



Children's cardiac nurse specialist team



This leaflet explains about the service the children's cardiac nurse specialist (CCNS) team provide.

What is the CCNS team?

We are a team of experienced cardiac nurses who have combined experiences of working on the children's cardiac ward, paediatric intensive care unit, fetal cardiology and in children's community nursing.

We provide expert care and support to children and their families with congenital heart conditions, arrhythmias, and inherited cardiac conditions.

We work closely with the doctors so we are able to give advice and information specific to each child.

We provide a link between hospital, home and community services, from birth up to the age of 18.

Who can use the service?

All children with a heart condition can access our service.

We attend and provide support in the following areas:

- Outpatient cardiac clinics at Evelina London.
- Rapid Access Clinic where we see urgent cardiac referrals.
- Joint cardiac clinics at some local hospitals.

- The cardiac inpatient unit at Evelina London.
- The neonatal unit at St Thomas'.
- Paediatric intensive care unit.

How can we help?

At diagnosis

- Explaining diagnosis and management options.
- Giving verbal and written advice.
- Giving advice on signs and symptoms to look out for.

Pre and post-operative care

- Providing advice and support before and after surgery.
- Liaising with community teams such as health visitors and community nurses.
- Discussing the surgical admission process.
- Providing support at your local hospital.

During hospital stays

We give support to children and families who are inpatients at Evelina London and visit the cardiac inpatient unit on a regular basis (Monday-Friday).

Advice on everyday issues

We provide information and advice on issues including immunisations, feeding, weight gain, saturations, hydration, travel, wound care, sports and much more.

Education and social care support

- Provide care plans for nursery and schools.
- Provide letters of support and cardiac diagnosis for various organisations, such as social services, housing and Disability Living Allowance.

Transition to adult services

- We attend a joint clinic with adult and paediatric services.
- We hold a transition information day twice a year for the child and a parent to attend. This is an opportunity to meet the adult congenital cardiac team, which includes a tour of the adult congenital cardiac services at St Thomas'.

How to get in touch

The CCNS team can help explain more about these services and help with any other related questions. Full contact details are on the back page.

We are not an emergency service. If you have a medical emergency please call 999.

Useful sources of information

Evelina Children's Heart Organisation (ECHO) is a charity that supports the families of children with congenital heart disease who receive treatment at the Evelina Children's Hospital. They have a rota of trained prenatal support volunteers who offer comfort and reassurance at this stressful time. ECHO also sponsors specialist antenatal classes for parents of heart babies to be treated at the Evelina Children's Hospital.

t: 07730 146 154

e: prenatalsupport@echo-evelina.org.uk

w: www.echo-evelina.org.uk

Children's Heart Federation (CHF) is a national charity and the umbrella body for voluntary organisations working to meet the needs of children and young people with congenital and acquired heart conditions and their families.

t: (Freephone info line) 0808 808 5000
(9.30am-4.30pm Mon to Fri)

w: www.childrens-heart-fed.org.uk

Contact us:

If you have any questions or concerns, please contact the CCNS team on 020 7188 4546 (Monday to Friday, 9am to 5pm).

Out of hours, please contact the inpatient cardiac unit on 020 7188 8849.

Joint email:

PaediatricCardiologyOutreachNurses@gstt.nhs.uk

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003 10am to 5pm, Mon to Fri

e: letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department. **t:** 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints)

e: complaints2@gstt.nhs.uk

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A list of sources is available on request