

Going home after your child's heart surgery

Information from Savannah Camel ward

| Patient name | Hospital number | Date of birth |
|--------------|-----------------|---------------|
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Going home

Going home is an important step in your child's recovery after heart surgery. This booklet has been given to you to help answer some of the questions you might have when your child leaves hospital.

You might be worried or nervous about taking your child home. These feelings are common and understandable. Our aim is to make going home as easy as possible and give you the necessary advice and support during your child's recovery.

Please speak to your Doctor, nurse or the outreach team before you leave hospital if you have any questions or concerns. You can also call the outreach team or Savannah Camel ward for advice when home.

Your ward discharge letter

You will be given a discharge letter when your child leaves hospital. This has important information about the 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 the event that 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

We have a team of cardiac outreach nurses called the Evelina London Cardiac Outreach Team who provide a support service for when you go home. They aim to call you within a week of discharge.

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 hospital and your local services, for example, your GP, midwife, health visitor, local paediatrician and schools.

The team will work with you and your Consultant or Doctor to ensure your child receives appropriate and individual care that meets the needs of your child and your family. The team is available Monday to Friday 9am – 5pm and can be contacted on 020 7188 4546.

Please speak to your doctor, nurse or the outreach team before you leave hospital if you have any questions or concerns. You can also call the outreach team or ward for advice when home.

What if my child is unwell at home?

There might be times when your child feels unwell. This could be something related to his or her heart condition or it could be an unrelated illness or infection.

Regardless of the problem, there will always be someone available to help you. Please seek advice as early as possible to prevent your child's condition worsening.

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

- has a sudden collapse and is unresponsive or you are unable to wake up your child
- is short of breath / has irregular breathing / making any new noises when breathing / 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 experiences any of the following symptoms within 48 hours of going home, please call the outreach team (020 7188 4546) or Savannah Camel ward (020 7188 8849) for advice.

- New cough (if your child hasn't got a cold)
- Sweating and/or cool clammy skin
- Significant changes in your baby or child's feeding or eating pattern
- Not passing urine as many times as normal
- Temperature above 38 degrees C
- Increased sleeping
- Increased sweating and/or cool clammy skin
- Puffy eyelids
- Irritability / inconsolable
- Recurrence of any arrhythmias (or irregular heartbeats) experienced prior to their hospital stay
- Recurrence of any symptoms experienced prior to their hospital stay
- New or increased vomiting

If your child is unwell after 48 hours, please call the outreach team (020 7188 4546) or Savannah Camel ward (020 7188 8849) for advice. Or take your child straight 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 local hospital.

Non-urgent advice:

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

They regularly pick up their messages throughout the day so please leave a message for them if they are not immediately available.

Outside these hours i.e. Monday to Friday, 5pm to 9am, weekends and bank holidays, please call Savannah Camel ward on 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 Savannah Camel 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.

Pain

Your child will need regular pain relief medication for a few days following surgery. It is important to 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 will have different needs. To prevent pain when handling small children / babies, it is best hold them behind their back and legs rather than under their arms. Your nurse can show you this. You can also talk to the team including the play specialist at the hospital about other ways to minimise pain and for distraction ideas.

Getting back to a normal routine

Your child will need time to recover at home and it may be some time before he or she 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 over time.

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 available at the end of this booklet. .

Babies and toddlers (0 – 2 years)

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

Toddlers can be quite unsettled or clingy in the first few weeks at home. This can be related to their experience in hospital and the change of routine and environment.

Young children (2 – 9 years)

Your child should recover three to six weeks after the operation. During the first two weeks, it is important that your child avoids rough play as much as possible, to allow the breastbone time to heal.

Contact games and certain sports should be avoided for up to six to eight 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 might take between two to three 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 he or she can manage.

Usually, your child can return to school four to six weeks after leaving hospital, but may 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 outreach nurse.

Playing sports

The cardiologists do not recommend contact sports or swimming for 8-12 weeks after surgery and until your child is reviewed in clinic and the wound has completely healed. How long it takes before a child can play other sports again will vary and depends on the age and cardiac condition of the child. It could be anything from 4-12 weeks after the operation. Your child's nurse or doctor will discuss this with you and give you more information before you go home and in your outpatient appointment.

Caring for the wound

Following cardiac surgery your child will have a surgical wound. A surgical wound takes around 8-12 weeks to completely heal. It will take approximately 3-4 weeks to scab over. While the wound is healing, your child may experience some of the following symptoms, but these are all normal events associated with wound healing:

- **Inflammation** – The skin around the wound site might experience inflammation. Inflammation is redness, slight swelling and pain. Inflammation is a normal response when the body has experienced trauma such as surgery. This inflammation should improve or lessen with time. If it increases then it could be a cause for concern and you should seek medical advice. Bruising might also occur around the site.
- **Pain** – It is normal for your child’s wound site to be painful following surgery. This can be managed with pain relief which should be given as advised by the ward team. Over time as the wound heals and the bruising and inflammation reduces, then pain should decrease and the need for pain relief will decrease. If the pain gets worse then this is cause for concern and you should seek 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. Beneath the wound 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 may experience **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 which will disintegrate by themselves and do not need to be removed. Some patients on Savannah Camel ward will have stitches that require removal before discharge. These stitches are removed approximately 7-10 days after surgery.

