

Children's Cardiac Nurse Specialist (CCNS) team

East Midlands Congenital Heart Centre

Information for Parents & Carers

Produced: August 2025

Updated: November 2025

Review: August 2028

Leaflet number: 1653 Version: 1.1

Who are we?

We are children's nurses. We have lots of experience in looking after children and young people who are born with heart conditions. You will see us at East Midlands Congenital Heart Centre in Leicester.

We give:

- support
- advice
- education

We can support babies, children and their families from birth through to when they are 18 years old. This is both whilst in hospital and when you are at home.

Who can access the CCNS service?

You can speak to us if your child:

- was born with a heart condition
- has a condition that affects the beating of the heart.
- has a heart condition that was passed on from a parent or runs in the family

You can call or email us. The number to call is at the end of the leaflet.

Other people who look after your child can call us, like:

- Nurses
- Community nurses
- Doctors
- Teachers
- Midwives
- Health Visitors

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

We are a central point of contact between:

- You.
- People that look after your child when you are at home.
- People who look after your child in your local hospital.
- People who look after your child when you are in Leicester Royal Infirmary.

When will I meet the team?

You can meet the team at any point during your child's journey, from birth to 18 years old.

You may meet us before your baby is born at a scan of your baby's heart. We will help you understand about your unborn baby's heart.

You can meet us in:

- Children's Cardiac Outpatients department
- Children's Cardiac Ward
- Children's Intensive Care Unit

You can meet us during your child's stay in any of the wards at Leicester Children's Hospital.

How can the team support me?

We can help you understand your child's condition. We can talk to you about your child's heart condition.

We can talk to you about:

- Heart medicines
- Tests for your child's heart
- Treatments for your child's heart

We can talk to schools and nurseries about your child's heart condition.

We can talk to Health Visitors and Children's Community Nurses about what your child might need at home.

We can sit with you when the doctors speak to you about your child.

This can be in:

- In clinic
- On a Ward
- When you are in Intensive Care

Practical support:

We can:

- give practical advice about staying in hospital with your child.
- write prescriptions for your child heart medications
- help you apply for money if your child is in hospital for a long time.
- write a letter to your work to let them know why you need time off.
- write a letter to your child's school to let them know why your child is in hospital.
- help you to apply for money from the government for your child. This will depend on your child's condition and their needs.
- direct you to information about your child's heart condition.
- refer your child to other people that can help like:
 - Play Specialists
 - Dieticians
 - Speech and Language therapists
 - Clinical Psychology team
 - Palliative care specialists

Support for your wellbeing:

We understand that finding out that your child has a heart condition or being in hospital can be frightening and stressful.

We can support you by listening to you and giving practical support when you need it.

We know that everybody manages this differently. You can talk to us at any point during your child's journey.

Sometimes you or your child might need to speak with the Clinical Psychology team. This can help you to understand and cope with growing up with a heart condition.

We can talk to you about this. We can make a referral to the Psychology team for you or your child.

How can the Children's Cardiac Nurse Specialist support my child or young person?

We can talk to your child about their heart condition and answer any questions they might have. Your child might have different questions to you. It is important that your child can ask questions that might be worrying them.

When your child is around 12 to 14 years old, you might meet the nurse who will help your child to understand their heart condition as an adult.



This process is called Transition. The nurse is called the Transition Nurse.

You and your child might meet the nurse a few times. This is to help them get ready to move into adult heart services.

How can I contact the Children's Cardiac Nurse Specialist team?

You can contact the team by calling:

0116 258 3338

Please leave your child's name, date of birth and contact number so we can call you back.

Messages are listened to throughout the day between 8am and 5pm, Monday to Friday (excluding Bank Holidays).

You can also email the team on: uhl-tr.emchcchildrenscardiacnursespecialists@nhs.net

This is not an emergency service. If your child is unwell call 999.

Where can I find out more information?

You can find more information about the range of services by going to the East Midlands Congenital Heart Network website:

www.emchnetwork.nhs.uk/

Or by scanning the QR code:



Your CCNS is: _____

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email uhl-tr.equalitymailbox@nhs.net



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