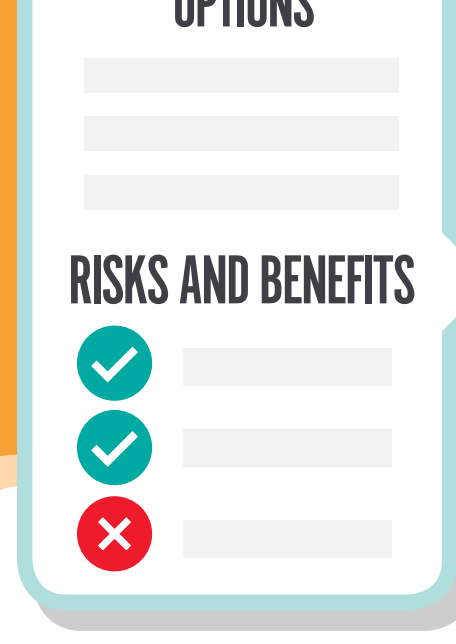


# your SURGICAL PATHWAY

The pathway below tells you more about what happens when your child has cardiac surgery. Your team may first talk to you about this in your local clinic and then refer you to Bristol Children's Hospital for specialist care.



Information from the investigations is discussed in a joint meeting with the cardiology and surgical team. Based on the information the team will consider together the options for surgical intervention.



If the team feel your child requires surgery, then you will be asked to attend a surgical clinic to talk through the options and risks and benefits of surgery.



Attending the surgical clinic



Following the surgical clinic you will receive a letter summarising your surgical clinic appointment. When the date for surgery is planned you will receive a letter inviting you to attend the pre-admission clinic and informing you of your child's admission date.



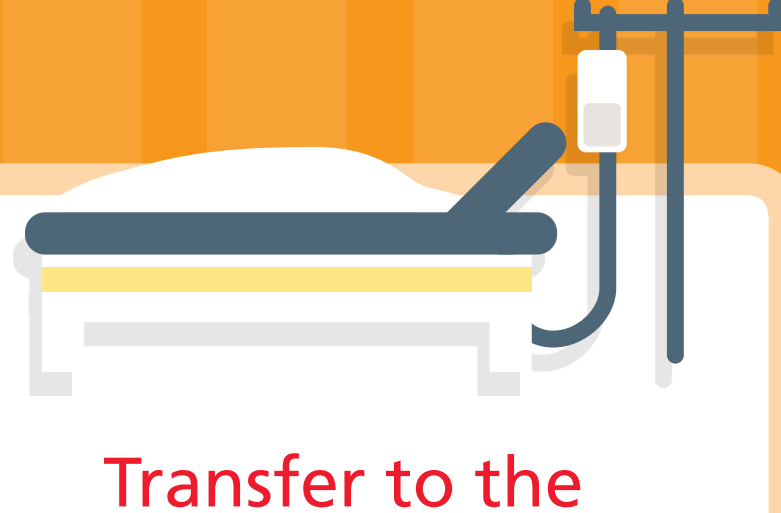
Attending the Pre admission clinic



Admission to the cardiac Dolphin ward



Coming for surgery



Transfer to the operating theatre



Admission to Seahorse Paediatric Intensive Care Unit



Transfer to Dolphin ward - High Dependency Unit



Dolphin ward



Before leaving the ward we will talk to you about aftercare and the plan for your 2 week follow up appointment.

## the OUTPATIENT PATHWAY



Aftercare information



# AFTER CARE – CARDIAC SURGERY

Recovery from Cardiac surgery will continue for many weeks after discharge from hospital. It is important to remember that your child may require prolonged periods of rest and will need to build up their stamina slowly to undertake all the activities they did before. Before you go home it is important you have all the information you need to help in your child's recovery. The key topics we will go through with you are;

- Medication to take home
- Wound care and signs of infection
- Play and exercise
- Returning to school/nursery and going on holiday
- Outpatient follow up
- Who to contact for advice

This list is not exhaustive and you may have additional questions. Please make sure you ask them before you go home and its ok to write some notes or reminders for yourself as there is often a lot of information to take in. All of the information we discuss with you is found in our "Discharge post cardiac surgery" booklet. We will give you a copy of this during your stay but if you want another copy please ask us.

# INVESTIGATIONS

There are a number of different investigations that your child may be asked to undergo. These include: ECG, echo, CT, MRI.

