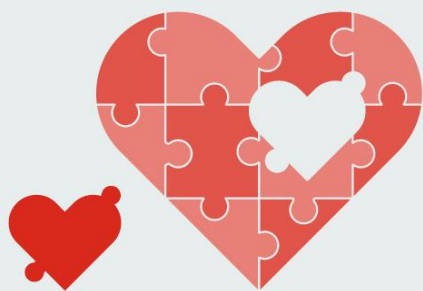


Single Ventricle Pathway  
Home Monitoring Programme (SVPHMP)

# Information for Parents and Carers

Baby's Name



## Your baby

Name	
Date of birth	
NHS no.	
Hospital no.	
Diagnosis	
Operation	
Date of Operation	
Cardiologist	
Surgeon	
Cardiac Nurse Specialist (CNS)	
Date of discharge onto HMP	
Birth Weight	
Discharge Weight	
Discharge Oxygen Saturations	
Target Oxygen Saturations	



# The Home Monitoring Programme (HMP)

A single ventricle defect is where only 1 of the pumping chambers (ventricles) develops properly. Without treatment, these defects can be fatal within a few weeks of birth.

Babies born with a single ventricle circulation will never have a “normal” heart.

As your baby grows they will need at least 3 stages of open heart surgery. The surgery aims to improve the circulation. This lets your baby grow and offers a good quality of life. You will hear it called “palliative surgery”.

The Home Monitoring Programme (HMP) keeps track of your baby between the 1st and 2nd of these stages. They are most at risk of becoming very unwell during this time. They can become unwell very quickly for a number of reasons:

- The tube that directs more blood to the lungs (shunt) becomes blocked
- The heart’s pumping chamber (ventricle) works less well
- The reconstructed main artery (aorta) becomes narrow
- Infection

By monitoring your baby at home, we can spot small changes. This will alert you and your Cardiac Nurse Specialist (CNS) to a potential problem early. If this happens your CNS may ask you to attend hospital for tests or a treatment to help relieve the problem. Your CNS will need to know as soon as possible if your baby becomes unwell.

Home monitoring can also help the cardiology team to plan the best time for your baby’s next operation.





# Training

## What will I be monitoring at home?

- Oxygen Saturation
- Weight
- Feed volume

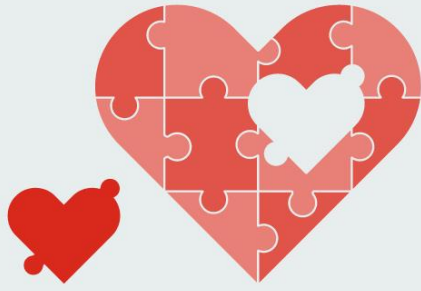
## Do I get any training?

Before you are discharged from hospital we will give you a package of training:

- Oxygen saturation monitoring and trouble shooting
- Use of the weighing scales
- Red Flags to help you recognise if your baby is becoming unwell
- Basic life support training (theory and practical)
- Nasogastric tube (NGT) feeding (if appropriate)

As part of the HMP your baby will also get:

- Weekly call from your CNS (usually on a Monday)
- Weekly weight and oxygen saturation by your community nursing team (this depends on where you live)
- Support from the EMCHC dietician and speech and language therapist (SALT) as needed
- Open access to your local emergency department or children's ward (this depends on where you live)
- A named paediatrician (this depends on where you live)



# Oxygen saturation monitoring

## What is oxygen saturation?

- Oxygen is carried in the blood, attached to red blood cells. Oxygen saturation is a measure of the percentage of red blood cells carrying oxygen
- The expected saturation range for your baby is 75-85% unless you have been told otherwise by your cardiology team

Your CNS will give you with an oxygen saturation monitor to take home. This will be on loan from the hospital. You will need to return it when your baby no longer needs this level of monitoring. We will teach you how to use the monitor and we will give you saturation probes. Only the probes the CNS team give you will work with your monitor. Replacements can be provided at clinic appointments or by post.

