

Paediatric cardiology home monitoring programme

Information for children, families and carers

We have given you this factsheet because your child is under the care of our paediatric cardiology home monitoring programme. It explains what the home monitoring programme is and how it can support you and your child after you leave hospital. We hope it helps to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

What is the home monitoring programme?

The home monitoring programme is designed to help monitor and support children with a heart condition at home while they are awaiting heart surgery or are in between stages one and two of their heart surgery.

The aim of the programme is to provide you with information, training and support so that you feel confident caring for your child at home and know who to contact if you have any concerns about your child's wellbeing. By working together and following the steps in this factsheet, we can help you keep your child well at home.

How can the home monitoring programme support my child?

As part of the home monitoring programme, you will:

- receive training on how to safely care for your child at home before they leave hospital
- receive training and equipment to weigh your child at home (you will need to weigh your child every **Monday, Wednesday and Friday**)
- receive training and equipment to measure your child's oxygen saturations (you will need to measure this **every day**)
- receive training to measure your child's daily milk or fluid intake
- have weekly home visits from your local children's community nurse (CCN)
- have weekly virtual (video or telephone) clinic appointments with a children's cardiac nurse specialist (CCNS) and a paediatric cardiac dietitian
- have regular outpatient reviews with a paediatric cardiology consultant (heart doctor)
- have access to use My Medical Record (if needed)

What training and support will I receive?

Our CCNS team and E1 Ocean ward nurses will prepare you for going home with your child by offering various training and support.

We will:

- provide you with a list of symptoms to look out for (known as cardiac 'red flags' – see section below) and information on how to contact us if you are worried
- show you how to use scales to weigh your child
- show you how to use an oxygen saturation monitor to measure your child's oxygen saturation levels
- explain how to monitor your child's milk or fluid intake
- offer you basic child life support training
- explain how to give your child their medication
- show you how to feed your child via their nasogastric (NG) tube (if applicable)
- arrange for you to spend a minimum of 24 hours on the ward with your child where you will provide all their care needs (we will be on hand for advice and support, but the aim of this exercise is to help you feel confident caring for your child independently before they leave hospital)
- give you our dedicated home monitoring programme mobile number (please note that you can only call this number while your child is on the home monitoring programme)
- set up weekly virtual (video or telephone) appointments to check on your child's condition
- set up weekly community nurse home visits for your child

Cardiac 'red flags'

Contact our CCNS team or E1 Ocean ward immediately using the mobile or telephone numbers on page 6 if your child:

- is more unsettled, quieter, or sleepier than usual
- has low oxygen saturation levels when resting (if it drops below _____)
- is not gaining weight or is losing weight
- is paler than normal
- is breathing faster, harder or in an unusual way
- is puffy around their face, hands, feet, or genital area
- feels unusually cool on their arms and legs when they are dressed
- is feeding less or is more sweaty or breathless when they feed
- is sick after more than half of their feeds in a day
- has fewer wet (wee) nappies
- has diarrhoea or vomiting
- has a high temperature (38°C or above)

We will ask you some questions and then advise you on the next steps.

We may advise you to take your child to:

- their general practitioner (GP)
- their local hospital
- E1 Ocean ward at Southampton Children's Hospital
- your nearest emergency department

We may also:

- ask your child's community nurse to arrange an additional visit
- speak to our paediatric cardiac dietitians for advice

Call 999 for an ambulance immediately if your child:

- is floppy, unresponsive or collapses suddenly
- suddenly becomes very unwell or turns a blue or grey colour

What care will my child receive at home?

Children's community nurse (CCN) visits

After your child leaves hospital, we will arrange for a CCN (or a health visitor depending on where you live) to visit you **once a week** at home. These visits will usually be on a **Wednesday**. The CCN or health visitor will contact you to arrange a suitable time to visit.

During each visit, the CCN or health visitor will:

- weigh your child
- check your child's oxygen saturation levels
- provide general support with feeding
- provide support with nasogastric (NG) tube feeding (if your child has one)
- assist you to use any necessary equipment
- offer general advice and support in caring for your child
- answer any questions you may have

After each visit, the CCN or health visitor will pass on the information from the visit to our CCNS team in preparation for your child's virtual (video or telephone) clinic appointment on Thursday (see below).

If your child needs to have their nasogastric tube **replaced** (for example, if it is pulled out), this will need to be done at your child's local hospital.

Virtual clinic appointments

We will arrange a video clinic appointment for your child **every Thursday**. This appointment will be with a member of our CCNS team and a paediatric cardiac dietitian. The appointment will usually last up to 30 minutes.

During this appointment, we will:

- check how your child is doing at home
- ask you about your child's feeding (milk and food)
- discuss any changes you may have noticed with your child
- advise how to help support your child's growth and development

We will record the information from this appointment in your child's electronic health record so the rest of their healthcare team can access this information and stay updated.

If you do not have a laptop, computer, or smartphone, this appointment can be arranged as a telephone call instead. Please contact us if this is the case for you.