An ECG (electrocardiogram) test looks at your heart's rhythm and electrical activity. A cardiac physiologist will place sticky sensors, called electrodes, onto your chest, arms and legs. These sensors are linked by wires to an ECG recording machine. The sensors can detect the electrical signals your heart produces each time it beats and the machine will record these electrical signals to see if they are unusual. You might not be able to see your recordings immediately as they will need to be looked at by a specialist doctor. This test only lasts a few minutes.

An echo (echocardiogram) scan looks at your heart and blood vessels. It's a type of ultrasound scan which creates a moving image of your heart. A cardiac physiologist or cardiologist will place sticky sensors, called electrodes, on your chest. These sensors are linked by wires to a machine that monitors your heart's rhythm. The cardiologist will then place jelly on your chest followed by a probe which will create the moving picture of your heart. This test can take between 15-60 minutes.

An MRI (magnetic resonance imaging) scan uses strong radio waves and magnetic fields to create a detailed image of your heart and blood vessels. An MRI scanner is a large tube that has powerful magnets. Not everyone has to have an MRI scan. However, if you do you will lie on a flat bed that's moved head first into the scanner. The scanner is operated by a radiographer in another room. They will be able to see you through a TV monitor and you can speak to them throughout the scan using the intercom. The scanner can make loud tapping noises so you will be given headphones or earplugs to wear. It's important to keep as still as possible during

the scan. Some small children are put to sleep, anaesthetised, to make it more comfortable for them because it can be quite a long procedure – up to an hour.

A CT (computerised tomography) scan (or CAT scan) is comprised of X-rays and a computer to produce detailed images of your heart and blood vessels. Radiographers will carry out the scan. Before the scan they may place a drip in your arm to give contrast material by injection so that they can see some parts of the heart or blood vessels more clearly. CT scans are usually performed when you are awake but lying down, sometimes we might wrap up a baby and feed them to keep them settled and sometimes we might give a light sedative to make it more tolerable for children. During the scan it's important to breathe normally and stay still. You can speak to the radiographer in the other room through an intercom, and they may ask you to breathe in and out or hold your breath. The scan can last between 10-20 minutes.

A 6-minute walk test is a simple procedure performed to give the doctor accurate information about the blood oxygen levels during exercise and to see how far you can walk in that time. Before the test begins the nurse will explain the test to you in detail and will answer any questions while resting. A probe will be put on your fingers. This will provide us with information about the blood oxygen levels. You will be asked to walk as far as possible for 6 minutes. The test will take approximately half an hour to complete. The length of the test may vary slightly depending on the oxygen levels during the test.

# SURGICAL CLINIC

The consultant cardiac surgeon, cardiac nurse specialist, psychologist, dental registrar and research nurse will meet with you to discuss the proposed operation and what to expect. The team will talk to you about a number of things, including:

- the type of operation;
- why they feel it is important for your child to have this done;
- the prognosis without the procedure;
- the risks and benefits to your child;
- the approximate timescale for surgery;
- advice about good dental hygiene to protect your child from infection;
- support that is available to you in your preparation for surgery.

This consultation is extremely important as we try to make sure that you are as prepared for the forthcoming operation as you can be. You may want to bring a note book with you with any questions that you have. You may also want to bring someone to this appointment to support you.

It often happens that after the consultation further questions come to mind. If this happens you can phone one of the cardiac nurse specialists to ask them. Alternatively, write down your questions on a sheet of paper and you can ask the surgeon when you meet them again the night before surgery.

# SEAHORSE PAEDIATRIC INTENSIVE CARE UNIT

Seahorse Paediatric Intensive Care Unit is the paediatric intensive care unit and is a regional centre for intensive care for children (from term newborn infants to 16 years of age) across all subspecialties.

Your child will be taken to Seahorse Paediatric Intensive Care Unit directly from theatre once the operation is complete. Here, your child will be looked after by a specialist intensive care nurse. Your Seahorse Paediatric Intensive Care Unit nurse will contact you once your child had been settled into the unit post operatively. Your child will be monitored by a nurse at the end of their bed, and doctors also regularly review your child. The nurse looking after your child will give you a 'Welcome to Seahorse Paediatric Intensive Care Unit' leaflet giving you lots of useful information about what to expect whilst your child is in Seahorse Paediatric Intensive Care Unit.

# COMING IN FOR SURGERY

## **Admission to the ward**

### **What will happen when we arrive?**

We hope that we will already have seen you in pre-admission clinic before the day of your child's admission. We will also need to see you and your child before the operation. This allows us to check that your child is well enough to undergo surgery. You will also be asked to sign the formal operation consent form at this time. This documents;

- that you have had the opportunity to discuss the operation with a surgeon,
- that you understand why we believe it should be done,
- what exactly is going to be done,
- that there are risks with doing the operation (we will give details of what these are),
- that you want us to proceed with the operation.

