

Leaving hospital after a heart operation



Information for families

Great Ormond Street Hospital
for Children NHS Foundation Trust

This leaflet from Great Ormond Street Hospital (GOSH) explains how to look after your child when they return home after heart surgery.

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If you see any of these signs in your child on either of their wound site or chest drain site:

- Your child is generally unwell
- They have a high temperature
- The site is redder than before and/or the redness is spreading
- The site feels hotter than the surrounding skin
- The site is oozing any fluid
- The site becomes swollen
- The site begins to smell
- Your child is complaining of pain at the site

Please consult your family doctor (GP) as soon as possible and inform staff on Bear Ward or a Cardiac Nurse Practitioner (numbers inside the back cover).

Discharge summary

When your child is ready to go home, you should expect to receive a discharge summary. The discharge summary acts as a record of what happened during your child's hospital stay, what medications have been prescribed, and details of any follow-up appointments or any further treatment required at GOSH. Your GP and referring hospital will also receive a copy of the discharge summary to inform them that your child has gone home and to explain any care or support you may need. If you did not receive your child's discharge summary when you left the unit, please wait five working days, if it does not arrive then please call the unit your child was admitted to and speak to one of the members of the team. If you have to access health services after you have been discharged, please show your discharge summary to the person seeing your child.

Going home

We aim to discharge children by midday. Travelling home by public transport should not cause any problems, but if possible, you should arrange for someone to collect you by car. The hospital provides a parking permit for the day of discharge. However, you are responsible for paying the congestion charge as a refund is rarely given. Remember that your child will need a car seat or seatbelt as usual, and if your journey is a long, take frequent rest and snack breaks.

Please note that the hospital cannot routinely provide transport home unless there is a medical need or your child is being transferred to another hospital.



Your child's wound

The wound sites should heal in the two to three weeks following surgery. The stitches (sutures) in the main wound will dissolve under the skin and do not need to be removed. The chest drain stitches will need to be removed five days after the drains came out. If they have not been removed before your child goes home, you should arrange for them to have this done at the GP Practice with the practice nurse.

It is important to keep the wound and surrounding skin clean. Your child should be washed daily after surgery using only clean water.

As soon as all the stitches and all dressings have been removed, your child can have a shallow bath or quick shower. The wound should be washed gently with warm water and mild unscented soap or diluted baby bubble bath, using a soft clean sponge or wash cloth. Do not soak the wound until all of the scabs have gone, usually around four weeks after surgery. Just before leaving the bath or shower ensure that the wound has a final rinse with clean fresh warm water. It is important to thoroughly dry the wound; you should pat the area with a clean dry towel or if possible allow the area to air dry. It is best for your child to wear clean cotton clothing while the wounds are healing.

Sticky plaster marks are hard to wash off so plaster remover can be helpful; please ask for this before you leave the ward if you think you will need some.

To promote good wound healing, we do not recommend the use of creams, lotions or oils on the area until after your child's follow up review. This is usually six to eight weeks after surgery. It is essential that your child has SPF 50 sun protection cream applied to the wound if the chest is exposed to the sun after six to eight weeks. However, we advise that covering with a t-shirt is the best option.

Please inform a member of the Cardiac Nurse Practitioner team or a member of Bear ward staff if there is a problem with your child's wound. They will then be able to offer you advice and inform your child's surgical team. We may advise you to consult your local medical services as soon as possible.

General health advice

Following surgery, we hope that your child's health has improved. However, there is always a small risk that complications may arise. Below is a list of signs and symptoms to look out for, this is not an exhaustive list so if you are worried about your child, you should seek medical assessment locally.

- **Increased breathlessness** (at rest or with feeding)
- **Change in normal colour** – such as blueness, paleness, rash, flushing
- **Decreased feeding** (volume or frequency)
- **Changes in behaviour** – including lethargy/tiredness, irritability
- **Increased sweating** – more than usual
- **Puffy/swollen** face, hands or feet
- **Decreased amounts of urine** – for example, fewer wet nappies or passing urine less.
- **Fevers** without a cause
- **Poor weight gain** – children under a year old should be weighed weekly for the first month after surgery by your health visitor.

The Cardiac Nurse Practitioner team can be contacted for non-urgent concerns or queries, using the numbers on the back of this book.

