



University Hospitals Bristol
NHS Foundation Trust

Patient information service
Bristol Royal Hospital for Children

Discharge advice following cardiac surgery



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Bristol Royal Hospital
For Children

Introduction

This information booklet will provide you with the important information you will need before taking your child home after cardiac surgery.

At the back of this booklet, we have left space so that we can add anything additional that may help you regarding your own child's particular needs. You can also use this space to write any additional questions or concerns you may have for the team who have cared for your child.

Getting home

Taking your child home after cardiac surgery can feel very daunting; this is normal. There are some important contact numbers at the back of this booklet so you know how to reach us if you are unsure of something or have a question once you have gone home.

You will be given a discharge summary letter. This is an important record of your child's stay in hospital; it is useful to take this with you if you need to go to a different hospital. A copy will be sent to your GP, health visitor and local paediatrician.

You will then be seen by your cardiology consultant, usually within two weeks of being discharged. This may be here in Bristol, or sometimes we can arrange this to be in your local hospital.

We will let you know where you will be seen on the day of discharge.

Wound care

It usually takes two to three weeks for the skin around your child's wound to heal. If your child's wound is in the middle of their chest, it can take up to three months for the bone to heal. The clear stitches around the wound will dissolve and do not need removing. Any black or blue chest drain stitches DO need removing. These stitches are usually removed 7 days after the drain comes out. If you have been discharged from hospital by this date, you will need to make an appointment with your GP practice nurse to have them removed. Your ward nurse will advise you on timings before you go home.

It is normal for the wound to feel itchy as it heals. It will often appear pink around the edges as it is healing.

Contact your GP or cardiac nurse specialist 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
- the wound becomes very painful / hot to touch.

It is important to keep the wound clean and dry. Avoid wetting the wound until all stitches are removed. Once the wound is healing, use only warm water and mild soaps, and avoid soaking the wound until the scabs have fallen off (usually around four to six weeks). We do not recommend using creams or lotions until the wound is fully healed.

Do not expose the scar to the sun for at least six weeks. After this, it is important to use SPF 50 sun protection, and ideally a t-shirt to cover the scar to avoid burning.

Medicines

Your child may be discharged with medications. The team caring for your child will give you information about the medications that your child needs to take. It's important to stick to the times and doses you've been given until your follow up appointment with your cardiologist. The hospital will provide you with your first supply of medication, which will usually last two weeks. Repeat prescriptions need to be arranged with your GP and local pharmacy.

Important things to remember:

- allow plenty of notice when ordering your repeat prescriptions; remember this cannot be done over the weekend/bank holidays
- 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, as some medications come in different strengths – always clarify with your pharmacist.

It's important to continue with regular pain relief for several days after discharge. You will be advised before going home which pain relief you can give, and how often.

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.

General advice

We hope your child will continue to recover and progress well at home. However, there is always a small risk complications can occur. You should seek medical advice should your child display any of the following signs and symptoms:

- puffiness or swelling, particularly in their face, hands and feet
- increased sweating
- change in their colour
- increased breathlessness
- temperatures.

Call 999 if:

- you hear persistent grunting in your child, noisy breathing or severe shortness of breath
- your child is floppy and unresponsive
- there are prolonged changes in your child's skin colour, such as the skin is significantly more blue or grey than usual, is cold to touch or waxy looking.

It is normal for your child to take a few days to settle back into their routines. Speak to your GP, health visitor or cardiac nurse specialist if:

- your child stops or significantly reduces feeding/eating
- they are losing weight

- their urine output significantly decreases
- they become significantly tired or irritable.

It's important to try and normalise your child as much as possible, so visitors should be encouraged if appropriate. However, we would advise you to avoid this if any of them are unwell. Your child's immunity may temporarily be a bit low after a major operation, such as cardiac surgery and an infection can delay recovery.

Play and exercise

- It is important that rough play is avoided for six weeks.
- Try to avoid picking your child up from under their arms for six weeks.
- We do not advise swimming until at least six weeks after surgery.
- Try to avoid nursery or playgroup for four to six weeks, it is a good idea to speak to the person in charge before your child starts back.
- All contact sports and activities that could involve a blow to the chest should be avoided for three months, 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 seen in clinic and the doctor or clinical nurse specialist (CNS) has said it is okay to restart introducing these activities.

