

Going home after your child's cardiac catheterisation

Information from Sky cardiology ward

Patient name

Hospital number

Date of birth

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After the procedure

This leaflet is to help you know what to expect, from when your child returns from having a cardiac catheter, to when you have left the hospital. This does not cover every procedure but covers some of the routine aspects of caring for your child.

While your child is on the ward, the cardiac catheter team will give the ward team a plan for when your child can leave hospital (be discharged). This will specify whether:

- your child needs to stay overnight
- medicines are needed
- any other investigations or tests are needed (for example, ECHO scans, or X-rays)

The cardiac catheter team will review all of the investigation results and your child's clinical observations before you leave.

Your nurse will be monitoring your child frequently after the procedure. This includes checking their heart and breathing rates, oxygen levels, blood pressure, temperature, pulse, and the sites used for the catheter. Please let them know if you have any concerns about your child.

Your child can get out of bed when they have woken up properly. They might be a bit wobbly at first, so they will need to do this slowly and might need some help.

If your child needs to go to the toilet before they can get out of bed, and they no longer wear a nappy, please let your nurses know and they will help you. Your child might need to use a bottle or bedpan on the bed.

It is common for a child to feel sick or vomit after a general anaesthetic. We can sometimes give medicine to stop this. We will encourage your child to start drinking water first, and slowly reintroduce normal diet and drinks.

It is common for there to be some bleeding at the catheter insertion site, especially when the child starts to move around.

If your child has a dressing over the site, the nurse will also check it regularly. If you notice any bleeding in between checks, please let your nurse know.

Sometimes, patients need to be given a medicine called heparin after a cardiac catheter procedure. This is given if their pulses are difficult to feel. It means your child will need blood tests (to monitor the level of the medicine in the blood) and might need to stay in hospital longer.

Leaving hospital (discharge)

Most children have recovered within a few hours of a cardiac catheter procedure and will be ready to leave hospital later that day or the next day.

Before your child is discharged, they will need to have:

- eaten and drunk enough
- peed
- had their cannula (thin tube in the back of their hand or arm) removed
- had any stitches and dressings removed

You will also need a discharge letter from the ward team.

Your child's 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 visits.

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.

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 early as possible to prevent your child's condition getting worse.

Take your child to your nearest emergency department (A&E) if they have any of these symptoms after their cardiac catheter.

- Repeat of any arrhythmias (irregular heartbeats), they had before their treatment (children who've had a radiofrequency or cryoablation).
- Pins and needles, pain or numbness in the legs or feet.
- Cold, pale or mottled feet or legs.
- Swollen legs.
- Significant bleeding at the catheter site. Apply pressure to try to stop it and **phone 999 immediately**.

If your child has any of these symptoms, call the clinical nurse specialist (CNS) team in normal working hours, **voicemail** 020 7188 4546 or 111 or Sky cardiology ward, **phone** 020 7188 8849 for advice.

- Significant changes in your baby or child's feeding or eating pattern.
- They are not peeing as many times as normal
- They have a temperature above 38C within 48 hours of discharge home
- They are sleeping more than usual
- They are more sweaty than normal and/or have cool clammy skin have puffy eyelids
- They are irritable or they cannot be comforted.
- have red, oozing or painful groin site.

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 the Sky Cardiology ward as we may not have a bed for them. However, your child will be transferred to Evelina London if both your local paediatric doctors and the cardiologists at Evelina London decide they need to be admitted for cardiac care. We have a team on call 24 hours a day.

Caring for the wound

Your child can bath and shower as normal following the procedure. The wound should be washed each day to keep it clean, making sure the wound is fully dry after cleaning will help to prevent an infection. Please do not put any oil or moisturiser on the wound until it has fully healed. This usually takes a few days.

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. This is also true for any child who has shunt or stent in their heart or heart vessels. Please check with your nurse or doctor if you are not sure if this applies to your child. During periods of hot weather or when your child is unwell, it is very important that they drink lots of fluid. If they have vomiting, diarrhoea or poor feeding, please make an urgent appointment to see your GP on the same day or attend your nearest emergency department.

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

Going back to school

Your child can help decide, with members of the cardiology team, when to return to school and how much activity he or she can manage. Please ask the team before you go home. It is a good idea to meet with your child's teacher to discuss your child's needs before and after the procedure. If the school needs more information or advice, please speak to the outreach nurse.

Dental hygiene

Good dental hygiene is important for all children, but it is essential for children who have had heart surgery 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 once 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 up to the age of seven.

Your child's medicines

Your child might need to take medicine for some time after going home and the hospital pharmacy will give you 2 weeks supply of medicines. You will need to renew the prescription with your GP as soon as possible. Some medications need to be supplied specially and therefore you should ensure you request a new prescription a few weeks before you will need them, especially around public holidays. It is very important to make sure you do not run out of the medicines.

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

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

Your child's medicines 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 GP or your local pharmacy how to get further supplies.

Giving medicines

It is important to follow the instructions on the medicine container, as the amount to be given (dose) can vary. Different strengths of preparations are available and when you renew your prescription, you might not get the same strength. Please double check the dose with your pharmacist each time you renew the prescription.

Within reason, the medicine should be given at 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 times that avoid the need to give medicines during school hours. There is a chart on the next page which you can use.

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

If your child vomits after you give the medicine, please do not repeat it, just give the next dose as normal. If this happens frequently, please contact the outreach team for advice.

Babies should be given most medicines before their feed as they may vomit if the medicine is given after being fed.

Please do not put the medicine into your child's bottle. If your child refuses to take it they will not have received all of their medication.

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

Sugar-free medicine

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

Storing medicines at home

- Please keep all medication out of your child's reach. The ideal place is in a locked cupboard.
- Please 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.
- Please ask your pharmacist to supply the medicines with child-proof lids.

Please check with your cardiologist or clinical nurse specialist before administering over the counter medicines as some are not compatible with cardiac medications and some cardiac conditions.

Immunisations

We recommend following the national immunisation schedule. Exceptions include:

- If your child has low immunity please discuss with your immunology consultant about what vaccines they can receive.
- Children who are taking salicylate medicines, such as aspirin, should not receive the nasal flu vaccine. There are however other flu vaccines available and your doctor, nurse or pharmacist will be able to give you more information on what is most suitable for your child.

Travel

Before booking a holiday, please check with your Consultant that they are happy for your child to travel. In addition, you will need to make sure you have informed your insurance company and airline of your child's heart condition; that you have a copy of the discharge letter with you; that all medicines are in their original bottles / boxes and that you know where the nearest hospital is to where you are staying. The airline may require a letter from your Consultant stating that your child is fit to travel. If you need any more information, please contact the outreach team.

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

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

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 **email** 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

British Heart Foundation, **web** www.bhf.org.uk

Medicines for Children,

web www.medicinesforchildren.org.uk

Contact us

If you have any questions or concerns about your child's cardiac catheterisation, please contact the cardiology CNS team, **voicemail** 020 7188 4546, Monday to Friday, 9am to 5pm, if there is no response, please leave a message) **email** PaediatricCardiologyCNS@gstt.nhs.uk. Out of hours, please contact Sky cardiology ward, **phone** 020 7188 8849.

Consultant at Evelina London

Name

Secretary

Phone

Local children's specialist

Name

Clinical nurse specialist (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.uk

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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

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. To make a complaint contact the resolution department **phone** 020 7188 3514 **email** 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

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

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing, **web** www.nhs.uk



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