Getting back to normal

Following cardiac surgery, it may take your child a few days to settle back into their normal routine, including eating, sleep and activity levels.

Feeding

By the time your child is discharged from hospital they should have an established method of feeding, ideally this will be the same method as before surgery. If this is not possible, we will support you and your child to feed in the best way possible to allow them to be discharged home.

We may involve your health visitor or a local dietitian to help support you, and ensure your child continues to gain weight once they are home.

Sleep

While in hospital your child's sleep pattern will be disturbed. It is not unusual for them to struggle with sleeping, or complain of having nightmares once discharged home. Getting back into a normal routine and providing reassurance for them is important and will help most children get back to their normal sleep pattern very quickly.

If they are still struggling with sleeping after a few weeks, please contact the Cardiac Nurse Specialist team for advice and support.

Returning to everyday life

After any serious surgery children can be affected in many different ways. Some children may become more 'clingy', emotional, quiet or withdrawn. Try to go back to your usual family routine, and talk to your child positively about their hospital stay. Avoid comments such as 'nasty doctors, scary hospital' and so on, as your child will need to come to hospital and see medical staff over the coming years. If things do not improve within a few weeks, please contact the Cardiac Nurse Specialist team who can offer advice and support.

Children should be encouraged to get back to normal activities as they feel able.

However, the following should be avoided:

- Being picked up under the arms for six weeks
- Rough and tumble play for six weeks
- Swimming, biking, climbing for six weeks
- Large gatherings and anyone obviously unwell for two weeks
- Play school, child minders, nursery, or school for four weeks. They may need to start back slowly, perhaps half days initially. This varies from child to child so discuss it with the school. If you need a letter for school, please ask the discharging team for this.

If you are taking a new baby home, you need to remember that most of your concerns will be those of any new parent and will include worries about feeding, sleep pattern and weight gain. It is normal that you should have additional worries relating to your child's heart condition. Ensure you have contact details for your health visitor who will be able to support you.

If you or your teenager has any questions about recovery, please contact our Cardiac Adolescent & Transition Clinical Nurse Specialist (details on back page).

Giving your child medicines

It is very likely that your child will be discharged on medication. Most children will continue to take medicines until the first outpatient appointment, when they will be reviewed by the medical team.

A member of the ward team will talk to you about the medicines and teach you how to give them before you go home.

We will give you information about the specific medicines your child is prescribed. Please read labels carefully every time you give a dose, but particularly when you get a new supply. The hospital will give you two weeks' supply of medicines, but you will then need to ask your GP for a repeat prescription to take to your local pharmacy. Your local pharmacy may not have these medicines in stock, so you will need to get the repeat prescription in plenty of time.

Give your medication as directed. If your child vomits or spits out the medication it could be harmful to repeat the dose and cause an overdose, so if you are not sure then please call the Cardiac Nurse Specialist team for advice.

Once at home, it is important that you are organised with your child's medications, perhaps making a list or chart or setting an alarm on your phone to ensure your child gets the right medications at the right time.

Giving pain relief

- Pain killers should be given regularly – this may need to continue for several days after discharge. Follow the instructions you have been given about how much to give and when.
- Different types of pain killer work well together – for instance ibuprofen and paracetamol can be given at the same time.
- Do not wait for the pain to get very bad before you give your child pain killers
- Giving pain killers at bedtime will help your child sleep through the night
- If your child is still in pain, pain is increasing or you are concerned about the severity of the pain then contact your GP or the cardiac nurse practitioner team.
- Ibuprofen – a non-steroidal anti-inflammatory drug (NSAID) – can be given three times a day, every six to eight hours with food.
- Paracetamol can be given four times a day, every four to six hours. An overdose is very dangerous so do not give more than the prescribed amount.
- Weaning analgesia is done by gradually omitting (leaving out) doses each day. Start with ibuprofen first, once this is no longer required, you can then reduce the number of

paracetamol doses until no more is required. If your child is still in pain then stop weaning at this point and try again the following day if comfortable.

Immunisation

Most children with cardiac conditions should be immunised according to the usual schedule. However, we recommend that you:

- Wait for four weeks after surgery before continuing with the immunisation schedule
- If your child is going to have further surgery, we advise that your child should not be immunised four weeks before admission
- If your child has been offered the seasonal flu protection by vaccine or nasal spray, please consult with your cardiologist or the Cardiac Nurse Specialist team.
- Do not forget to book immunisations if the schedule has changed, it is very important your child is immunised

If your child has a condition that alters their ability to fight infection, then please discuss any immunisations with the specialist overseeing this aspect of your child's health.

