

# Leaving hospital after your child's heart surgery

Information from Sky ward

Patient name .....

Hospital number .....

Date of birth .....

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## Leaving hospital (discharge)

Leaving hospital is an important step in your child's recovery after heart surgery. This booklet will answer some of the questions you have when your child leaves hospital.

You might be worried or nervous about taking your child home. These feelings are common and understandable. We try to make leaving hospital as easy as possible, and will give you the necessary advice and support during your child's recovery.

### **Your ward discharge letter**

You will be given a discharge letter when your child leaves hospital. This has important information about their stay in hospital. Please keep it in a safe place and bring it with you to clinic appointments.

It should also be taken with you on holidays in case your child needs to be seen by a health professional.

Copies of this letter are sent to your GP and any other doctors who have been involved in your child's care.

### **Your support network**

Our clinical cardiac nurse specialist (CNS) team provide a support service for when your child leaves hospital. They aim to call you within a week of leaving.

The nurse will advise and support you in caring for your child at home, arrange reviews as necessary, and be your link between Evelina London Childrens hospital and your local services, for example, their GP, midwife, health visitor, local paediatrician and school.

The team works with you and your child's doctors to make sure your child receives appropriate and individual care that meets the needs of your child and family. The team can be contacted, phone 020 7188 4546, Monday to Friday, 9am to 5pm (you can leave a message and we will phone you).

Please speak to your doctor, nurse or the CNS team before you leave hospital if you have any questions or concerns.

## If your child is unwell

There might be times when your child feels unwell. This could be something linked to their heart condition, or it could be an unrelated illness or infection. Whatever the problem is, there will always be someone available to help you. Please get help as soon as possible to prevent your child's condition from getting worse

Phone 999 **immediately** and ask for an ambulance if your child:

- suddenly collapses and is unresponsive, or you cannot wake up your child
- is short of breath, has irregular breathing, is making any new noises when breathing, or is breathing significantly faster or slower than normal
- complains of chest pain
- has a change in skin colour (for example pale, bluey, mottled) lasting more than a few minutes

If your child gets any of these symptoms within 48 hours of leaving hospital, call the CNS team, **phone** 020 7188 4546, Sky cardiology ward, **phone** 020 7188 8849 or NHS 111 for advice.

- New cough (if your child hasn't got a cold).
- Significant changes in their feeding or eating pattern.
- Not peeing as many times as normal.
- Temperature above 38C.
- Increased sleeping.
- Increased sweating or cool clammy skin.
- Puffy eyelids.
- Irritability or they cannot be comforted.
- Repeat of any arrhythmias (irregular heartbeats) that they had before their hospital stay.
- Repeat of any symptoms they had before their hospital stay.
- New or increased vomiting (being sick).

### **Urgent advice**

If your child is unwell and you need urgent medical advice take your child immediately to your nearest emergency department (A&E). You should take your child's discharge letter with you as it contains important information that will be helpful for the doctors.

### **Non-urgent advice**

If you think your child's illness is related to their heart condition, please call the CNS team, **phone** 020 7188 4546, Monday to Friday, 9am to 5pm.

Messages are collected regularly throughout the day, so please leave a message if they are not available.

Outside office hours (Monday to Friday, 5pm to 9am, weekends and bank holidays) call Sky cardiology ward, **phone** 020 7188 8849 for advice. If you want some general advice about your child's health, please contact your local health visitor or GP.

Please **do not** bring your child to Sky cardiology ward, as we might not have a bed for them. Your child will be transferred to Evelina London if your local paediatric doctors and the cardiologists at Evelina London decide they need to be admitted for cardiac care.

## Pain

Your child will need regular painkillers for a few days after surgery. It is important that you make sure your child's pain is well controlled. Your nurse or pharmacist will give you information about this when you are in hospital, as each child has different needs.

To prevent pain when handling small children or babies, it is best hold them behind their back and legs rather than under their arms. Your nurse can show you how to do this.

You can also talk to the team and the play specialist at the hospital about other ways to minimise pain, and for distraction ideas.

## Caring for the wound

After cardiac surgery your child will have a surgical wound. A surgical wound takes about 8 to 12 weeks to completely heal. It will take about 3 to 4 weeks to scab over.

While the wound is healing, your child may get some of the following symptoms, but these are all normal events associated with wound healing.

### Inflammation

The skin around the wound site might become inflamed. This is redness, slight swelling and pain. Inflammation is a normal response when the body has had surgery. This should improve in time. If it gets worse, it could be a cause for concern, and you should get medical advice. Bruising might also happen around the wound.

### Pain

It is normal for your child's wound site to be painful after surgery. This can be managed with painkillers which should be given as advised by the ward team. As the wound heals and the bruising and inflammation reduce, the pain should decrease. If the pain gets worse, this is cause for concern and you should get medical advice.