This is an extremely important consultation. If you have any questions that remain or you have thought of since the time we met you in outpatients, this is the time to discuss them so that we can make sure that you are as ready as possible to proceed to surgery. Whilst every effort will be made to ensure that the surgeon you meet will be the surgeon performing the operation, this is not always possible. However, the surgeon carrying out your child's operation will always be experienced enough to do it well.

### **Will there be more tests?**

The anaesthetist, who will be looking after your child during the operation, will also come to meet you and your child during this time. This is an opportunity for you to ask questions and to discuss the anaesthetic options available to your child and about intensive care.

The nurse who admits you to the ward will go through your family information and take your child's temperature, heart rate, blood pressures and saturations. They will tell you when your child needs to stop eating and drinking. If you have not attended the pre-admission clinic, the nurse will also take your child's height and weight and arrange for a blood test, Echo and Electrocardiogram.

Can we visit the Intensive care Unit?

Your nurse will usually be able to arrange a visit to the Seahorse Paediatric Intensive Care Unit. This is a very big and busy room where your child will stay for observation following their surgery. Visiting Seahorse Paediatric Intensive Care Unit before your child is admitted will help you familiarise yourselves with the environment. We will try our very best to offer this to you, but it may not be possible if the unit is closed to visitors which is sometimes necessary.

### **What if my child's procedure is cancelled on the day?**

Unfortunately it may be necessary to cancel an operation from time to time on the day it is planned. This usually happens for the following reasons:

- An emergency patient has been admitted and needs to take priority
- Previous operations may take longer than expected due to unforeseen circumstances
- There may not be enough staff to do the operation safely either in Seahorse Paediatric Intensive Care Unit or in theatre
- There may not be a Seahorse Paediatric Intensive Care Unit bed available
- Your child may have become unwell overnight

If we know in advance that a cancellation is likely to happen, we will try to contact you before you leave home. If you are already at the hospital, we will do everything we can to

rearrange the surgery within a short time to avoid a wasted journey. However, this may not always be possible. If your child's operation is cancelled we will talk to you about the reasons.

## **The day of the operation**

### **How do I help my child get ready for surgery?**

On the day of your child's operation, please ensure that your child has been bathed or showered and young people have removed any jewellery or nail polish. Your child will need to stop food or milk 6 hours prior to surgery and clear fluids from 2 hours. Your ward nurse and the anaesthetist will give you specific times for your child. They may also be given a "pre-med" to help them be calmer before surgery.

Can I go with my child to theatre?

When theatre calls your child will be taken down to theatre by a nurse. It is usually possible for at least one parent to accompany your child down to the anaesthetic room and this is something that you can discuss the day before with the anaesthetist. Your child may need a hospital trolley if a pre-med has been given. A porter will push your child on the trolley. You can usually stay with your child until they are asleep

### **How long will surgery take?**

Before the operation we will give you an estimated time of how long the procedure will take, but sometimes parts of the operation can take longer than we expect. This does not necessarily mean that anything has gone wrong. As well as the actual time to do the procedure, there is also anaesthetic time while your child goes to sleep and is prepared for surgery with the necessary catheters etc that the anaesthetist will have explained. Once your child has arrived in Seahorse Paediatric Intensive Care Unit time is needed while the machines are set up and your child is settled there.

However, we do understand that this can be a very stressful time and if you are worried that all this is taking longer than anticipated, you can speak to the cardiac nurse specialist or cardiac surgery coordinator.

Where should I go during surgery?

Your child's nurse will then take you back up to Dolphin ward to pack up your child's belongings. Following your child's operation they will be a patient on Seahorse Paediatric Intensive Care Unit and so will no longer have a reserved bed on Dolphin ward. There is a storage area for your child's suitcase on Dolphin ward whilst they are in Seahorse Paediatric Intensive Care Unit, so ask your nurse to show you where this is if required. You may choose to stay in the hospital during the operation but families have told us that it can be helpful to go out. Whichever you choose, we will make sure we have a means of contacting you so that we can let you know as soon as your child comes out of surgery. You can then go to the Seahorse Paediatric Intensive Care Unit parents' room and we will come to see you as soon as we are free.

