, however at times this may be difficult, so we ask for your patience and understanding. Night staff try to work quietly and avoid turning on lights wherever possible but there are times when a light does need to be turned on to assess your child.

To allow access to your child overnight, as well as for the safety of nursing and medical staff, please return all furniture, bags, toys and televisions to their storage areas. Check with your evening nurse where to position your fold-out bed.

If your child drinks overnight, if you change a nappy or they go to the toilet, please let the nurse know so that we can keep a record of their fluids.

Breastfeeding



Information for breastfeeding mothers

Cardiac surgery is a significant event that may affect your milk supply and your baby's ability to breastfeed before and after surgery. Your breast milk is very important to your baby because of the protection it provides and this is especially important at this time. However, after cardiac surgery there may be some factors that need to be considered when re-establishing breastfeeding.

The cardiac team, in conjunction with the Hospital Lactation Consultants and the Child and Family Health CNC, are here to help and support you through this process. Breastfeeding remains a personal decision and the team will support you in whatever feeding decision you feel is best for you and your baby.

Please ask to see a Lactation Consultant or Child and Family Health CNC if you need support with breastfeeding or expressing during your stay. For more information, please refer to the breastfeeding and cardiac surgery factsheet (available at www.heartcentreforchildren.com.au) which provides a guide to some of the issues that may be experienced.

You can also visit the ABA website at www.breastfeeding.asn.au or call the breastfeeding helpline on **1800 686 2686**.

Play in Hospital

Child Life Therapy

A hospital stay can be a challenging and unfamiliar experience for children and their families. Recognising this, the Child Life Therapy team aims to minimise stress and promote effective coping by providing play, education and self-expression activities.

Before admission, the Child Life Therapist is available to help prepare your child for surgery and hospitalisation. This is done using a variety of developmentally appropriate resources, including photographs, social stories, medical play and visits to certain areas of the Hospital. If you feel your child would benefit from this, it is recommended that you phone the Child Life Therapy Department on (02) 9845 3717 prior to your child's Preadmission visit.

During admission, the Child Life Therapist can provide support in the following ways:

- assisting children to develop coping strategies, such as imagery and deep breathing, to reduce anxiety
- providing support during medical procedures and utilising distraction techniques to help children focus on something relaxing and engaging
- offering therapeutic play activities that help children to express their feelings in a safe and non-threatening environment eg. playdough, painting and feeling charts
- providing developmental play experiences to normalise the environment
- creating sticker or goal charts to assist in medicine taking, behaviour management and adjustment to new treatments

Playroom

Toys, books and a variety of other resources are available in the playroom on the ward. If you would like to use this space during your hospital stay, speak to nursing staff to get the key. Please ensure you leave it neat and tidy when leaving. A playgroup is held in the playroom once a week for patients and their siblings.

Starlight Room

The Starlight Room, located on level two, is available for patients and siblings. It has a wide range of fun activities, including movies, art and craft and video games. The Starlight Captains regularly visit the ward and children who are not yet able to leave the ward can join in the fun with Captain Starlight Shows being broadcast to their bedside TV's.

Livewire

Livewire is an innovative program dedicated to meeting the needs of adolescents within the Hospital setting. This program helps to transform the hospital experience through ward-based activities, special workshops and providing space for young people to interact.

Clown Doctors

Clown Doctors visit all wards, including PICU. They help treat children with medicine of a different kind... fun and laughter!

Therapy Dogs

Therapy Dogs visit the wards of the Hospital every Wednesday afternoon, providing comfort to children and their families.



Feeding issues



Malnutrition and poor growth are both common in infants and children with cardiac disease. This may be because of:

- tiring easily while feeding, leading to low total intake
- fluid restriction
- poor absorption
- increased energy expenditure
- early satiety (feeling of fullness)
- poor appetite
- frequent infections
- frequent use of antibiotics, affecting gut bacteria

Sometimes your baby will need help with feeding. They may need a nasogastric tube (see PICU section) to allow them to get their daily volume without using too much energy. They may also need a feeding tube if they have not developed the ability to suck for feeds. Speech Pathologists and nursing staff are able to assist with helping your child learn this skill. This can be a very stressful experience for families, but it is quite normal following cardiac surgery.

Your baby may be sent home with a tube if feeding issues do not resolve in hospital. If so, you will be provided with education about tube feeds and how to manage them. Appropriate community follow up will be organised to help your baby transition back to normal feeds.

