



Discharge advice following cardiac surgery



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Introduction

This is a general information booklet and has been designed to help you prepare for going home. While most families look forward to going home we appreciate that this can also be a worrying time. The information in this booklet is very general only and will not answer all your questions. It should be used along with other information you will be given about your child's surgery and after care.

Do ask the team looking after your child if you have any other questions.

Getting home

If possible you should arrange for someone to collect you by car. Remember that your child will need a car seat or seatbelt as usual (a towel placed underneath the belt can sometimes make it more comfortable) and if your journey is a long one, take frequent rest and snack breaks.

The hospital cannot provide transport home unless you are being transferred to another hospital.

It is okay for most children to travel by public transport but it can be more tiring for child and family.

General points

Your child has recovered enough to go home and should continue to make a steady recovery. After heart surgery children may be a little withdrawn or seem to be 'not quite themselves'. Younger children may take time to settle back into their routines. Areas that are commonly disturbed include feeding / eating, sleeping and toilet routines. As your child returns to his or her normal environment they will start to feel secure again and their general wellbeing should improve. Older children may find it helpful to talk about their experiences in hospital.

For parents taking babies home, you may also have concerns that every parent with a small baby has, i.e. feeding, weight gain, sleeping etc. The ward will ensure that your health visitor is updated on your child's condition and s/he will get in touch with you to make an early appointment to provide support.

Although you do not need to isolate your child from visitors or other children when you get home it is a good idea to limit the number of people they are in contact with. If any visitors have a 'flu' or a cold, then it is probably best to avoid them for a few days. Your child's immunity may be a bit low after a major operation, and as an infection could delay their recovery, it is best avoided.

Over the next few weeks when your child is recovering, there may be times when your child feels unwell, this may be something related to his or her heart condition or it could be an unrelated illness or infection. If you are concerned about your child, then please do contact the ward – particularly if you have not yet been to an outpatient's appointment. You may be then advised to see your child's GP, bring your child into the Emergency Department / ward, or go to your local hospital.

For general advice about your child's health, please contact the cardiac nurse specialist or your health visitor.

You will be given a copy of your child's discharge letter and it is useful to take this with you if you need to attend another hospital.

Dial 999 immediately and ask for an ambulance if your child:

- **Has a sudden collapse and is unresponsive**
- **Is severely short of breath**

Although this is uncommon it is important that you know what to do if this should happen.

Play and exercise

In the first six weeks it is important that rough play is avoided to allow the chest to heal. If your child is attending nursery / playgroup it is a good idea to speak to the person in charge / teacher before your child starts back at the nursery.

All contact sports and activities that could involve a blow to the chest should be avoided and you need to make sure that your child and the school know of these limitations.

Your child should also avoid strenuous exercise such as cycling and running until they have been given the 'OK' by the cardiologist. Please speak to the doctors for further advice.

Returning to school

We would normally recommend that children do not return to school or nursery for approximately four to six weeks after discharge from hospital, but this will vary from child to child, but certainly not before you have been back to an outpatient appointment, approximately two weeks after discharge. It is a good idea to discuss returning to school with the doctor at the appointment clinic.

Your son or daughter may be keen to return to school, they can help decide when they feel ready. They may need to start with half-days or just specific lessons. The school may be able to send work home so your child does not fall behind.

It is a good idea to see the teachers or school nurse prior to going back, as this allows you to discuss any considerations your child may need. If the school require any further advice, then please speak to the liaison nurses – contact number at the back of this booklet.

Wound care

Your child's wound should heal within two to three weeks but it may take longer than you expect. When healing is occurring many children will complain of it feeling itchy and this is normal. The wound should look pink around the edges as it is healing.

You are advised to contact the ward if you notice any of the following:

- The wound is red, or swollen
- There is oozing or weeping from the wound
- The wound edges have separated.

Some children do get a wound infection and they need to be treated on advice by the cardiology team.

It is advisable to avoid baths until the wound is fully healed. However as this can be some time a shallow bath with no bubbles or a shower is usually alright about two weeks after the operation, but make sure that the child does not immerse themselves in the water. Do not use cream / lotion on the scar until it is fully healed, this can take up to six weeks.

Do not let the scar get exposed to the sun and we advise no swimming until your child has received the 'OK' from the cardiologist at the clinic.

When you leave the hospital there may still be a stitch where your child's chest drain was removed. This can be taken out at your GP's surgery. You need to get in touch with the GP surgery / practice nurse to arrange this. The sutures usually come out seven days after the drain was removed, so check the date with the ward before discharge.

Many parents find using a small towel to pad the car safety belt is useful while the wound and sternum are healing.

Information about endocarditis

Bacterial endocarditis is a serious infection that affects the lining of the heart known as the endocardium. The infection is caused by infection getting into the blood stream and settling on the heart. It is extremely rare in normal hearts, but children with some congenital heart defects are at a higher risk of this infection.

Because of the potential risk, there are several things we advise you to do:

- Ensure your child has good dental hygiene, regular dental check ups and that your dentist knows about your child's heart condition.
- Piercing and tattooing: Avoid any body piercing or tattooing as these carry a high risk of infection. Piercing on or around the mouth is very risky. You should check with your cardiologist if ear piercing should be carried out with antibiotic cover.