### Scab

In most wounds a scab will form. A scab is a clot of blood which forms naturally to protect the wound from infection and allow the wound to heal. Under the scab, blood vessels and tissue continue to grow and repair. This strengthens the wound. It is normal for your child to experience tingling and itching around the wound site.

Your child might get a **pulling feeling** around the stitches. This occurs as the wound edges are pulled together and normal blood supply restored.

### **Stitches**

Most wounds will have dissolvable stitches. These will disintegrate by themselves and do not need to be removed. Some children on Sky cardiology ward will have stitches that need to be removed either before they leave hospital or by your children's community nursing team. Our team will let you know before you leave.

### **Wound dressing**

Your child's wound dressing will usually be removed 5 days after surgery. If your child leaves hospital before this, the ward team will arrange for the community nursing team to do this.

### **Wound complications**

If your child has any of the following symptoms, it might be a sign of an infection. If any of them occur, you should contact your GP and the outreach team. We have a wound review service, which the outreach team can organise for you to see.

- An increase in redness around the wound.
- An increase in swelling around the wound.
- An increase in pain.
- An offensive smell.
- An increase in discharge (pus, blood or straw-coloured fluid) from the wound
- The edges of the wound separate (break down)
- High temperature (fever)

## **General care**

Your child's wound might remain tender and sensitive for some time after surgery. You can give painkillers as directed by a doctor or pharmacist. If your child has hiccups or is coughing, this can cause pain. It can help to hug a pillow to their chest.

Your child might complain of itchiness at the wound site. This is normal but if it doesn't settle, speak to your GP or pharmacist about medicine to reduce this. Keeping the wound cool will reduce the itching. You should keep the wound covered with light, clean clothes so that your child does not scratch it.

It is important that the wound is not exposed to the sun and does not get sun burnt, so make sure it is kept covered.

## **ISLA**

ISLA is a secure app that lets us monitor your child's wound without you having to bring them to hospital. We will ask for your permission (consent) before we create an account for you. Before you leave hospital, we will show you the app, and your child's details will be entered onto it. This will include information about them, the type of surgery they had, and the stitches we used to close the wound.

A photo of their wound will also be added to the system. This will act as a starting point for monitoring the wound.

The clinical team will ask you to upload any symptoms, or a photo, so that they can decide if any treatment is needed. We will then contact you to let you know if anything needs to be done.

## **Bath time**

If your child is old enough, it is recommended that they have a shower rather than a bath. This is a way that you can avoid getting the wound too wet.

If you do bathe your baby or child, make sure the bath water does not come above waist height, and that the wound is **not submerged**. If the wound becomes soaked, the edges can become soft. This means that the wound will take longer to heal, and it can lead to infection.

Tips when washing your child:

- Do not rub the wound dry. Instead pat it with a clean towel.
- Do not use any soap, shower gel, oil, talc, lotion or moisturiser on the wound until it has completely healed (usually 8 to 12 weeks). These can irritate the wound and delay healing

## **Chest drain site**

Chest drain stitches need to be removed 5 to 8 days after the chest drain has been taken out.

If your child is an inpatient, their nurse will remove them. If they have been discharged, the ward team will arrange for the community nursing team to do it. Your child's nurse will tell you when this should be.

## Hydration (drinking enough fluids)

If your child has been diagnosed with a cyanotic heart condition (blue children), it is very important that they do not become dehydrated.

The same applies for any child who has a shunt or stent in their heart or heart vessels or is on diuretics. Please check with your child's nurse or doctor if you are not sure if this applies to your child. During hot weather or if your child is unwell, it is very important that they drink lots of fluid.

If they are being sick a lot (vomiting), have diarrhoea or are feeding poorly, you should make an **urgent appointment** to see your GP on the same day. If you cannot see your GP, contact the outreach team or Sky cardiology ward for advice (contact details are at the end of this booklet).

Please note that if your child has diarrhoea or is vomiting, they will not be absorbing their medicines as normal. This can have a serious effect on your child. If they are on diuretics (medicines to make them lose salt and water, such as furosemide or spironolactone), this can make them more dehydrated. **Do not stop the medicines, but get medical advice on the same day.**

## Getting back to a normal routine

Your child will need time to recover, and it might be some time before they can return to a normal routine. Your child's sleep pattern might change after the different routine in hospital, but it will return to normal.

Being in hospital can be a challenging time for your child and the whole family. It is good for them to talk about their experiences. The hospital has trained counsellors available to support you (contact details for counsellors and support groups are at the end of this booklet).

