

Home Monitoring Programme

Information for families



Single Ventricle Service

Patient name:

Great Ormond Street Hospital
for Children NHS Foundation Trust

About your baby

Name:

Hospital number:

D.O.B:

Diagnosis:

Operation:

Date of operation:

Cardiologist:

Surgeon:

Your named
Cardiac Nurse Specialist is:

Date of discharge from GOSH:

Birth weight:

Weight when leaving GOSH:

Oxygen saturations
on leaving GOSH:

Target oxygen saturations:

What is the Home Monitoring Programme?

We have developed the Home Monitoring Programme at Great Ormond Street Hospital (GOSH) to help monitor your baby between stage 1 and stage 2 of surgery, when they are seen as most fragile.

Babies born with single ventricle hearts will never have a 'normal' circulation. The surgeons are able to perform surgery to improve their circulation in several stages with the aim of enabling your baby to grow and have a good quality of life.

However, after the first stage, babies can very quickly become unwell. This may happen for several reasons such as:

- The shunt (the tube that directs more blood to the lungs) is blocking
- The heart's pumping chamber is working less efficiently
- The reconstructed body artery is becoming narrow
- Chest infection

If this happens, your baby needs to come into hospital for investigations and possibly an intervention to help relieve the problem. Your Cardiac Nurse Specialist (CNS) will need to know as soon as possible if your baby is becoming unwell. By monitoring your baby at home, you can pick up small changes quickly which may help us anticipate a problem early.

Home monitoring can also assist the cardiac team in planning the best time for your baby's second operation.

What will I be monitoring?

We will ask you to check and record your baby's:

- blood oxygen saturation levels
- weekly weight
- feed volume each day from bottle and/or feeding tube

Training

We will give you a package of training before you leave GOSH which includes:

- Saturation monitoring and troubleshooting
- 'Red flags' (recognising signs of deterioration in your child)
- Basic Life Support (BLS)
- Nasogastric (NG) tube feeding

As part of the Home Monitoring Programme, your baby will receive:

- Weekly weight checks, usually by the Health Visitor
- Weekly saturation measurements by the Community nursing team
- Daily oxygen saturations done at home by you
- Weekly calls from a named Cardiac Nurse Specialist
- 'Open access' to your local Accident and Emergency (A&E) department or children's ward



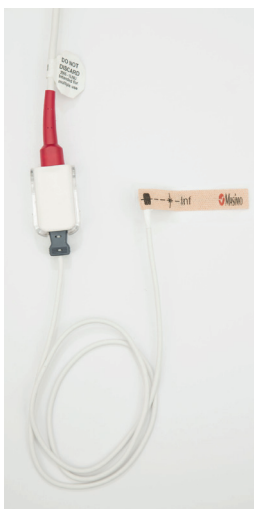
Saturation monitoring

Your Cardiac Nurse Specialist will provide you with a saturations monitor, similar to the one pictured below, to take home. This equipment will be on loan from the hospital and you will need to return it when your baby no longer requires this level of monitoring. We will teach you how to use the equipment and provide you with a few saturation probes to take home. Your Community Nurses will supply you with more probes as needed. Always keep a spare one in the house.

We ask you to check your baby's oxygen saturations once a day for about 20 minutes. We normally suggest doing this first thing in the morning when getting your baby up and ready for the day.

By doing the saturations in the morning, if there are any concerns you have the rest of the day to seek the help or advice you might need.

**Saturation range:
75-88%**



What is oxygen saturation?

Oxygen is carried on the red blood cells attached to haemoglobin molecules. Oxygen saturation is a measure of how much oxygen the red blood cells are carrying as a percentage (%) of the maximum it could carry.

When should I be worried?

Your red flags should provide you with a guide to recognising signs of deterioration in your child.

1. The expected or optimum saturation for your baby is 75% to 88% unless you have been told otherwise.
2. It is important that your baby does not become dehydrated. You should let your CNS know if your baby:

As long as your baby is feeding as usual and is waking for feeds and passing urine – an isolated low saturation reading is usually not a problem.

If, however, when you measure the saturation you find that it is lower than the optimum level for your baby, check it again in an hour.

If the saturation continues to be low, please call your CNS team or the Cardiology Ward at GOSH for advice. They will advise you what to do and may ask you to bring your baby in to hospital for assessment; this will be your local hospital initially.

A high oxygen saturation reading can also be a sign of problems. If your baby's saturation stays above 86% on several occasions, we may ask you to bring your baby to GOSH for assessment.

- Is not feeding well
- Is passing less urine than normal
- Starts to have any diarrhoea or vomiting

If diarrhoea or vomiting is severe, you may need to go to your local hospital. Again call your CNS or the Cardiology ward for advice.