Tips for your video appointment

- **Find a quiet space** where you feel comfortable.
- **Have your child nearby** so we can see them.
- **Keep a log of your child's feeding** (including the volume of milk they take each feed, the time it takes for each feed and the total volume of milk they have in a day) as we will discuss this during the appointment.
- **Keep a log of your child's weight** (you will need to weigh your child every Monday, Wednesday and Friday) **and daily oxygen saturation level measurements.**
- **Write down any questions** you would like to ask us in advance so we can answer these during the appointment.

We understand that life with a child can be busy. If you are running late for your appointment or have any problems, you can message or call us on **07585 564348**.

Will my child still have appointments at the hospital?

As part of the home monitoring programme, your child will have regular face-to-face reviews with their paediatric cardiology consultant at the hospital. How often this will be will vary depending on your child's condition, but appointments are usually every two to six weeks. These appointments may be held at Southampton Children's Hospital or your local hospital. Please refer to your child's appointment letter for more information.

At these appointments, your child's paediatric cardiology consultant will:

- check your child's progress
- answer any questions you may have
- make sure your child's care plan is on track

Please be aware that your child will often have an electrocardiogram (a test that records the electrical activity of the heart) and an echocardiogram (a scan of the heart to see how well the heart is working) at these appointments. Both tests are quick and painless.

My Medical Record

My Medical Record is an online service provided by University Hospital Southampton NHS Foundation Trust (UHS) that gives you access to your own digital health record. It can be viewed securely from any web-enabled device, such as computers, laptops, tablets and smartphones.

The My Medical Record app is available to download on iOS and Android.

The community nursing team may use My Medical Record to document your child's home visits. My Medical Record helps everyone involved in your child's care see up-to-date information about your child, including their:

- weight
- oxygen levels
- feeding details

This means the whole of your child's healthcare team can work together to make sure your child gets the best care. If you would like more information about My Medical Record, including how to register for it, please ask us or visit: www.uhs.nhs.uk/for-patients/my-medical-record

Frequently asked questions

What should I do if I am concerned about my child being unwell at home?

There may be times when your child feels unwell. This could be something related to their heart condition, or it could be an unrelated illness or infection. Whatever the problem, there will always be someone available to help you.

- **If you want some general advice about your child's health**, contact your child's GP, health visitor or NHS 111.
- **If you feel that your child is very unwell**, go to your nearest emergency department or call **999** for an ambulance immediately. The healthcare team caring for your child will contact us if they have concerns about your child's heart condition.
- **If you think that the problem is related to your child's heart condition**, contact our children's cardiac nurse specialist (CCNS) team (Monday to Friday, 9am to 4pm) or E1 Ocean ward (out of hours) for advice using the details on page 6.

We may ask you to take your child to your local hospital for a review. Some children may have 'open access' to their local children's ward. If this is the case, you can take your child directly to your local children's ward. If your child does not have open access, you will need to take your child to your local emergency department. We will advise you if you have open access when your child leaves E1 Ocean ward.

Are there other 'home monitoring' type programmes?

Yes. At Southampton Children's Hospital, we also have a 'fragile baby programme' for children who are at home waiting for heart surgery. Although the two programmes are similar, the level of monitoring and support is different based on the child's underlying heart condition. Children on the fragile baby programme are not as high risk, so they receive slightly less reviews and do not need to take weighing scales or an oxygen saturation monitor home with them.

Is one review a week enough?

Yes. For children on the home monitoring programme, weekly reviews with the CCNS team and paediatric cardiac dietitian, as well as weekly CCN home visits and regular cardiac consultant reviews, are enough to spot any changes in your child's heart condition. This level of contact has been shown to be safe and effective for children on this programme.

How long will my child be on the home monitoring programme for?

The length of time your child will be on the home monitoring programme will vary depending on their heart condition. Your child will remain on the programme until:

- they have had their planned heart surgery
- their healthcare team feels they no longer need close monitoring

Your child's healthcare team will review your child's progress at each stage and will discuss any changes to their monitoring plan with you.

When your child is well enough to leave the home monitoring programme, we will discuss who to contact if you have any queries or concerns in the future. We will also give you a separate factsheet with more information about what to expect after your child leaves the programme.

Contact us

If you have any questions or concerns, please contact us.

Children's cardiac nurse specialist (CCNS) team
Mobile: **07585 564348** (Monday to Friday, 9am to 4pm)

Alternatively, if your question is not urgent, you can email us: ccnsfamilies@uhs.nhs.uk

We will aim to return your call or reply to your email within two working days.

If you have any concerns **outside of these hours**, call E1 Ocean ward using the details below.

E1 Ocean ward
Telephone: **023 8120 6470** (24-hour line)

Ask to speak to the nurse-in-charge and explain that your child is on the **home monitoring programme**.

Useful links

www.nhs.uk/conditions/congenital-heart-disease

www.uhs.nhs.uk/departments/blood-heart-and-circulation/congenital-cardiac-services/childrens-congenital-cardiac-services

www.oceanward.co.uk

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone 0800 484 0135 or email PFSH@uhs.nhs.uk

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit www.uhs.nhs.uk/additionalsupport