A lifetime of specialist care

Royal Brompton & Harefield NHS
NHS Foundation Trust

Royal Brompton Hospital

When your child goes home after heart surgery

Table of contents

This leaflet gives you general information about when your child goes home after heart surgery. It does not replace the need for individual advice from a qualified healthcare professional. Please ask if you have any questions.

Going home

Some children are well enough to go home just a few days after surgery. Others need more time to recover and may need to stay in hospital for longer. Your child's cardiologist (heart doctor) or surgeon will discuss this with you.

This leaflet explains what to expect when your child does go home and will help you plan his/her recovery.

Get advice 24 hours a day

If you are worried about your child's health or need advice when you are back at home, you can speak to a nurse on Rose Ward 24 hours a day.

You can also speak to our clinical nurse specialists in children's cardiac care from 9am-6pm, Monday to Friday. See useful contact details page 12.

When to contact us

Please call us if your child:

- becomes more breathless, or if his/her breathing becomes noisy
- looks more blue (in colour)
- does not feed well or sweats during feeds
- lacks energy
- does not put on weight
- loses weight
- is irritable (cannot be easily comforted).

Or if he/she has:

- a puffy face or body
- dry nappies
- a fever
- blood in poo (stools) – particularly newborn babies.

If your child collapses and does not respond (react) to you, or becomes very short of breath, please call 999 for an ambulance. If possible, give the ambulance crew a copy of the discharge summary we give you when your child goes home (see Follow-up care page 7).

Remember: Royal Brompton and Harefield hospitals do not have accident and emergency (A&E) departments.

Medication and prescriptions

We will give you medication to last for two weeks at home. Your nurse/pharmacist will discuss the medication with you. We will also give you a letter to take to your GP to get a prescription for more medication. It is important that you visit the GP within a few days of being back at home so you do not run out.

While your child is in hospital, your nurse will show you the best way to give medication. You can ask your nurse to practise this with you while your child is in hospital.

It is very important to take medication until your child's cardiologist tells you to stop. If your child does not take the medication, he/she may take longer to get better and you may need to bring him/her back into hospital.

We will also explain how to give your child paracetamol to ease (help) pain once you are at home. But make sure you always check the instructions on the bottle or box. If the paracetamol is not helping your child, contact your GP or our clinical nurse specialists for advice.

Remember to keep all medication out of reach of children. The best place to store it is in a locked cupboard. Some medication needs to be kept in the fridge or in a cool, dark place. Please read the label carefully.

Tips for giving medication to your child

- Try and give the medication at the same times each day.
- Give the medication to your child before feeds – unless the medication label or prescription says otherwise. Some children may vomit (be sick) if you give them medication after a feed.
- If your child vomits or spits out the medication straight away, you can give it again.
- If your child vomits more than half an hour later, do not give the medication again until the next dose is due.
- Do not put medication in your child's bottle because he/she may not finish it, and so not have the full dose.

If you need help, please contact our clinical nurse specialists or the medicines information line (see page 12).

Feeding your child

It is important to encourage your child to eat to reach a normal weight as this will help him/her get better. But it may take some time for your child put on weight.

See your health visitor regularly to check your child's weight, and particularly if you notice any unusual weight loss or weight gain.

You can also contact our clinical nurse specialists for advice on any problems you have feeding your child (see page 12).

If your child is aged five or under, you can ask your health visitor for help with feeding too.

Babies with heart conditions are sometimes given high-calorie milk. If your baby is on a special milk, our dieticians will contact your local hospital to check he/she is getting enough milk. You will need a prescription from your GP to get more special milk.

Over time, your child's appetite (interest in eating) should return to normal.

Tube feeds

If your child goes home with a nasogastric (NG) tube, we will train you in tube feeding. We will also refer your child to the local community children's nursing team which can offer support and advice on tube feeding.

Contact our clinical nurse specialists if you have any more questions.

Stitches

We will usually remove any chest drain stitches (blue) about five days after the surgical drains (tubes that drain fluids from wounds) have been removed. This will usually happen before your child goes home.

If it does not, your nurse will tell you when to have the chest drain stitches removed at your GP's surgery or in our day case unit.