### **Will you be able to update me during the operation?**

We will not be able to do this while your child is in surgery. This is because everyone in the operating team is focussing on your child's operation and it is important that they aren't interrupted. However, if there are any events that we need to talk to you about whilst your child is in theatre, we will contact you.

## **What to expect after theatre**

### **Where will my child go after surgery?**

Your child will be taken to Seahorse Paediatric Intensive Care Unit directly from theatre once the operation is complete. Here, your child will be looked after by a specialist intensive

care nurse. Seahorse Paediatric Intensive Care Unit will contact you once your child had been settled into the unit post operatively. Your child will be monitored by a nurse at the end of their bed, and doctors also regularly review your child. The nurse will try to answer any questions you may have, and will refer to a doctor any questions he/she is unable to answer. The nurse looking after your child will give you a 'Welcome to Seahorse Paediatric Intensive Care Unit' leaflet giving you lots of useful information about what to expect whilst your child is in Seahorse Paediatric Intensive Care Unit. Its important to realise that your child will look rather different after surgery and will look rather pale. There will be breathing tubes attached by tapes to some of the face, there will be dressings and catheters in various places such as the side of the neck, hands and wrists and in the groin area.

#### **What equipment will my child need after surgery?**

After surgery your child may have some of the following equipment and items attached to them:

##### **Ventilator**

Your child may have a tube down their nose or mouth to support their breathing (ventilation) after surgery. For this, they will need sedation with medication. During their recovery the ventilator will gradually be reduced until they are able to breathe on their own without the machine. They will then be 'extubated' (the tube removed). We may give them additional oxygen after this either using a face mask or prongs inserted into the nostrils. In infants we may use head box oxygen which allows us to give warmed, humidified oxygen to the child that will allow them to cough and keep their lungs clear more efficiently.

##### **Nasogastric tube**

This is a fine tube that is passed through the nostril into the stomach. This allows us to give food and medication. Intravenous access & 'Arterial line'

Your child will usually have a small plastic catheter placed in their neck, often referred to as a "Central Line". This is a very important item as it allows us to measure the pressure within the heart and also to give medications securely into the circulation. These include drugs that will help control the blood pressure as well as medication. Another small plastic catheter will be placed into a vein somewhere else, usually a hand or foot, that will allow us to give fluids and other medications as required.

There will be a small plastic catheter inserted into an artery, most often at the wrist or at the top of the leg. Often referred to as an "Arterial Line". This is used to monitor the blood pressure and is also used to take out blood samples to check on the functioning of the lungs and informs us how best to set up the Ventilator (see below).

##### **Monitoring**

Your child will be connected by wires to a number of other monitors that give us continuous information on a number of other vital signs. These include oxygen saturation, heart rate and rhythm, respiratory rate, temperature and blood pressure. These are all shown on a large monitor that is above your child's bed.

Pacing wires

Most children will have little wires coming through their skin. Normally these wires are wound up and attached to the child's chest but sometimes they may be attached to a pacing box. They can be used to control the heart's rhythm and are sometimes necessary after a heart operation if the conduction system in the heart has been affected by the operation. If the pacing wires are being used, this is usually temporary. A day or so after the operation, if they are not being used, they can be removed often under sedation, particularly for smaller children, by gently pulling them out. This is not painful, but creates a tickling sensation as they come out.

##### **Chest drains**

After cardiac surgery each child will have one or two chest drains coming out of their chest. These are necessary to remove any fluids that build up after the operation. The drains will remain in place until the fluid has stopped being

produced. This may be a number of days after the operation. When it is time for them to be removed, they are pulled out after the child has been given some sedation. A black stitch is used to close over the small incision that is left behind and this stitch will be removed 5 days after the drains have been removed, either in the hospital or by your district nurse.

Urinary catheter

Each child has a catheter placed to drain the bladder after a heart operation. The amount of urine that is produced is a very sensitive and useful indicator of how the heart is functioning after the operation and how your child is recovering. It is therefore very important to know accurately how much urine is being produced.

##### **Transfer to the ward**

#### **When will my child transfer to the ward?**

Once the clinical team are happy that your child is stable after the operation and no longer needs to be on the intensive care unit, they will be transferred to the ward. This may be on the day after the operation or a number of days later: it depends on your child's progress. Initially they will go to the High Dependency Unit (HDU). This is a very good sign that your child is on the road to recovery and is ready to move from one to one care, to the specialist care of the HDU nurses, who each look after two patients. This care will usually be provided on Dolphin ward in the specialist HDU, but may also be provided on Seahorse Paediatric Intensive Care Unit on some occasions. We realise this will be a time of adjustment so please talk to the cardiac nurse specialist and the nurses caring for your child if you have any questions or worries.