Reducing the risk of endocarditis

Bacterial Endocarditis (BE) is a life-threatening infection of the endothelium. This is the smooth surface of the inside parts of the heart, including the heart valves.

Any child or adult can develop BE although it is very rare. People at greatest risk of BE have a damaged heart valve, an artificial heart valve, prosthetic material within the heart or other heart defects.

Infective endocarditis is caused by certain types of bacteria and organisms which get into the bloodstream in large numbers. Once in the blood stream they attach to an area of endocardium which is rough and an infection develops.

There are things you can do to reduce the risk of endocarditis:

- **Good oral hygiene.** Gum disease and tooth decay can cause infective endocarditis. Your child should clean their mouth and teeth twice a day with fluoride toothpaste and have check-ups at the dentist every six months.
- **Body piercing and tattoos** should be avoided entirely as they have a high risk of infection.

Endocarditis in its early stages is similar to having influenza or flu, but it does not go away as quickly. Your child may feel generally unwell, have a high temperature, aches and pains, night sweats, weight loss or joint pain. If your child has a high temperature that is unexplained or prolonged, it is very important to seek medical help locally – ideally at your nearest Accident and Emergency (A&E) Department or your GP.

The National Institute for Health and Clinical Excellence (NICE) provide national guidance on the management of infective endocarditis, and as a service we will always aim to follow the latest national guidance. This currently does not recommend children receiving antibiotics to cover before dental procedures. However, always inform your dentist that your child has a cardiac condition, and if your child requires any other surgery or procedures, always let the specialist performing the procedure and cardiologist know of your child's history.

Follow up after discharge

One of the Cardiac Nurse Practitioners will try to call you within three working days of discharge to see how you and your child are following discharge. Before you leave, please check that we have your correct contact details for you. If you do not receive a call, please get in touch using one of the numbers on the back of this booklet. Most children are seen by the doctor within four to six weeks of discharge, but if we need to see your child sooner, we will discuss this with you before going home. If not given to you before you go home, the date and time of the outpatient appointment will be posted to your home address.

If you do not receive an outpatient appointment within four weeks of discharge, please contact us.

At your follow up appointment you will be able to discuss the following

- Booking a holiday abroad
 - holiday insurance for your child
- Days out to an amusement park or fun fair
- Flying
- Swimming
- Strenuous activities or extreme sports
- Going diving

Further information can be obtained from:

Helping your child with congenital heart disease, staying healthy – available on our website at www.gosh.nhs.uk or from the Cardiac Nurse Practitioner team.

Children's Heart Federation factsheet on endocarditis and dental work available online at www.chfed.org.uk or by telephoning 0808 808 5000

The **British Heart Foundation** offers support and advice to anyone affected by heart disease. Call their helpline on 0300 330 3311 or visit their website at www.bhf.org.uk

Discharge checklist

It may be helpful to complete this checklist to make sure you have all the information you need before going home.

- Have I provided up to date contact details?
- What arrangements have I made for going home?
- Do I have a copy of the discharge summary?
- Where and when will the outpatient appointment take place?
- When should the stitches be removed?
- Have my community team been contacted?
- Do I understand my child's medicines and how to give them?
- Do I know how to re-order them and when to stop them?
- Do I understand what my child can and cannot do for the first few weeks?
- Do I understand when my child can return to nursery or school and what to tell them?
- How will I care for the wound?
- What symptoms should worry me?
- Has someone spoken to me about endocarditis?
- Do I need any special equipment or feeds to take home?
- Am I clear when to continue my child's immunisations?
- Do I need any further information?

Useful numbers

GOSH switchboard	020 7405 9200
Bear Ward	020 7829 8829
Walrus Ward Day Care	020 7813 8349
Cardiac Nurse Practitioners and Nurse Specialists (Monday to Friday from 9am to 5pm)	020 7405 9200 ext 5774
Cardiac Adolescent & Transition Clinical Nurse Specialist:	020 7813 8143
Social Work department	extension 5320

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Compiled by the Cardiac Nurse Practitioners

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