The wound from the operation is stitched together with dissolvable stitches. These do not need to be removed, but will dissolve over a period of about six to eight weeks. But if a stitch pokes out of the top or bottom of the wound and is causing irritation (red or sore), it can be cut off at skin level. This should be done by a doctor or nurse. Please ask your clinical nurse specialist for advice.

Wound care

We usually remove the dressing that your child has from the operation before you leave hospital. However, sometimes we need to arrange for the dressing to be removed after your child leaves hospital. If this happens, we will discuss it with you before your child goes home.

Your child can have a shower or wash with a flannel after the operation. But it is important not to soak the wound (make it completely wet) for three weeks after the operation.

When your child is having a shower, please keep the wound away from the showerhead. After a shower or wash, please dry the wound with a clean towel. It is important not to rub the wound or the area around it vigorously (too hard). Try to dress your child in loose fitting clothes so that the skin does not become irritated (red or sore).

To prevent infection, please make sure the wound is covered while your child is eating or drinking.

The wound should also be covered and kept out of the sun for one year after the operation.

If you think the wound is infected

If the wound is infected, it will look red and angry and may feel hot to the touch. It may be swollen and there may be fluid or pus coming from it. Your child may feel unwell, have no energy, be irritable (cross) or have a high temperature.

You need to contact the clinical nurse specialists or Rose Ward.

If your child has a fever and there are signs that the wound is infected, you must take him/her to the emergency department (A&E) of your local hospital as soon as possible.

Your child may need to have a course of antibiotics. A sample of the tissue, skin, or fluid from the wound may also need to be tested to find out what has caused the infection.

Follow-up care

Within six weeks of going home from hospital, your child will have a follow-up appointment with a cardiologist in the outpatients department at Royal Brompton or Harefield.

We will post the appointment letter and information to you. If you have not received a letter within a week of going home, please call our ward clerk on **020 7351 8543** (who arranges appointments for both hospitals).

At first, your child may need to come for a follow-up appointment every three to six months. As time goes on, appointments will probably only be needed once a year or less.

If your child is aged five or under, we will let your health visitor know when he/she goes home after heart surgery.

If you do not hear from the health visitor within a week of your child going home, please contact him/her direct. If you do not have contact details for your health visitor, please call your GP's surgery. You can also go to a baby clinic at your local health centre for checks on your child.

We will give you a full discharge summary (clinical report about your child) when you go home.

This will include information on the treatment and medication your child will need to take. Your GP will get a copy and we can also send it to your health visitor and community nurse, if needed.

Please keep the summary safe. It is helpful for future appointments or if your child needs to go back to hospital.

Getting back to normal

Every child is different and will recover at his/her own pace. Some children may have trouble sleeping, eating or returning to their normal daily activities.

Try to get back into your usual daily routine when possible. However, it is important to take things slowly during the first few weeks, so take care not to plan too many activities.

Going out

Your child can go out, but should keep away from children and adults who are unwell for the first two weeks after the operation. This is to reduce the risk of infection.

It is important that you do not plan a holiday abroad before your child has his/her first follow-up appointment.

Lifting up your child

Please do not lift up your child under the arms for three months after the operation. This will put too much pressure on the chest while it is healing (mending). Instead, lift your child by placing one of your hands under his/her head and the other one under the bottom.

Going back to school

Your child should not go back to school until six weeks after the operation.

At the first follow-up appointment, the cardiologist will discuss with you when your child can go back to school.

If the follow-up appointment is more than a few weeks after your child is back at home, you should contact our clinical nurse specialists for advice (see page 12).

Endocarditis

Endocarditis is an infection of the lining of the heart and valves. It is caused by bacteria entering the blood from outside the body. It is a very rare, but serious condition.

Some children with heart conditions are at risk of this infection – mainly those who have had a valve replacement or have cardiomyopathy (a general term for diseases of the heart muscle).

Symptoms of endocarditis are different depending on the age of the child.

Get in touch with us if you child shows the following signs:

If your child is aged under five:

- is lethargic (tired) and has no appetite (not hungry)
- has a fever
- is sweating
- is breathless (breathing fast).