#### **What's the difference between the High Dependency Unit and the rest of Dolphin ward?**

Whilst on HDU, your child will be reviewed on the doctors rounds twice a day, which start at 9am and 4.30pm. On the ward round you will see doctors from Dolphin ward, doctors from Seahorse Paediatric Intensive Care Unit and nurses from HDU. You can speak to the team as part of the ward round but if at any time you are worried about your child, speak to the nursing staff. They will talk to you about your questions or concerns and agree a plan of action with you. There is also a poster by the side of your child's bed which will remind you how to raise any concerns so that we can take the very best care of you and your child.

After a time, your child will be well enough to move onto the main part of Dolphin ward. Here, the nurses are all experienced in looking after patients following heart surgery or with heart conditions and each nurse will look after three patients. This is a further sign that your child is recovering well. During this period we will start talking to you about discharge. You will find out more about looking after your child following cardiac surgery, and particularly what medications they need and what they do. Again, your child will be reviewed by one of the consultant cardiologists on the ward round every day, usually in the early part of the morning. This is an opportunity for you to meet the doctors and ask any questions that you may have as we want you to be as much a part of the care of your child as possible. Also we do not want you to worry about things when we can help reassure you. However, being able to contact your doctor is not solely limited to these times and if you ask your nurse, a time can be arranged for you to meet with anyone in the team.

#### **Who else is there to support us?**

There is a wide team available to support you and your child during your stay; you can talk to the cardiac nurse specialist and or the clinical psychologist all of whom are regularly available on the ward. The play specialist will be able to help your child understand and cope with their time on the ward as well as providing activities and entertainment.

You can find out more about these services from your child's nurse.

If you need more practical support, you can ask for a referral to our 'Martha Care' Family Support worker or contact her direct via the LIAISE team.

# PRE-ADMISSION CLINIC

The pre-admission clinic appointment is to ensure that your child has all the necessary tests and investigation prior to their admission and to ensure that they are well enough for surgery/catheterisation. It is also your opportunity to tell us about any particular needs your child may have, ask any further questions or talk about any worries.

The clinic is held every Thursday morning and 1st 3rd and 5th Monday afternoon in the outpatients department here in the Bristol Royal Children's Hospital. This is often quite a long appointment, taking up to four hours. You will meet lots of different hospital staff:

- A nurse will greet you and will carry out routine observations (pulse, blood pressure etc.)
- Your child might have an echocardiogram (ECHO), and an electrocardiograph (ECG) carried out by cardiac specialists;
- A chest x-ray will often be taken by one of the radiographers;
- The phlebotomist may need to take a blood test;
- You will be seen by the doctor;
- A play specialist will be in the waiting area to play games and help prepare your child for hospital. They can also offer distractions for your child during investigations and will also be available to give you a tour of the ward;
- You'll speak to the Cardiac Nurse Specialist about your child's admission/patient journey and any concerns you may have. A Psychologist will also be there to discuss any worries and offer you further support if needed.



# DOLPHIN WARD

Dolphin ward is on Level 6 (The Blue floor) of the Bristol Royal Hospital for Children.

We are a specialist cardiac ward and cardiac High Dependency Unit (HDU). Children of all ages are admitted to this ward.

There is a mixture of cubicle rooms and four-bedded bays for patients. In all bed-spaces the child can be centrally monitored. The monitors and alarms are linked to a monitor at the nurses' station.

Staffing on HDU is two patients per nurse, as a step-down process from Seahorse Paediatric Intensive Care Unit. If HDU is busy, you may have your step-down period on Seahorse Paediatric Intensive Care Unit. The ward is staffed with three patients per nurse.

We welcome and encourage parents to carry out as much of their child's care as they wish and where possible to try and maintain children's normal routine. However, please ask your child's nurse for help if you need it.

## What to Bring

If you know that your child is going to be staying in hospital overnight, it is a good idea to bring some or all of the following. Please try not to bring in excess items as this will clutter the bed-space, which needs to be kept tidy at all times to allow access to the patient.

- Change of clothes
- Nightwear
- Nappies
- Slippers
- Toothbrush/paste
- Hairbrush/Comb
- Toiletries
- Favourite toy/magazines/books
- Any medication your child normally takes (this will be kept in the ward drug trolley)
- Feeding bottles (we provide sterilising bags)
- Special feeds/milk
- Change of clothes, nightwear, toiletries etc, for parents' personal use.