Returning to school

- We would normally recommend that children do not return to school or nursery for approximately six weeks after surgery.
- Your son or daughter may be keen to return to school earlier. Please wait until your follow up appointment and discuss this with your cardiologist or contact the cardiac nurse specialists.
- Your child 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 – please liaise directly with the school.

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 bacteria getting into the bloodstream and settling on the inside of the heart. Children with some congenital heart defects are at a higher risk of this infection.

Because of this risk, we recommend:

- good dental hygiene with dental check-ups every six months
- ensure your dentist is aware of your child's heart condition
- take your child to your GP if they've been experiencing flu-like symptoms for longer than ten days
- try to avoid piercings and tattoos as these carry a high risk of infection.

Please note: historically, antibiotics have been offered routinely as a preventative measure for patients at a higher risk of infective endocarditis. However, there is little evidence to

support this practice. For discussion of this evidence, see the full guidelines at: www.nice.org.uk/CG064

Here's a useful link explaining a little more about endocarditis:

<https://www.bhf.org.uk/heart-health/conditions/endocarditis>

Immunisations

It is important that children with heart conditions avoid potentially serious diseases. Discuss your child's routine immunisations with your GP, cardiologist and cardiac nurse specialist. We usually advise you to delay routine immunisations for at least six weeks following surgery, to ensure your child has fully recovered from the procedure. You can check this with the doctor or cardiac nurse specialist at your outpatient appointment or via telephone.

Going on holidays

The majority of children have no difficulties with air or sea travel, we generally advise to wait at least three months following surgery. However there are exceptions; please discuss this with your cardiologist or cardiac nurse specialist.

Things to remember when you travel:

- Take a clinic or discharge letter with your medication and child's details on it
- remember to take enough medication
- cover the scar as much as possible, and use at least factor 50 sun protection
- ensure your child stays well hydrated
- it's important you have holiday insurance – if you need any advice on companies, please contact the cardiac nurse specialist.

Things to think about as you're going home:

- 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?
- Who can I contact if I have a problem?
- Do I have any other questions or concerns before going home?

The cardiac nurse specialists

The cardiac nurse specialist (CNS) team is made up of 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.

You may know which CNS is linked to your cardiologist, so feel free to ask for them in person, but otherwise, any of the CNS team will be able to help with your query or pass on a message for you.

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.

If no one is available at the time of your call, please leave your name and number and someone will get back to you.

Please note: for families living in Wales, your first point of call will be the Welsh cardiac nurse specialists team, who are available Monday to Friday, 8.00am to 4.00pm on **02920 744 753** or **02920 745 184**.

Contacting us

We are available Monday to Friday, 8.00am to 4.00pm.

You can contact us by phoning: **0117 342 8286** or **0117 342 8578**

If we are not available, please leave a message with your child's name, date of birth and your telephone number, and we will get back to you as soon as possible.

Alternatively, you can email us on:

CardiacNurses@UHBristol.nhs.uk

Useful contact numbers

Ward 32 **0117 342 8332**

0117 342 8679

Outpatients **0117 342 8440 / 8441**

Cardiac Pharmacist

Call switchboard on **0117 342 0000** and ask for them to bleep **3091**.

If you are calling for medical treatment advice or any urgent medical issues, you should contact the on-call paediatric cardiology registrar on **0117 923 0000**, bleep number **2424**.

Cardiology secretaries

Rob Martin	0117 342 8855
Graham Stuart	0117 342 8852
Alison Hayes	0117 342 8855
Andy Tometzki	0117 342 8853
Robert Tulloh	0117 342 8856
Mark Walsh	0117 342 8852
Demetris Taliotis	0117 342 8856
Patricia Caldas	0117 342 8853
Michael Yeong	0117 342 8854
Catherine Armstrong	0117 342 8853
Guido Pieleš	0117 342 8854

Useful websites

<http://www.swswhd.co.uk>

<http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children>

<https://www.medicinesforchildren.org.uk/>

<https://www.lhm.org.uk/>

<https://www.heartfamilies.org.uk/>

Notes and queries

Please note that if for any reason you would value a second opinion concerning your diagnosis or treatment, you are entirely within your rights to request this.

The first step would usually be to discuss this with the doctor or other lead clinician who is responsible for your care.

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, audio or PDF format, please email patientleaflets@uhbristol.nhs.uk.

