University Hospitals Bristol NHS
NHS Foundation Trust

Patient Information Service
Bristol Royal Hospital for Children

Hypoplastic Left Heart Syndrome

- Information for parents and staff



Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.

Above + Beyond
For Patients. For Health. For Bristol.

Important Information for your GP/doctors at your local hospital:

_____has Hypoplastic Left Heart Syndrome (HLHS) and has had a Norwood Stage 1 procedure at the Bristol Royal Hospital for Children 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 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 _____ 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 8578 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 and 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 Hypoplastic Left Heart Syndrome (HLHS) going home after stage one surgery

As you are aware your child has HLHS. This is a serious condition which means that your baby does not have a "normal" heart and circulation and will need three operations as well as several investigations and continuous follow up by both your cardiologist and local paediatrician.

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

When to call the cardiology team:

- If there are any significant changes in your baby's feeding pattern/poor appetite.
- Increased sleeping.
- Increased sweating and/or cool clammy skin.
- Puffy eyelids.
- Working harder to breathe/new cough.
- Change in skin colour, especially around the mouth and nose lasting more than a few minutes
- Not as many wet nappies as usual.
- If your child develops diarrhoea and/or vomiting.
- Temperature above 38 degrees C.
- Baby doesn't handle as well (irritable/constant crying).
- Changes in scar: redness, oozing, swelling or opening.

If you see any of these symptoms in your child you should call the cardiology team.

Remember to take this document and your discharge letter from Bristol Royal Hospital for Children (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 on **0117 342 8286** or the on call paediatric cardiology registrar on **0117 923 0000** bleep **2424**.

When to call 999:

- **Persistent grunting, noisy breathing and/or struggling to breathe.**
- **Floppy and unresponsive baby. Unable to wake him/her up.**
- **Prolonged changes in your baby's skin colour – more blue/ grey than usual, cool to touchy, waxy looking.**
- **If your baby is choking.**

Pre-discharge guidelines for staff caring for babies with Hypoplastic Left Heart Syndrome following stage 1 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
Pre discharge investigations: • Chest X ray • ECG • Echocardiogram	 _____ _____ _____
Named cardiology consultant documented on cover page of patients notes and entered on Heartsuite	
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	
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.	
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	

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

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, Braille, Audio, or Email, please call the Patient Information Service: 0117 342 3728 / 3725

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