## Admission

If your child is unwell prior to admission please notify the ward as the admission may need to be arranged for when your child is better.

Please call the ward prior to travel to check that a bed is still available. Contact information can be found at the bottom of this page. If your bed is not ready when you arrive we will still continue with the admission process and you will be able to wait in the play room/parents' room.

A nurse will welcome you to the ward, and you will then have the opportunity to ask any questions about your child's specific needs. The hospital passport is available to complete online pre-admission for any child with additional learning needs/disabilities.

## What to Expect

Patients on the ward may be having surgery, cardiac catheterisation or being admitted for monitoring or investigations. Further information is available in specific information leaflets for surgery and catheterisation. Please ask your nurse if you have not yet received them.

## Visiting

- You are welcome to be with your child at all times. Friends and family may visit after the doctors' ward rounds at approximately 10 a.m. Siblings are also welcome to visit, but we ask for no more than two visitors to a bed-space at a time. There is a parents' room where visitors can wait. To help us settle the children, please limit the visitors to just parents after 8 p.m.
- The door to the unit is controlled by an intercom system and anyone visiting will have to press the buzzer to gain access. This creates a secure environment for all children on the ward. Please ensure that the door is locked behind you when you enter or leave and do not allow anyone you do not recognize to gain entry. We may not always be available to answer the door immediately, so please be patient. We know you are there but we may be caring for a child at the time.
- If any visitors are unwell we ask them not to visit to protect the children on the ward. Please check with the doctors and nurses to determine what is best.
- If any visitor has diarrhoea and vomiting they must not visit the ward until 72 hours following the end of symptoms.
- To reduce infection, please use alcohol gel on entering and leaving the ward.
- Please check with staff if you have any questions about visitors.

## Quiet time

- Quiet time is between 1 and 2 p.m., during which we encourage children and their families to have some protected rest time, free from procedures and non-urgent investigations.

## Accommodation

- We aim to provide accommodation for parents wishing to stay with their

child, but this is not always possible.

- We have one pull-down bed by your child's bed for one parent to stay on the ward. Parent beds are not available on Seahorse Paediatric Intensive Care Unit or the High Dependency Unit. At this time, we encourage parents to get rest away from the ward.
- In order to help the housekeeping staff to keep the ward environment clean and tidy we would ask you to have the pull-down bed put away by 8 a.m. There is a small locker at each bedside. Please try to keep luggage to a minimum.
- Parent bathrooms and showers are available on the ward. If you have any concerns about cleanliness during your stay, please speak to your nurse.
- There is parent accommodation in Ronald McDonald House, based on St Michael's Hill. Please let us know on admission if you wish to apply for a room. This facility is provided free of charge, but there is likely to be a waiting list. This cannot be pre-booked and priority will be given to families whose children are in Seahorse Paediatric Intensive Care Unit or HDU.
- We are unable to accommodate siblings overnight on the ward during your admission. However, if this is going to cause difficulties for you, do let us know.

## Meals and refreshments

- There is a variety of pre-packed baby-milks available and the hospital also has a milk-kitchen (Special Feeds Unit) where staff will make up any special feeds that your child may require.
- For older children there are cereals, bread, sandwiches, yoghurts, crisps and fruit available. Breakfast, lunch and are provided for your child each day. The housekeeper will order food in the morning and will ask patients for their menu choices. We encourage the child and family to be involved in this. The menu aims to meet most people's needs and vegetarian dishes are available every day, but if you need help with making suitable choices, please speak to the housekeeper.
- There is a snack trolley on the ward where you can help yourself to food and drink for your child. This is usually kept outside of the ward kitchen. Unfortunately parents are not allowed into the kitchen. Please ask the nursing staff for any assistance.
- There is a parents' and visitors' rest room next to the ward for you to use while you are staying with us. This is shared with Ward 31. Tea and coffee is provided but you will need to bring in your own milk for drinks.
- Hot drinks must not be brought back onto the ward for safety reasons.
- You can store your own food in the cupboards or fridge for Dolphin ward. Please label your food and take unused items with you when you leave.
- A microwave, basic crockery and cutlery are provided. Your assistance in keeping the room tidy and comfortable for everyone's use is greatly appreciated.
- We ask that parents consume food in this dining room rather than on the ward, as there are children on the ward who are not able to eat or drink and it can cause some distress.
- There are vending machines where you can buy sandwiches and snacks on Levels 2 and 3 (in the outpatients department). There is also a Royal Voluntary Service (RVS) shop on Level 2 (main entrance) where hot drinks and small selection of hot food is served. This is open from 8.30 a.m. to 6 p.m., Monday to Friday and from 10 a.m. to 4 p.m. on Saturday and Sunday.
- In the Bristol Royal Infirmary (adjacent to the hospital) there are some shopping outlets and coffee shops that are open every day, including W H Smith, Boots, Marks and Spencer's Simply Food and Costa Coffee.
- There is a Tesco within walking distance (about ten minutes) if you wish to purchase food.
- Bristol's central shopping area (Broadmead), with all of the usual high street names, is a ten-minute walk from the hospital should you need additional clothing, toiletries etc. during your hospital stay.
- There are also some leaflets on the notice board near the parents' rest room on the ward detailing local places to eat, or takeaways that deliver to the hospital. Although we do not endorse any of them in particular, some visitors have used them.