General care

Your child's wound may remain tender and sensitive for some time after surgery and therefore you can give pain relief as directed by a doctor or pharmacist. If your child has hiccups or is coughing, this may cause pain.

Your child might also complain of itchiness at the wound site. This is normal but if it becomes bothersome, please speak to your GP or pharmacist about medication to reduce this. Keeping the wound cool will reduce the itching. Please keep the wound covered with light, clean clothes so that your child does not scratch it.

It is important to ensure that the wound is not exposed to the sun / gets sun burnt so please ensure it is kept covered.

Bath time

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

If you do bath your baby or child, please ensure the bath water does not come above waist height and that the wound is not submerged. If the wound becomes soaked then the edges can become soft and the wound is more

likely to break down. This can greatly delay healing and can lead to infection.

Other 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 powder, lotion or moisturiser on the wound as they can irritate the wound until it has completely healed (8-12 weeks after surgery)

Chest drain site

Chest drain stitches need to be removed 5-8 days following removal of the chest drain. If your child is an inpatient then your child's nurse will remove them. If you are discharged before your chest drain stitches are due for removal then you will need to make an appointment for them to be removed by the practice nurse at your GP surgery. Your nurse will tell you when this should be.

Wound dressing

Your child's wound dressing will usually be removed five days after surgery. If your child goes home before this day, you will need to go to the GP for the dressing to be removed. If there is a need for regular dressing changes, the ward team will arrange for a community nurse to change this for your child.

Wound complications

If your child experiences any of the following signs and symptoms it might be an indication of infection and you should contact your GP and the Outreach team. We

have a wound review service which the Outreach team can organise for you to attend.

- An increase in redness around the wound
- An increase in swelling around the wound
- An increase in pain
- An offensive odour
- An increase in discharge from the wound (pus, blood or stew like fluid)
- Wound break down (the edges of the wound separate)
- High temperature

Your child's medication

Your child might need to take medication for some time after going home and the hospital pharmacy will give you two 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. We will explain when and how to give the medication before you go home. Some people find the instructions difficult to understand straight away, so please do not hesitate to ask us questions.

If your local pharmacist has problems supplying your medication, 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 medication might need to be measured in an oral syringe. You will be given some syringes with the medication before you go home. Please discuss with your GP and / or your local pharmacy how to get further supplies.

Giving medication

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

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

Within reason, the medication 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 medication or on your fridge door. Tick off the medication 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.

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

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

Please note: Babies and children often keep medication in the back of their mouth. Please check to make sure they have swallowed the medication.

Sugar-free medication

Please ask your pharmacist to give you sugar-free medicines 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 medication 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.

If your child is on diuretics, it is likely that they will pass urine within an hour of having the medicine.

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

If you would like the Savannah Camel team to help you make a medicine chart, please ask. There is a chart at the end of this pack which you can use. Medication times can be adjusted so that medicines do not have to be given during school hours – please ask your nurse for help with this.

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.

Hydration

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, as well as some children that have saturations below the

normal 95% and above. 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. If you are unable to see your GP, please contact the outreach team or Savannah Camel ward for advice. Contact numbers are at the end of this booklet.

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.

Immunisations

Please wait six weeks after surgery before giving your child any immunisations. After this, it is important that your child receives their immunisations as normal. However, if your child has low immunity, they must not receive live vaccinations. If you are unsure about this, please contact the outreach team or Savannah Camel ward. Please note, if your child is due to have surgery, they should not have the vaccinations less than four weeks before. Please call your outreach nurse or discuss with your doctor for more information. Please be aware that 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

further 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 ensure 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.

Useful sources of 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.

t: 07715 208077 **w:** www.echo-evelina.org.uk **e:** admin@echo-evelina.org.uk

Little Hearts Matter: for families of children born with Hypoplastic Left Heart Syndrome and any other single ventricle condition. **t:** 0121 455 8982 (24 hours)

w: www.lhm.org.uk **e:** info@lhm.org.uk

Children's Heart Federation: can give information on a wide variety of issues for parents or carers.

t: Freephone: 0808 808 5000, Monday to Friday 9.30am to 9.30pm **w:** www.childrens-heart-fed.org.uk

British Heart Foundation: **w:** www.bhf.org.uk

Medicines for Children:
www.medicinesforchildren.org.uk

Your contact names and numbers

Consultant at Evelina London:

Name

Secretary

Contact details

Local paediatrician

Name

t:

Cardiac outreach nurse

Name

t: 020 7188 84546

e: Paediatriccardiologyoutreachnurses@gstt.nhs.uk

Savannah Camel ward

Name

t: 020 7188 8849 / 85656

Dietitian

Name

t: 0207 188 4568

Appointments

t: 0207188 4000

Please have your child's hospital number to hand

Counselling team

Name **t:** 0207 188 4568

GP

Name **t:**

Heath visitor

Name **t:**

Contact us

If you have any questions or concerns about your child's cardiac catheterisation, please contact The Cardiac Outreach Team on 020 7188 4546 (Monday to Friday, 9am to 5pm). Out of hours, please contact Savannah Camel on 020 7188 8849.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.evelinalondon.nhs.uk/leaflets

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.

t: 020 7188 3003 10am to 5pm, Monday to Friday

e: letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

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A list of sources is available on request



Medicine chart

| Medicine | What it's for | Dose | Time to take medicines | Special instructions | Common side effects |
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