**If you think your baby looks unwell
or you are concerned then call 999**

Red Flags

For carers and parents of shunt-dependent infants

1. Saturations: between 75% and 88%
2. Change in breathing patterns: fast, irregular, tracheal tug, nasal flare, head bobbing, noises, recessions.
3. Change in colour: mottled, dusky, pale
4. Dry nappies: more than 4 hours between wet nappies
5. Diarrhoea: more than once in 24 hrs.
6. Not feeding well:
 - More than one vomit in 24hrs
 - Tired and sweaty while feeding
 - Decreased feed volume
(no more than 20 minutes on the bottle/breast)
7. Temperature: fever? Operation site infected?
8. Poor weight gain or weight loss?
9. Change in behaviour: lethargic, irritable, restless.

If you trigger a Red Flag then call the CNS team for advice on ext 5774/the Cardiology ward 7848. In an emergency, call 999

Feeding

We will explain the appropriate volume of feeds for your baby before you leave hospital. As your baby grows and gains weight, the volume of feeds will be increased.

It is important your baby gets the required volume of feed to ensure they stay hydrated. If your baby has any episodes of vomiting or diarrhoea then call your CNS or the Cardiology ward for advice.

You may wish to record the feed volumes and number of nappies your baby has in a chart like the one below. If you would find this useful then let your CNS know and they will provide you with some blank charts to use.

DAY:	Monday	WEIGHT:	3.6kg
DATE:	28th Aug 2015	O2 SATS:	92%

Time (am/pm)	Breast (minutes)	Bottle (mls)	Nappies	Comments
6am	-	65mls	1	20ml orally, the rest down NG tube
9am	15 mins	-	0	Right side
12am	5 mins	50mls	2	Left side, tired on breast so used NG tube
3pm	-	65mls	1	45ml orally, the rest down NG tube
6:30pm	25 mins	-	2	Right side, large dirty nappy
9pm	-	75mls	1	Took full volume orally
12:45am	20 mins	-	2	Left side, small dirty nappy
3am	-	65mls	1	Used NG tube as baby sleeping
5am	5 mins	-	1	Small comfort feed
				Total volume fed today: 320mls (& 70 mins)

Caring for the equipment

It is important that you care for the equipment borrowed from the hospital in the appropriate way. This will ensure that the information collected about your child is reliable and correct.

- Store the equipment in a dry, smoke-free environment.
- Keep the equipment clean and out of the reach of children
- Clean the equipment with a soapy damp cloth. Take care not to expose the electrical components to water.
- Ensure wires are kept tidy and electrical components are always covered.
- Keep the equipment switched off when not in use.
- Please call the hospital if you have any problems or concerns about the equipment loaned to you.
- Please return the equipment on the date discussed. If this changes for any reason then please let us know.

Patient name:

D.O.B:

Hospital number:

Date:

I, parent/guardian of _____ have agreed to the terms and conditions of borrowing the equipment listed below. I have been taught the appropriate use of the items and how to care for them.

I will ensure they are returned to the Cardiac Nurse Specialist Team on the date stated, or as requested.

I will contact the CNS team if there is a fault with the equipment.

I understand the equipment on loan is a tool for guidance only and to seek medical advice if I am concerned about my child's health and well-being.

If the items are not returned I understand the Trust has the right to charge me the full amount of such equipment.

If the items are returned in a manner that they cannot be used without being repaired, I understand the Trust has the right to charge me the full amount of such equipment, or for the repair, if the cause of the damage is due to poor care of equipment.

Please sign for the items of equipment that have been loaned to you:

Equipment	Biomed number	Agreed date of return	Signature of parent/guardian
Pulse oximetry monitor			

Parent's/guardian's name and signature:

Staff name and signature:

Training and discharge checklist:

Action to take	Trainer PRINT & SIGN & DATE	Parent/carer PRINT & SIGN & DATE
BIS training	1	1
3 sessions with main carers	2	2
	3	3
Masimo Sats monitor training	1	1
3 sessions with main carers	2	2
	3	3
Trouble shooting/Red flags.	1	1
3 sessions with main carers	2	2
	3	3
Referral to local paediatrician BEFORE discharge		
Contact with Health Visitor [HV]		
Referral to community children's nurse team [CCNT].		
Contact CCNT and Health Visitor couple of days prior to discharge.		
Named Social Worker and or psychologist.		
SALT and Dietician referral and feeding plan.		
Date for Friday clinic with Dr Giardini & Dr.Dedieu		
MRI at 3 months, pre-Glenn		
Discharge summary faxed to CCN and HV		
Referral to hospice services, Langan's/Rainbow Trust		

Important contact numbers

In an emergency call 999

At Great Ormond Street Hospital

Switch: 020 7405 9200

Cardiac Nurse Specialist Team: extension 5774 (Mon-Fri 8am-4pm)

Cardiology ward: extension 7848
(out of hours and at weekends)

Other:

In the community

Children's community nursing team:

Health visitor:

Local hospital:

Open access:

Name of paediatrician:

Other:

Appointments

MRI scan:

Cardiac surgery:

Pre admission:

Notes:

Notes:



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Compiled by the Cardiac Nurse Specialist team

in collaboration with the Child and Family Information Group

Great Ormond Street Hospital for Children NHS Foundation Trust
Great Ormond Street
London WC1N 3JH

www.gosh.nhs.uk