## Breast Feeding

We support breast-feeding mums. Breast pumps are available from ward staff. If you would like some support or advice on breast-feeding, please speak to your child's nurse.

We offer breast-feeding mothers three meals a day until their child is six months old. If you would like to access this service, please speak to the housekeeper.

## Play

- We have a well-equipped playroom which we share with Ward 31. There is a full-time Play Specialist available during the week. There are games and activities suitable for older children and teenagers, including DVDs and games consoles.
- Children (including brothers and sisters) must be accompanied by an adult whilst in the playroom.
- There is also an indoor and outdoor play-centre on Level 5 for children who are well enough to leave the ward and for siblings. Again, an adult must accompany all children.

- If you bring in any of your child's toys, please ensure that you do not misplace them as we cannot accept responsibility for losses.
- Free Wi-Fi access is available. Please see your nurse or ward clerk for assistance.

#### People you may see on the ward: Staff who wear uniform

##### *Ward sister or Charge Nurse*

You will recognise them by their navy uniform. They are in overall charge of the ward and can help if you have any questions your nurse cannot answer.

##### *Matron*

Matrons look after a group of wards and help support the nursing team. You can ask to speak to them if you wish. They wear grey tunics with red piping.

##### *Senior Staff Nurses*

These nurses will be in charge of the shift. They wear a grey striped uniform with dark blue epaulettes.

##### *Staff Nurses*

These nurses will provide the majority of your child's care. They wear a grey striped uniform with light blue epaulettes. At each shift, a new nurse will be allocated to your child and will introduce themselves, so that you always know your first point of contact for your child's care.

##### *Health care assistants*

HCA's provide support to the nursing team. They wear a grey striped uniform with brown epaulettes

##### *Student nurses*

You may meet nurses on placements on the ward who are in training. They wear a light blue uniform

##### *Technician*

If your child needs an Echo or ECG, the technician will carry this out. They wear red polo shirts.

##### *Housekeepers*

Our housekeeper makes sure that all patients have food and clean linen. She also supports the ward in ordering supplies. She wears a yellow tunic.

##### *Domestics*

This team make sure the ward is clean and tidy. They wear green-and-white striped tunics

##### *Play therapists*

Our play team wear blue polo shirts. They are available Monday to Friday, 9 a.m. to 4 p.m. to assist with procedure distraction and entertainment at the bedside, in the ward playroom and play centre. People you may see on the ward: Staff who don't wear uniform

##### *Doctors*

Doctors' ward rounds usually start between 9 a.m. and 10 a.m., starting with HDU. One of the consultants will see the children most mornings. This is the time when plans for your child's care are made, so you may wish to be present at this time. You may wish to have someone with you to support you at this time. During the day there is a Cardiology Registrar and/or junior doctor on the ward; they organise X-rays and Echos and take blood samples where necessary. You can make arrangements to talk to the cardiology consultant if you wish by speaking to your child's nurse.

##### *Ward Clerk*

They will help welcome you to the ward and make sure we have your correct details. Please ask them if you need help with any of the practical aspects of your stay, such as where to find parent facilities.

##### *Dieticians*

This team is on the ward most days to support special nutrition needs. Please let the nurse looking after your child know if you would like to speak to them.

##### *Cardiac Nurse Specialists*

Our specialist nurses cover the ward every day (Monday to Friday, 9 a.m. to 4 p.m.) and will pop in to see you. They will discuss your child's care with you and provide information about their cardiac condition. They can refer you to local support groups and discuss financial and psychological support. If you would like to talk to them more urgently, please ask the nurse looking after your child to contact them.