If your child is six-years-old or over and has:

- a sudden high fever
- headache
- muscle weakness
- and vision (eyesight) changes.

Children at risk of endocarditis may need a course of antibiotics before dental treatment or surgery. Please ask us for advice.

Dental hygiene

One of the ways an infection (such as endocarditis) can enter the body is through the mouth. This is why it is important children brush their teeth regularly and limit the food and drink containing high amounts of sugar that they eat. Your child needs to visit the dentist every six months for check-ups.

Body piercings or tattoos

If your child is old enough to want body piercings, please discuss this with us first. We advise children not to have tattoos because they can get easily infected and this increases the risk of developing endocarditis.

Immunisations

We recommend that children with heart conditions have the usual childhood immunisations. But please speak to us if your child is due to have any immunisations.

Support groups

You may find these support groups useful.

The Brompton Fountain is a charity that supports families of children under the care of Royal Brompton Hospital for severe and life-threatening heart and lung conditions.

Website: **www.thebromptonfountain.org.uk**
Tel: **03300 22 92 91** (direct line)

Children’s Heart Federation is dedicated to helping children with congenital or acquired heart disease and their families in Great Britain and Northern Ireland.

Website: **www.chfed.org.uk**
Freephone infoline: **0808 808 5000**
(Monday to Friday, 9.30am-2pm)

British Heart Foundation provides health information for people with heart conditions.

Website: **www.bhf.org**
Tel: **020 7554 0000**
Heart helpline: **0300 330 3311**
(Monday to Friday, 9am to 5pm)

Little Hearts Matter provides information on single ventricle conditions, such as hypoplastic left heart syndrome and pulmonary atresia.

Website: **www.lhm.org.uk**
Tel: **0121 455 8982**

Down’s Heart Group provides support and information about heart problems related to Down's Syndrome.

Website: **www.dhg.org.uk**
Tel: **0300 102 1644**

Max Appeal is a charity providing support to families of children affected by DiGeorge syndrome (this is also called 22q11.2 deletion syndrome, or velo-cardial-facial syndrome).

Website: **www.maxappeal.org.uk**
Helpline: **0300 999 2211**

The Somerville Foundation supports young people and adults with congenital heart disease.

Website: **www.thesf.org.uk/about-us**

Helpline: **0800 854 759** (answerphone at weekends)

Useful contact details

Rose Ward (ask for the nurse in charge)	**020 7352 8121** extension **2411**, **2412** or **2413** (24-hour)
Clinical nurse specialists in children's cardiac care	**020 7349 7727** (direct line available Monday to Friday from 9-6pm)
Children's outpatients department	**020 7352 8121** extension **4004** (Monday to Friday, 9am-5pm)
Royal Brompton general outpatients department (to change your appointment)	**020 7351 8011** (Monday to Friday, 9am-5pm)
Harefield children's outpatients department	**01895 823 737** extension **5573** (Monday to Friday, 9am-4pm)
Medicines information line	**020 7351 8901** (Monday to Friday, 9am-5pm)

Family liaison manager	**020 7352 8121** and ask for **bleep 1274** (Monday to Friday, 9am-5pm)
Dietitians	**020 7352 8121** and ask for extension **8465** (Monday to Friday, 9am-5pm)

The adult congenital heart disease (ACHD) transition team

This team of clinical nurse specialists at Royal Brompton and Harefield works with children and their families from the age of 12 to prepare for the move from the paediatric (children's) cardiology service to our adult service.

Tel: **020 7351 8764** (direct line)
Email: **TransitionCHD@rbht.nhs.uk**

Your notes

If you have concerns about any aspect of the service you have received in hospital and feel unable to talk to those people responsible for your care, call PALS on:

- Royal Brompton Hospital – 020 7349 7715
- Harefield Hospital – 01895 826 572

You can also email pals@rbht.nhs.uk. This is a confidential service.

Royal Brompton Hospital
Sydney Street
London
SW3 6NP
tel: 020 7352 8121
textphone: (18001) 020 7352 8121

Harefield Hospital
Hill End Road
Harefield
Middlesex
UB9 6JH
tel: 01895 823 737
textphone: (18001) 01895 823 737

Website: www.rbht.nhs.uk

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