As of 17th March 2008, NICE is recommending that antibiotics should no longer be offered before medical and dental procedures, unless the procedure is at a site where there is already a suspected infection.

The reason for this change in guideline is because dental and medical procedures are no longer thought to be the main cause of infective endocarditis.

If you have been receiving antibiotics for dental treatment in the past, you can talk to your cardiologist about the recent changes in the guidelines and how these affect you.

Dental hygiene

It is known that people who have bad dental hygiene with cavities/unhealthy gums force bacteria into their bloodstream when chewing/biting. It is important that your child has regular dental checks, and you should register your child with a dentist if you have not already done so, even before they have teeth! Please ensure that the dentist treating your child knows about your child's heart condition.

However, good dental care is advisable for all children. Many children's medicines contain large amounts of sugar that can damage their teeth and gums. Ask the pharmacist if sugar-free medicines are available.

Make sure they brush their teeth regularly, and avoid giving them sweet foods and drinks between meals and last thing at night.

Immunisations

It is important that children with heart conditions avoid potentially serious diseases, so in consultation with your GP and cardiologist, make sure that your child has all of the routine immunisations. If your child is due immunisations within a few weeks of the operation, we advise that you delay this for at least six weeks, to ensure your child has fully recovered from the procedure. Check this with the doctor at the outpatient's appointment.

Going on holidays

The majority of children have no difficulties with air or sea travel. However we would advise that you discuss any holiday plans that you have with the doctor you see at the outpatient's appointment. In general the advice is to wait about three months.

When you do go on holidays ensure that you have adequate medication, and as with all children avoid too much exposure to the sun (cover scar) and ensure that your child does not get dehydrated.

If you need any advice on companies that provide holiday insurance contact the cardiac nurse specialist.

Medicines

The team caring for your child will give you information about the medications that your child needs to take. As with all medications:

Keep medicine locked away from children, and check the storage instructions, some medicines need to be kept in the fridge.

Do not share medicine with anyone.

Seek advice from a doctor or pharmacist before giving other medications

Always read the labels carefully, particularly when you get a new supply. Make a note of the actual dosage and check the dosage with your pharmacist each time you renew the prescription.

The medicine may not be stocked by your pharmacy so please give them plenty of notice when you need a new prescription. It is worth remembering that you will not be able to renew your prescription at weekends or bank holidays. The hospital's pharmacy will be able to advise your pharmacy if they are experiencing difficulties.

Within reason the medication should be given at the same time each day with the same number of hours between doses.

Giving medicine to your child

Babies should be given their medicine before a feed when possible.

Do not put the medicine in your child's bottle or drinks as if they do not finish the drink they will not have had the correct dose.

If giving liquid medicine

Sit your child in a comfortable upright position and place the syringe tip into the side of their mouth and give slowly.

If giving a tablet

Check with your pharmacist if you can crush or dissolve the tablet, and then mix it with water / juice and give the correct amount.

It is sometimes worth mixing the medicine with a spoonful of yoghurt

Discharge checklist

Below is a list (not exhaustive!) of the issues you need to think about before leaving:

- Are my contact details correct? (so we can let you know about appointments)
- Where and when will the outpatient follow-up take place?
- Do I understand my child's medicines and how to give them?
- How will I care for the wound?
- Do I understand what my child can and cannot do?
- When should stitches be removed?
- What symptoms should worry me?
- Do I need any special equipment or feed to take home?

The nurse specialists

The cardiac nurse specialist team is made up of five experienced nurses who have backgrounds in cardiac nursing, paediatric intensive care and expertise in other areas such as arrhythmias. We are here to provide practical, emotional and educational support and advice to all children and their families who have heart conditions.

This can be at any time but particularly:

- During pregnancy
- At diagnosis
- Pre-admission
- During an In-patient stay in hospital
- At home
- In out-patients
- During transition to adult services.

We are happy to become your point of contact at the hospital and welcome calls from you or any of the health professionals involved in your child's care.

Contacting us

You can contact us by phoning: **0117 342 8286 / 8578** and asking for:

Cathy Harrington

Diane Barlow

Lisa Patten

Jess Hughes

Debbie Riddiford

Useful contact numbers

Ward 32	0117 342 8332 0117 342 8679
Cardiac nurse specialists	0117 342 8286 (answerphone out of hours)
Outpatients	0117 342 8440 / 8441

Cardiology Secretaries

Rob Martin	0117 342 8855
Graham Stuart	0117 342 8852
Alison Hayes	0117 342 8804
Andy Tometzki	0117 342 8853
Robert Tulloh	0117 342 8856
Bev Tsai-Goodman	0117 342 8862
Mark Walsh	0117 342 28852
Gareth Morgan	0117 342 8853

As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients.

While your child is under our care, you may be approached about them taking part in research. To find out more please visit: www.uhbristol.nhs.uk/research-innovation or call the research and innovation team on **0117 342 0233**.



For access to other patient leaflets and information please go to the following address:

www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients/

Hospital Switchboard: 0117 923 0000



Minicom: 0117 934 9869



www.uhbristol.nhs.uk



For an Interpreter or Signer please contact the telephone number on your appointment letter.



For this leaflet in Large Print, Braille, Audio, or Email, please call the Patient Information Service: **0117 342 3728 / 3725**

