



Hypoplastic left heart syndrome

Information for parents and staff



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Important information for your GP or doctors at your local hospital:

_____ has hypoplastic left heart syndrome (HLHS) and has had a Norwood stage one procedure at the Bristol Royal Hospital for Children (BRHC) on: _____.

_____ will need further operations, the next being around the age of four to six months.

Occasionally, between the first and second stages of surgery, the circulation of the blood can become unstable, and for this reason we would like to be kept informed of any contact _____ has with health care professionals.

We would encourage you to contact our unit if you are concerned or in any doubt with regards to _____'s wellbeing. This is particularly important within the first six months of life.

If you are calling to let us know that you have seen the child or have any general questions, please call the paediatric cardiac nurse specialists on **0117 342 8286** or **0117 342 8578** during normal working hours. 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 no **2424**.

Important contact names and numbers

Bristol Royal Hospital for Children (BRHC)

Switchboard	0117 923 0000
Ward 32	0117 342 8332 / 8679
Paediatric cardiac nurse specialists	0117 342 8286 or 3983 or radiopage via switchboard
On-call paediatric cardiology registrar	Bleep 2424 via switchboard
Paediatric dietitian	0117 342 8802 or bleep 2780/3651

Your named team

Consultant cardiologist:

Phone no. 0117 342

Consultant surgeon:

Phone no. 0117 342

Cardiac nurse specialist:

Phone no. 0117 342

Local paediatric consultant:

Phone no:

Some helpful information

Acceptable vital sign ranges for _____ at rest are:

Oxygen saturations between _____ and _____ %

Heart rate between _____ and _____ bpm

Respiratory rate between _____ and _____ /min

These are only a guide; if you or your doctor have concerns, then your child should be discussed with the cardiology team.

Current medications

Drug: Dose:

Frequency:

Drug: Dose:

Frequency:

Drug: Dose:

Frequency:

Drug: Dose:

Frequency:

Discharge height: **Weight:**

Discharging doctor's signature:

.....

Information for parents of babies with HLHS – going home after stage one surgery

HLHS is a serious condition which means that your baby does not have a 'normal' heart and blood circulation. They will need three operations as well as several investigations and continuous follow-up by your cardiologist and local paediatrician.

Your baby has had their first stage operation and the cardiology team now feels that they are well enough to go home. We fully appreciate that this is a very worrying and anxious time for parents, and we have put together this leaflet in order to provide you with some useful information to help you to care for your baby at home.

When to call the cardiology team

Please call the team if:

- there are any significant changes in your baby's feeding pattern or your baby develops a poor appetite
- your baby is sleeping more than normal
- your child experiences increased sweating or cool clammy skin
- your child has puffy eyelids
- your child is working harder to breathe or develops a cough
- there is a change in your child's skin colour, especially around the mouth and nose lasting more than a few minutes
- your child doesn't have as many wet nappies as usual
- your child develops diarrhoea or vomiting
- your child's temperature is above 38 degrees celsius
- your baby is irritable or is constantly crying

- there are changes in your baby's scar such as redness, oozing, swelling or an opening.

If you see any of these symptoms in your child you should call the on-call paediatric cardiology registrar (see number on page four).

Remember to take this document and your discharge letter from BRHC with you every time you see your GP or go to A&E. If you are unsure whether or not your baby has any of these symptoms, you can call the cardiac nurse specialists for advice or the on-call paediatric cardiology registrar.

Call 999 if:

- **you hear persistent grunting in your child and noisy breathing or if your child is struggling to breathe**
- **your child is floppy and unresponsive or you are unable to wake them up**
- **there are prolonged changes in your baby's skin colour. This could involve the skin turning more blue or grey than usual, being cool to touch or becoming waxy looking**
- **your baby is choking and you've already intervened to provide basic life support.**

Pre-discharge guidelines for staff caring for babies with HLHS following stage one surgery

The pre-discharge checklist must be completed and signed off by the registrar for the ward on the day of discharge.

Action	Date and signature
<p>Pre-discharge investigations:</p> <ul style="list-style-type: none"> • chest X ray • ECG • echocardiogram 	<hr/> <hr/> <hr/>
<p>Named cardiology consultant documented on cover page of patient's notes and entered on Heartsuite.</p>	
<p>MRI and/or cardiac catheterisation to assess suitability for second stage must be arranged prior to discharge from hospital and parents informed of date whenever possible.</p>	
<p>First clinic follow-up must be with consultant cardiologist no longer than two weeks after discharge. All follow-up visits must be at a paediatric cardiology consultant clinic or, if booked into a registrar clinic, the patient must be reviewed by a consultant.</p>	
<p>Patient must be discussed with local paediatric consultant/hospital prior to discharge from Bristol. Medical handover must be conducted by at least a registrar grade doctor or above and documented in the medical notes.</p>	

Action	Date and signature
All children must have a dietitian referral before discharge.	
Resuscitation training provided for parents before discharge home.	
Cardiac nurse specialists to arrange twice weekly weights and oxygen saturations to be performed in the community.	

This completed discharge protocol and a full discharge letter must be sent to:

(tick when completed)

- Parents
- General practitioner
- Community nursing team
- Local consultant paediatrician
- Copy to the patient notes
- Cardiac nurse specialists

Notes/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.

Smoking is the primary cause of preventable illness and premature death. For support in stopping smoking contact **Smokefree Bristol** on **0117 922 2255**.

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 under our care, you may be invited to take 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.