The role of Dietitians

Your doctor may recommend a Dietitian review. There is a Dietitian available in PICU and on the cardiac ward.

The Dietitian recommends breastfeeding or expressed breast milk as the optimum feed for infants with cardiac disease. If your child is not growing properly, breast milk can have calories added. If your child is not breastfed, the Dietitian can organise infant formula.

If your child develops a chylothorax (lymph fluid around the lungs), a special formula and/or diet will be recommended.

The role of Speech Pathologists

Speech pathologists don't just help with speaking. They are also involved in helping babies and children with feeding and swallowing problems. They also work with older children with delayed speech and language development. Babies with cardiac conditions may:

- tire during feeding
- have reduced strength of suck, although oral movements may be appropriate
- not wake easily for feeds
- be disinterested in eating, particularly if they have had long-term Nasogastric (NG) feeding
- have poor weight gain

A Speech Pathologist can help by observing a baby feeding and making changes to their feeding regimen, the equipment used or the feeding technique. They work closely with the family to promote pleasant feeding experiences and aim to get the baby feeding to their full capacity.

Incentives and support

Additional support and resources

The Children's Hospital at Westmead (CHW) supports patients and their families in a variety of ways. Many of these are outlined in the Parent's Handbook available on their website. www.schn.health.nsw.gov.au/files/attachments/parent_handbook.pdf

Heart Beads

The Heart Beads Program allows your child to collect unique beads for the different heart procedures and treatments they have gone through during their stay in hospital. At the preadmission clinic or after being admitted to the ward, you will be given a brochure about the program and the opportunity to enrol and begin your Heart Beads journey. Heart beads are free and a great way to trace your child's hospital journey and reward them for their courage.

They also help your child to talk about what they have been through with family and friends. Please ask the nursing staff for a brochure if you have not already received one.

Chaplaincy Team

There are chaplains available at the Hospital to support patients and families of all faiths. You don't need to be religious to ask for support.

Please speak to a nurse if you would like to see a Chaplain. You are welcome to visit the Quiet Room any time for prayer or quiet contemplation. It is always open and located on level two, adjacent to the Starlight Room.

Volunteers

It may be possible for a Volunteer to stay with your child if you need to leave the bedside for a short time. Volunteers are also available to escort you around the Hospital if you're not sure of the way. Please ask nursing staff or the staff at the Main Entrance for more details. The Volunteers' Shop on level two stocks gift items, handmade crafts, toys and children's clothing at reasonable prices. All proceeds from this shop are donated back to The Children's Hospital at Westmead.



Ward Grandparents Program

The Ward Grandparents Program is a service available through the Social Work Department. If your child has a long admission, a trained Ward Grandparent volunteer can regularly spend time with your child if you can't be there or when you need a break.

Sibling Care

Operating hours:

Monday – Friday: 9am – 3pm

Saturday and Sunday: 9am – 12 noon

Located on level one, Sibling Care is a service run by hospital-trained volunteers and provides supervision for newborn infants to children up to six years of age, who are siblings of patients in hospital. Fees are \$1 per child per hour, however allowances are made for special circumstances, through the Social Work Department. Parents and carers are not to leave the Hospital while their child is in Sibling Care.

Discharge home

The length of your child's stay in hospital will depend on what type of surgery they had and also how well they progress.

Before discharge, your child will have tests to make sure they are well enough to go home.

Taking your child home after heart surgery can be a daunting. If you have any questions, please ask. You will be given a nursing discharge summary detailing your follow-up medication and appointments. If the medical discharge summary is not available when you leave, it will be posted to you in the mail.

Follow-up appointments

You will be given follow-up appointments with the Surgeon and the Cardiologist. Before the follow-up visit to the Surgeon your child should have a chest x-ray. You will be given an x-ray form together with the appointment cards before being discharged.

Medications

- Your child may need medication for a few weeks or sometimes longer, depending on the heart condition and the type of surgery they have had. The Cardiologist or Surgeon may adjust or stop the medication in follow-up visits.
- During your hospital stay you will be given instructions on how to give medications to your child. The more comfortable you feel about giving medications to your child while you are in hospital, the easier it will be at home.
- The Hospital Pharmacy will provide a small supply of medications free of charge. Any medications that are not readily available in the community may be purchased at the Hospital Pharmacy for a standard fee. You will be given a prescription for the Hospital Pharmacy and a separate prescription for your local chemist.