##### *Clinical Psychologist*

The psychologist works Monday and Tuesday mornings and is available if you would like additional support, or to discuss experiences whilst your child is an inpatient. Please let the nursing staff know if you would like to speak to her.

##### *Anaesthetist*

The anaesthetist will come and speak to you prior to theatre or cardiac catheterisation. This is generally the evening before your child's procedure or early on the morning of the procedure.

##### *Surgeons*

The surgeon will come and discuss the operation with you, then sign the consent form, usually the evening before surgery. Please make sure that you are on the ward after 4.30 p.m. the night before surgery so you can meet them. If your child is in for a cardiac catheter then it will be a cardiologist who does this.

##### *Discharge*

When your child is ready to go home, you will need to wait for your discharge letters and discharge medications. We aim to try and get this done in the morning but it can occasionally take longer. If your child is well enough we may ask you to move out of your bed and use the playroom or discharge lounge. This is to allow us to clean the bed ready for another child. Please do not leave until you have received the discharge letter. The letters will normally advise you of any follow-up appointments. We will also provide you with an information leaflet about your child's procedure and aftercare advice with contact numbers. If you need advice following discharge you can ring the ward, contact the Cardiac Nurse Specialists or ring your GP.

##### *Additional information*

###### *Financial support*

This may be available to help with the cost of car parking and travel to the hospital to visit your child through various sources. We also have a Martha Care worker who can offer additional support for longer stay patients. Please ask your child's nurse if you would like to discuss the help that is available.

###### *Interpreter services*

Should you require any assistance such as a foreign language or sign language interpreter, please let us know so that we can arrange this for you.

###### *Religious support*

The hospital has a multi-faith prayer room located on Level 4, which is always open. The hospital chaplaincy team can be contacted during the day and an out-of-hours/on call service is available. This team is non-denominational and available for all faiths.

###### *Mobile phones*

Mobile phones may be used on the ward. However, we would ask you to keep them on silent for receiving calls and messages. Please do not receive calls late at night on the ward. Remember to bring your charger with you.

###### *Hospital Car Park Passes*

These are available from Main Reception on Level 2 for the families of patients staying overnight. For more information about parking and other parent support, please click here.

###### *Electrical Items*

Please be aware that we cannot accept responsibility for expensive items brought into the hospital such as smart phones, laptops, iPads or other electrical items. You are welcome to use these items but please be aware that staff may need to check that they are safe.

###### *Escalating concerns*

If you are concerned about your child, please speak to your named nurse in the first instance. If you feel that your child requires a clinical review, you can request this from either the on-call consultant or a member of our outreach team and they will discuss your concerns with you and agree any necessary action. This will be recorded in your child's notes. Support for you

We know that being in hospital with your child can be a difficult experience. We want to support you as much as we can but we need to ensure our staff are supported to carry out their work. If you feel you need help to manage your hospital stay, please let us know. If you would prefer to speak to someone in confidence, please call our LIAISE team on 0117 342 8065 and they will be able to talk through the options available to you. They are available Monday to Friday from 9 a.m. to 4 p.m. The NHS has a ZERO tolerance policy on physical or verbal aggression. We value your opinion

We welcome your comments on your stay on Dolphin ward. You can either complete a comments card, available from our reception desk or ask to speak to the Ward Sister or Nurse in charge.

###### *Useful contact numbers*

Dolphin ward	0117 342 8332 0117 342 8679
Cardiac Nurse Specialists Answerphone out of hours)	0117 342 8286 (8am to 4pm -
Outpatients	0117 342 8440 / 8441

# AFTER SURGERY

As soon as possible after heart surgery, your child can start some exercises to enhance their recovery, help expand their lungs to get rid of any mucus (preventing chest infections) and promote their independence so you can get home sooner! These exercises will encourage your child to 'get moving' from a very early stage postoperatively and will be advised by your nurse or physiotherapist. They also help to reduce pain, anxiety, strengthen muscle, help with posture and increase fitness. They focus on three main aspects:

- Deep breathing e.g. blowing bubbles, encouraging deeper breaths
- Coughing and clearing any mucus
- Moving around e.g. At first, help your child to sit up in bed. Next, help them to get up and sit in a chair. For younger patients picking them up for a cuddle or on your lap is an excellent position. Finally, help your child to start walking around the room and ward.

After the operation, these exercises may be enough to help your child get better. But some children have trouble expanding their lungs, or they cannot get rid of the mucus on their own. If your child is having trouble, the nursing staff will refer them to a physiotherapist for further help and advice.