We will ask you to check your baby's oxygen saturation once a day. You can do this at a time that suits your family life. Please only do spot saturation checks. Do not leave the probes attached. They may cause harm. Please do not try to check your baby's oxygen saturations in an emergency.



# Red flags

## When should I be worried?

The Red Flags are signs of your baby becoming unwell (see below).

If your baby is feeding as usual, waking for feeds and having plenty of wet nappies, the odd low oxygen saturation reading (below 75%) is usually not a problem, but please contact the team for advice. Within working hours you may call your CNS. They may advise you to take your baby for review at your local hospital. Please see **Important Contacts** for out of hour's information.

A high oxygen saturation level can also be a sign of a problem. If your baby's saturation level stays above 86% a few times please tell your CNS.

**IF YOU THINK YOUR BABY LOOKS UNWELL OR YOU ARE CONCERNED THEN CALL 999**

### For parents and carers of babies with a shunt or stent dependant circulation

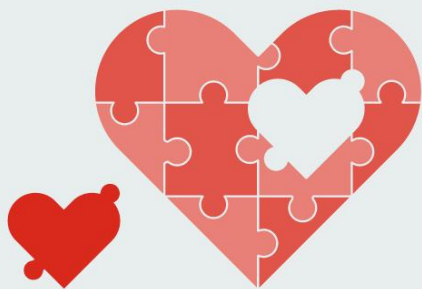
- Oxygen saturation lower than 75%
- Changes in breathing (may be fast, slow, irregular, look like they are working harder to breath, bobbing their head, sucking in on their neck below the throat, nostrils look bigger when breathing out, making different noises, grunting chest/ribs sucking in)
- Change in colour (blue, grey, mottled, dusky, pale, waxy)
- Dry nappies (more than 4 hours between wet nappies)
- Diarrhoea (more than once in 24 hours)
- Not feeding well (been sick more than once in 24 hours), tired and sweaty when feeding, less milk taken in than usual or less breast feeding time)
- High temperature above 38 degrees
- Poor weight gain or weight loss
- Change in behaviour (lethargic, sleepy when due a feed, floppy, irritable, inconsolably crying, high pitched cry, unresponsive)

If your baby triggers a red flag please call the CNS team for advice within office hours or call ward 1 outside of these hours (see important contacts page for office hours and contact numbers)

**IN AN EMERGENCY CALL 999**







## Feeding

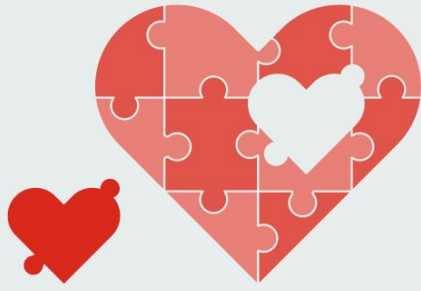
We will explain the right amount of feed for your baby before you leave hospital. As your baby grows and gains weight, the amount of feed will be increased. It is important your baby gets the right amount so they stay well hydrated. If your baby is being sick (vomiting) or has diarrhoea then call your CNS for advice.

We work closely with the dietician. They will work with the community team as needed. Your baby may be referred to the Speech and Language Team (SALT) if needed for help with oral feeding. The dietician and SALT may come to your weekly clinic appointment with your CNS.

Some babies need a nasogastric tube (NGT) to make sure they get enough nutrition and fluid. You will be supported to manage this at home.

You may wish to record the feed volumes and numbers of nappies your baby has in a chart. If you would find this useful then let your CNS know. They will give you with some blank charts to use.

It is important your baby does not become dehydrated. You should let your CNS know if your baby is not feeding well, is passing less urine than usual (having less wet nappies), or has diarrhoea or is being sick (vomiting). If diarrhoea or sickness is bad you may need to go to your local emergency department.



## Caring for the equipment

All of the equipment for the HMP is kindly donated by one of our local charities, Heart Link.

Please look after the equipment borrowed from the hospital. This will make sure the information you collect about your baby is correct. We will ask you to sign a loan agreement before you are able to take the equipment home.