Wound care

- Your child's dressing will be removed before you are discharged, unless otherwise instructed. It is okay to clean the wound briefly and gently in the shower but it is best not to immerse or soak it in the bath until after your follow up appointment with your surgeon. This also applies to swimming pools. Please contact the Cardiac CNC if you notice any redness, swelling or oozing.
- The scar will fade with time. Once you are home you can wash the incision gently and pat dry. Avoid using harsh soaps. At your follow-up appointment, approximately two weeks after discharge, your surgeon will advise you about using moisturisers and ointments.
- The breast bone takes approximately six weeks to mend. Contact sports and lifting your child under the arms is not recommended during this time. Normal activities should be resumed after six weeks unless advised otherwise.
- Sun exposure can slow the healing of your child's scars. Protect your child's scars from direct sunlight for as long as the site looks pink and raised. It will eventually go back to their normal skin colour.

Activity

It is a good idea to keep strenuous exercise to a minimum in the two weeks after discharge. A rest during the day can be helpful.

Normal activities should be able to be restarted after the follow-up with your Cardiologist, unless they tell you otherwise. If you have any questions regarding contact sport, check at your follow-up appointments.

You may commence tummy time after your surgical follow up appointment.

Discharge home

Diet

- Your child may eat and drink as usual, unless otherwise specified. If a Dietitian has been involved in your child's feeding in hospital, it is important to follow this routine at home.
- Encourage a healthy, balanced diet that promotes healing and recovery, including fruit, vegetables, meat and dairy products. Continue a nutritious diet throughout their childhood, as this will assist in healthy growth and development.
- It is important to watch your child for signs of dehydration. These include less wet nappies, urinating less or a darker colour, dry mouth or sunken fontanelle (the soft spot on your baby's head).
- Remember to give your child extra drinks on hot days or when they have been very active.

School

It is best not to let your child return to school or day care until after the first post-operative follow-up visit. After most routine operations your child should be able to return to school four to six weeks after their operation. The Surgeon should give you an idea then of when normal activities can be resumed. If a medical certificate is required, please ask your doctor or nurse before discharge.

Immunisation

- If your child is due for immunisations it is better to wait until after the follow-up appointments. Vaccinations may cause a reaction that can be confusing when trying to determine if an illness is due to the surgery, or the side-effects of the vaccine.
- Speak to your Cardiologist to discuss when to give your child their next vaccination dose.
- Current recommendations suggest delaying the measles, mumps, rubella (MMR) or varicella vaccines for six months following cardiac surgery. If your child is due for these vaccinations, please speak to your bedside nurse or the Cardiac CNC.



Dental care

- It may seem strange, but many of the germs in our mouths are the germs that can cause infections in our hearts. It is important to encourage your child to brush their teeth at least twice every day and have regular dental check ups.
- Talk to the Cardiologist before your child has any dental treatment. They will advise you if your child needs to take any special precautions beforehand.
- Some children with certain heart defects will need oral antibiotic medication before and after dental procedures.

The first few weeks at home

Your child's routine will have been upset during their hospital admission. You can expect some temporary personality changes in your child. This is usually caused by the fairly traumatic period in hospital and lack of usual routine. During this time you need to support and reassure your child. Everything should be back to normal in a few weeks.

Complications can occur after you return home. Some warning signs of illness are:

- fever above 37.5 degrees centigrade
- vomiting
- increasing loss of appetite
- lethargy/weakness
- abdominal pain/back pain/shoulder pain
- increasing breathlessness
- dry cough
- redness/pus/excessive pain at incision site

Discharge home

What to do if you are worried

If the above problems develop or if you have any other concerns, please call the Hospital and ask to speak to your child's Cardiologist, Cardiac Nurse, or the Cardiac Fellow on-call.

Take your child to the Emergency Department at your closest hospital. Inform the emergency doctor and nurse that your child has had recent heart surgery. Give the admitting doctor or nurse a copy of the medical discharge summary.

If you see your GP or go to another hospital, it is important to let us know, especially in the first few weeks after surgery. Please call the Cardiac CNC (phone number listed at right) during business hours, or the ward after hours.

If your child looks very sick you should call an ambulance to take your child to the nearest hospital.

Phone numbers:

Cardiac CNC..... (02) 9845 2345

Cardiac Department (02) 9845 2345
(Monday to Friday 8.30am – 5pm)

Edgar Stephen Ward (02) 9845 1133

The Children's Hospital at Westmead
Switchboard (02) 9845 0000

Additional information can be found at

www.heartcentreforchildren.com.au

or by calling us on (02) 9845 2345.