### **Babies and toddlers (up to 2 years)**

Your baby or toddler will not remember the experience of heart surgery and should recover within 2 to 4 weeks

Toddlers can be quite unsettled or clingy in the first few weeks after leaving hospital. This can be related to their time in hospital and the change of routine and environment.

### **Young children (2 to 9 years)**

Your child should recover 3 to 6 weeks after the operation. During the first 2 weeks, it is important that they avoid rough play as much as possible, to allow the breastbone time to heal.

Contact games and certain sports should be avoided for 6 to 8 weeks. Please speak with your doctor or nurse for more information.

### **Teenagers and young adults (10 years old and over)**

In this age group, recovery from surgery will vary, and can take 2 to 3 months.

### **Going back to school**

Your child can help decide, with members of the cardiology team, when to return to school and how much activity they can manage.

Your child can usually return to school 4 to 6 weeks after leaving hospital, but they might need to start with a half-day or just specific lessons. It is a good idea to meet with your child's teacher to discuss your child's needs before and after the surgery. If the school needs more information or advice, please speak to the CNS team.

### **Playing sports**

The cardiologists do not recommend contact sports or swimming until your child has had their first review after surgery. The time it takes before a child can play other sports again will depend on their age and cardiac condition.

### **Dental hygiene**

Good dental hygiene is important for all children, but it is essential for children who have had heart surgery. This is to help prevent endocarditis, which is a rare infection in the heart. Please ask for our leaflet, **Your child's heart problem and dental care**, for more information.

It is important that your child has regular dental checks when their teeth appear. Brushing your child's teeth is very important to prevent tooth decay and infections. A dentist or hygienist can show you how to do this properly. You can start to brush your child's teeth from the time they begin to appear. Parents should help with tooth brushing until children are 7 years old.

## Your child's medicines

Your child might need to take medicines for some time after leaving hospital.

The hospital pharmacy will give you 2 weeks supply of medicines. You will need to renew the prescription with your child's GP as soon as possible. Some medicines need to be supplied specially, so you must make sure you request a new prescription a few weeks before you need them. Delays, especially around public holidays can mean you run out, and it's important that your child doesn't miss any doses.

It is important that your child continues to take the medicine until the cardiologists tell them to stop. If your child does not take the medicine, it can slow their recovery and they might need to return to hospital.

We will explain when and how to give the medicine before you go home. Some people find the instructions difficult to understand, but you can always ask us questions if you are unsure.

If your local pharmacist has problems supplying your child's medicines, ask them to phone the Evelina London pharmacy and speak with a pharmacist (contact details are at the end of this booklet).

Your child's medicine might need to be measured in an oral syringe. You will be given some syringes with the medicine before you go home. Please discuss with your child's GP or local pharmacy how to get more.

## **Giving medicines**

It is important to follow the instructions on the medicine container, as the dose (amount to be given) can vary. Different strengths of medicines are available, and when you renew your child's prescription, you might not get the same strength.

Please double check the dose with your pharmacist each time you renew the prescription.

The medicine should be given at about the same time each day, with the same number of hours between doses.

An easy way to do this is to make a timetable or chart and place it wherever you keep the medicine or on your fridge door. Tick off the medicine when it is taken, until you get your routine established. If your child is at school, please ask your nurse to help you establish a routine that avoids giving medicines during school hours.

Babies should be given most medicines before their feed, as they might be sick if the medicine is given afterwards.

Do not put the medicine into your child's bottle. If your child refuses to drink it all, they will not have received all of their medicine.

Please note that babies and children often keep medicines in the back of their mouth. You should check to make sure they have swallowed the medicine.

## **Sugar-free medicine**

Please ask your pharmacist to give you sugar-free medicines, or those with the least amount of sugar in. This is especially important if the medicine is to be used for a long time. It will help to prevent problems with your child's teeth.

## **Storing medicines at home**

- Keep all medicines out of your child's reach. The ideal place is in a locked cupboard.
- Check the label on the medicine container for storage instructions. Some medicines need to be kept in the fridge or in a cool, dark place. If medicines need to be stored in a fridge, you might consider getting a lock for your fridge.
- Ask your pharmacist to supply the medicines with child-proof lids.

If your child is on diuretics, they will probably pee within an hour of having the medicine.

Please check with your cardiologist or CNS nurse before giving medicines you buy from a pharmacy or shop. Some shop-bought medicines are not compatible with cardiac medicines or some cardiac conditions.

If you would like the Sky cardiology ward nursing team or pharmacist to help you make a medicine chart, please ask. Here is an example chart which you can use. Medicine times can be adjusted so that medicines do not have to be given during school hours. You can ask your nurse for help with this.

