

What to expect after your child leaves the home monitoring or fragile baby programme

Information for children, families and carers

This factsheet contains information and advice about what to expect after your child leaves the home monitoring or fragile baby programme and who to contact if you have any concerns. 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 should I expect after my child leaves the programme?

After your child leaves the home monitoring or fragile baby programme, they will still be under the care of our paediatric cardiology team but the level of monitoring they will receive will reduce. This is because they are less at risk and need less monitoring.

What support will my child receive?

Paediatric cardiology consultant appointment

We will arrange a follow-up outpatient appointment for your child with their paediatric cardiology consultant (heart doctor) approximately six to eight weeks after they have left hospital after having surgery. Please see your child's appointment letter for more information.

At this appointment, your child's paediatric cardiology consultant will:

- review your child's condition
- perform 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)
- review your child's medication

Children's community nurse (CCN) visits

Your child will continue to receive home visits from a children's community nurse (CCN) for a short while after leaving the home monitoring or fragile baby programme. The CCN will usually visit you once a week until your child has their first follow-up outpatient appointment with their paediatric cardiology consultant.

During these visits, the CCN 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 still has an NG tube)
- offer general advice and support in caring for your child

For children who have had the Glenn operation

If your child has had the Glenn operation (an operation that involves connecting the main vein from the upper body (known as the superior vena cava) directly to the lung artery), we will ask the CCN to continue visiting you at home once a month for a further **three months** to monitor your child's weight.

For children who have gone home with a nasogastric (NG) tube

If your child has gone home with an NG tube in place, the CCN will usually be able to replace this tube for them at home. However, if your child has one of the following conditions, they may need to have their NG tube replaced in hospital (unless advised otherwise by their paediatric cardiology consultant):

- single ventricle circulation (a heart condition where you have only one working ventricle (pumping chamber) instead of two)
- poor heart function (when the heart is not pumping blood efficiently)

Dietetic support

Your child may remain under the care of our paediatric cardiac dietitian for ongoing support with feeding or we may transfer your child's care to their local dietetics team. We will discuss this with you before your child leaves the home monitoring or fragile baby programme.

When should I seek medical help?

After your child leaves the home monitoring or fragile baby programme, you will no longer have access to the dedicated home monitoring and fragile baby programme mobile number. If you have any concerns about your child's wellbeing, please follow the relevant guidance below.

- **For general illness concerns**, contact your child's general practitioner (GP), NHS **111** or attend your local emergency department.
- **For concerns 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) using the details at the end of this factsheet.

Call 999 for an ambulance immediately if your child:

- is floppy, unresponsive or collapses suddenly
- suddenly becomes very unwell

Contact us

If you have any questions or concerns, please contact us using the details below.

Children's cardiac nurse specialist (CCNS) team
Telephone: **023 8120 4659** (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)

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

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

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