Please call the CNS office if you have any problems with the equipment.

Please return the equipment in good time, so it can be cleaned, checked and given out to the next baby who needs it.







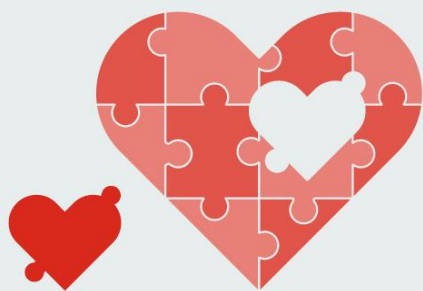
# Checklist before going home

The following training record should be completed before discharge home or transfer to the local hospital.

It is the responsibility of all trained staff caring for the baby to complete this document.

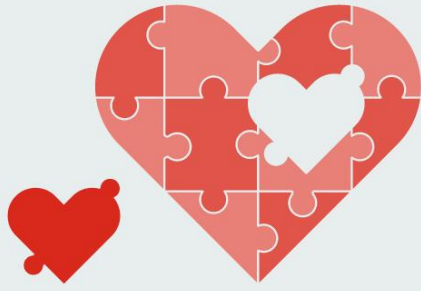
The CNS will introduce the HMP, oversee the training and follow up once discharged.

Training	Trainer (print, sign and date)	Parent/carer (print, sign and date)
Basic life support (BLS) DVD		
BLS practical demonstration		
Oxygen saturation monitoring	1	
	2	
	3	
Home weighing scales	2	
	3	
	4	
Medication (names, storage, drawing up, administration)	2	
	3	
	4	
NGT (if appropriate)		



## Checklist before going home

Action	Completed by (print, sign and date)
Refer to local paediatrician	
Refer to Health Visitor (HV)	
Contact HV pre discharge	
Refer to Community (CCN) Team	
Contact CCN pre discharge	
Psychologist Referral (discuss with CNS)	
Rainbows/Acorns Referral (discuss with CNS)	
Dietician Referral	
SALT referral	
Nirsevimab information given	
Ward review booked	
Consultant clinic booked	
CT scan at 4 months pre surgery	
Discharged summary completed <ul style="list-style-type: none"> <li>• Copy in hospital notes</li> <li>• Copy to CCN</li> <li>• Copy to HV</li> <li>• Copy to GP</li> <li>• Copy to Paediatrician</li> </ul>	<ul style="list-style-type: none"> <li>•</li> <li>•</li> <li>•</li> <li>•</li> <li>•</li> </ul>



# Important Contacts

**IN AN EMERGENCY CALL 999**

## Leicester Royal Infirmary

### Switchboard

0300 303 1573

### Cardiac Nurse Specialist (CNS) Team (Monday to Friday 8am – 6pm )

Trish Martin 07950 891 449

Nicola Holdback 07950 854 938

### CNS Office number

0116 258 3338

24/7 Answer phone service available. Messages triaged in order of priority.

### Cardiac ward 1 (out of hours)

0116 258 3961

## In the community

### Children's community nursing team

### Health visitor

### Local hospital

### Open access

### Name of paediatrician

### Other





## Appointment dates

Ward Review	
CNS SVPHMP clinic	
Consultant Clinic (4 weekly)	
CT Scan	
Consultant Clinic (4 weekly)	





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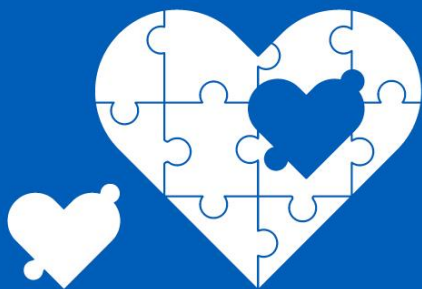




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Compiled by the Cardiac Nurse Specialist Team on behalf of the East Midlands  
Congenital Heart Centre at Leicester Royal Infirmary

August 2025

Acknowledgement to the Great Ormond Street Hospital CNS Team