Medicine chart

Medicine	To treat	Dose (amount)	Times to take medicine	Special instructions	Common side effects

## Immunisations

Please wait 6 weeks after surgery before giving your child any immunisations. After this, it is important that your child receives their immunisations as normal. If your child has low immunity please discuss with your immunology consultant about which vaccines they can receive.

Patients on the Home monitoring programme can have all vaccinations except the rotavirus vaccine.

If you are unsure about immunisations, please contact the CNS team or Sky cardiology ward team. Please be aware that children who are taking salicylate medicines, such as aspirin, should not receive the nasal flu vaccine. There are other flu vaccines available and your doctor, nurse or pharmacist will be able to give you more information about what is most suitable for your child.

## Travel

You should check with your child's consultant to make sure they are happy for your child to travel. You will also need to make sure you:

- have informed your insurance company and airline of your child's heart condition
- have got a copy of their discharge letter with you
- have all medicines in their original bottles or boxes
- know where the nearest hospital is to where you are staying, and how to get there (if you should drive or call an ambulance)

The airline might require a letter from your child's consultant to say that your child is fit to travel. If you need any more information, please contact the cardiac CNS team.

If the medicine bottles are more than 100mls, you will need to take a prescription to take them on board. You might want to contact the airline a month before you travel, to check there are no issues with the medicines or anything else.

## Acute kidney injury (AKI)

If your child has been diagnosed with an AKI during their stay in hospital, an appointment will be sent to you for an AKI follow-up clinic. This is usually 3 months after your child has left hospital. Please collect a urine (pee) sample to bring to the follow-up clinic. If you collect the sample the day before the appointment, it can be kept in the fridge overnight.

### When to get help

If your child had an AKI, you should monitor for these symptoms:

- Not peeing
- Feeling thirsty
- Diarrhoea and vomiting
- Swelling (oedema)

If symptoms occur, call the CNS team, **voicemail** 020 7188 4546 or Sky cardiology ward, **phone** 020 7188 8849 for advice.

For more information visit

**web** <https://www.infokid.org.uk/acute-kidney-injury>

## Support and more information

**ECHO** (Evelina Children's Heart Organisation), for those treated at Evelina London we support children, young people, teenagers and their families. From diagnosis, through treatment and care or bereavement.

**phone** 07715 208077 **web** <https://echo-uk.org/>

**email** [admin@echo-evelina.org.uk](mailto:admin@echo-evelina.org.uk)

**Little Hearts Matter**, for families of children born with hypoplastic left-heart syndrome and any other single ventricle condition. **phone** 0121 455 8982 (24 hours)

**web** [www.lhm.org.uk](http://www.lhm.org.uk) **email** [info@lhm.org.uk](mailto:info@lhm.org.uk)

**Children's Heart Federation**, for information on a wide variety of issues for parents or carers.

**freephone** 0808 808 5000, Monday to Friday, 9.30am to 9.30pm **web** [www.childrens-heart-fed.org.uk](http://www.childrens-heart-fed.org.uk)

**British Heart Foundation**, **web** [www.bhf.org.uk](http://www.bhf.org.uk)

## Contact us

For questions about your child's **cardiac catheterisation**, contact the cardiac outreach team, **phone** 020 7188 4546, Monday to Friday, 9am to 5pm. Out of hours, contact Savannah camel ward, **phone** 020 7188 8849.

For questions about your child's **cardiac surgery** contact the cardiology clinical courses team, **phone** 020 7188 4546, Monday to Friday, 9am to 5pm. If there is no answer, please leave a message. Out of hours, contact Sky cardiology ward, **phone** 020 7188 8849.

## Consultant at Evelina London

Name .....

Secretary .....

**Phone** .....

## Local children's specialist

Name .....

**Phone** .....

## Cardiology CNS team

**Voicemail** 020 7188 4546

**Email** PaediatricCardiologyCNS@gstt.nhs.uk

**Sky cardiology ward, phone** 020 7188 8849

**Dietitian** .....

**Phone** 020 7188 2013

**Appointments, phone** 020 7188 4000

Please have your child's hospital number ready

**Counselling team, phone** 020 7188 4538

**email** CounsellorsChildrensServices@gstt.nhs

## Dietitian

Name .....

**phone** 020 7188 2013

[illegible]

[illegible]

## **Evelina London Medicines Helpline**

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline, **phone** 020 7188 3003, Monday to Friday, 10am to 5pm **email** [letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

## **Your comments and concerns**

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS), **phone** 020 7188 8801 **email** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk). To make a complaint contact the resolution department **phone** 020 7188 3514 **email** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

## **Language and accessible support services**

If you need an interpreter or information about your care in a different language or format, please get in touch, **phone** 020 7188 8815 **email** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

## **NHS 111**

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day, **phone** 111 **web** [www.111.nhs.uk](http://www.111.nhs.uk)



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