

# Home monitoring programme

## Patient diary

**Patient's  
name:**

**Diagnosis:**

Please bring this booklet with you to all clinic appointments and hospital admissions

# Welcome to the home monitoring programme

**The home monitoring programme has been developed to help watch your baby closely between stages 1 and 2 of surgery, as your baby will be the most fragile during this period. With your support and by following the steps outlined in this diary, we can work together to assess whether your child is well enough to be at home.**

The programme aims to enable you, as parents or carers, to monitor your child’s weight, oxygen saturation levels and fluid intake at home. This will help you detect any potential change in their condition.

At each clinic appointment, the nursing and medical staff will use the information recorded in this diary to assess your child. A children’s cardiac nurse specialist (CCNS) will also phone

you weekly (at an agreed time) to check how your child is doing and gather the information you have collected. We can then put this data into your baby’s electronic notes.

Please monitor your child’s fluid intake, weight and oxygen saturation levels every day and record them in this diary. Please continue to take the recordings even if your child is admitted to hospital.

# About your baby

The healthcare professional caring for your baby will complete this section.

Name:	
Hospital number:	
Date of birth:	
Diagnosis:	
Surgery:	
Cardiologist:	
Surgeon:	
Date of discharge	
Birth weight:	
Weight on discharge:	
Oxygen saturations on discharge:	
Oxygen saturation parameters:	
Feeding plan:	



## Medicines on discharge from E1 Ocean ward

Time	Medicine	Dosage

## Red flags to look for

### Every day, please measure and record in your weekly diary:

- your baby’s weight
- the difference in their weight from the previous day
- your baby’s oxygen saturation levels
- your baby’s fluid intake

### Call us if:

- your baby is more unsettled, quieter or more sleepy than usual
- your baby’s resting oxygen saturations drop below \_\_\_\_\_
- your baby does not gain 20g each day for three days
- your baby loses more than 30g in one day
- your baby is feeding less than 100mls/kg/day)
- your baby is being sick more than half of his/her feeds in a day
- your baby has less wet nappies than usual
- your baby has diarrhoea or vomiting
- your baby has a temperature

### Please call us if you have questions or are at all concerned:

Children’s cardiac nurse specialist team (CCNS)

Telephone: **07585 564 348** (Monday to Friday, 9am to 4pm)

E1 Ocean ward

Telephone: **023 8120 6470** (evenings and weekends, 24 hours)

### Call 999 if:

- your baby is floppy and unresponsive
- your baby’s oxygen saturation consistently falls below \_\_\_\_\_
- your baby has any breathing difficulties such as grunting, noisy breathing, nasal flaring or if their ribs are more visible when breathing
- you notice prolonged changes to your baby’s skin colour such as more blue/grey than usual, or if your baby’s skin is cool to touch.



## How to weigh your baby

Weigh your baby each morning around the same time, just before a feed, and before they have any medicines.

- Make sure the scales are set to 0.00kg.
- Weigh your baby naked.
- Note down the weight in the home monitoring diary on page 6. Use the table below to change the weight from kilograms to grams.

### Weight conversion table

Weight in kilograms	Weight in grams
2.755	2755
2.805	2805
2.850	2850
2.905	2905

### To work out your baby's weight gain from day to day, use the calculator on your phone:

1. Enter the number of your baby's new weight in grams.
2. Press the subtract (-) button.
3. Enter the number of your baby's weight from yesterday.
4. Press the equals (=) button. This will give the difference in weight gained in grams.

## How to use your oxygen saturation monitor

1. Place the oxygen saturation monitor on a flat surface so it does not fall.
2. Ensure the monitor is plugged in and switch it on.
3. Place the probe on your baby's finger, toe or foot at a time when they are calm. Use the same part of the body each time, as this is more reliable.
4. Wait a few moments for the monitor to pick up the pulse signal.
5. Only read the results when a good trace is showing. If the trace is not good, the result may not be correct.
6. The oxygen saturation level reading should appear on the front screen along with the heart rate reading.
7. If your baby is crying or unsettled, the saturation level is likely to read lower than normal. Wait until your baby is calm and try again.
8. Leave the monitor attached for about 20 minutes as it may take this long to pick up the correct reading.
9. When the saturation level reading is accurate as possible, record the number in the home monitoring diary.
10. Contact us if you have any questions or concerns.
11. Switch off monitor.

Please note that the finger probe is only for spot checks of saturation level. Do not leave it on for long periods of time, as this could result in tissue damage from the pressure of the probe.

**This equipment is not intended for use in an emergency situation. If you are worried about your baby's colour or breathing, call 999 immediately.**

# Equipment contract

Name:

Hospital:

Date:

I/we, parents/guardian of ..... have agreed to the terms and condition below. I have been taught the appropriate use of these items and how to care for them. I will ensure they are returned to Ocean ward on the stated date.

I have been provided with information regarding the process to follow if there is a fault with the equipment.

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

### Please sign for the equipment that you have been loaned:

Equipment	Serial number	Signature of parents/guardian
Weighing scales		
Carrying bag		
Instruction manual		
Pulse oximetry monitor		
Probe		
Instruction manual		
Agreed date of return		

### Equipment borrowed from the hospital must be cared for in an appropriate way:

- Store the equipment in a dry, smoke-free environment.
- Keep the equipment clean and out of reach of children.
- Clean the equipment with a soapy damp cloth, as demonstrated on the ward. Take care not to expose the electrical components to water.
- Ensure the wires are kept neat and tidy, and electrical components are always covered.
- Keep the equipment turned off when not in use. Do not allow the battery to run out.

Please call the hospital if you have any problems or concerns about the equipment loaned to you. It is very important that the information collected about your child is reliable and correct.

Please return this equipment on the date discussed with you.

	Name	Signature
Parent/guardian's name and signature:	<input type="text"/>	<input type="text"/>
Hospital staff name and signature:	<input type="text"/>	<input type="text"/>

# Contact us

If you have any questions or concerns, please telephone our team of nurses:

## **Children's cardiac nurse specialist team (CCNS)**

Telephone: **07585 564348** (Monday to Friday, 9am to 4pm)

If there's no answer, telephone E1 Ocean ward: **023 8120 6470**

## **Out of hours**

Telephone the children's cardiology registrar on call: **023 8077 7222 Bleep: 2812**

If there's no answer, telephone E1 Ocean ward: **023 8120 6470**

Ask to speak to a cardiac registrar and explain that your baby is on the home monitoring programme.

**In an emergency please ring 999.**

If you need a translation of this document, an interpreter or a version in large print, Braille or on audiotape, please telephone **023 8120 4688** for help.