

Psychological support when your child has congenital heart disease

E.Midlands Congenital Heart Centre

Last reviewed: January 2024

Next review: January 2027

Information for Patients

Leaflet number:1089 Version:2

What does the paediatric psychology service do?

Paediatric psychologists are registered practitioners who have higher qualifications in psychology. They have experience of working with young people **who are born with** (congenital) heart problems, and their families. We believe that by talking about difficulties and practicing new skills, children and families can cope better.

We know that coping with congenital heart disease (CHD) can be hard at times. We also believe that children and families are all unique, with many strengths. We work with the medical teams involved in your care to offer holistic and personalised care. It can be in a form of an assessment, treatment or consultation, holding the wider family system in mind.

Our psychology service works with young people aged from 0 to 19 years, who have congenital heart disease (CHD), and their families. We work with children and families living in Leicester, Leicestershire, and Rutland. We also work with patients who live within the area covered by the East Midlands Congenital Heart Centre (EMCHC) Network. This covers Nottinghamshire, Derbyshire, Lincolnshire, Northamptonshire, and beyond. Any child and family being supported for CHD by a cardiologist or paediatrician, whether inpatient or outpatient, can be seen by the psychology team. Young people over 16 years can consent to their own treatment. See more on our website at www.emchnetwork.nhs.uk/en/page/clinical-psychology

Our aims:

- We want young people and their families to live well with congenital heart disease.
- We can help people with making sense of emotional problems they might be having.
- We can also help people towards living happy lives.

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

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

How can the paediatric psychology team help?

Our job is to listen to your problems and help find a way forward. Some of the kinds of problems that we can help with are:

- Understanding, coping, and growing up with CHD
- Worries about treatment, needles and/or surgery
- Upsetting memories of past treatment or time in hospital
- Dealing with feelings related to your heart condition. This could be things like feeling different because of your scars or because you cannot do certain things
- How your CHD affects other people in your family
- Difficulty sticking to a treatment plan, or worries about coming into hospital for tests
- Supporting you with your readiness to transition to Adult Services
- Assessment of cognitive difficulties that people with CHD sometimes have. These can be things like:
 - problems with paying attention
 - problems with learning
 - problems with remembering
- talking to the people who support you locally, for example your school, GP, community nurse, or social worker if you have one.

Talking to the psychology team can help you to understand why you feel the way you do. You can find new ways of coping with things. If you think it would be helpful for you to see a psychologist, you can **ask your doctor or nurse to refer you**.

What will happen if I am referred for an assessment?

We will phone or write to you offering you an appointment. You do not have to come if you do not want to. First appointments can last up to 90 minutes. They can take place face to face at the hospital where you have your heart care follow-up, or another place closer to home, like a different hospital. We can do telephone or video assessments if this is easier for you.

We usually talk to the family all together at first. We might speak to you on your own if you want this. We will talk to you about your concerns and how we could help. We will ask you questions about things like:

- how you are getting on with you heart condition
- how your heart condition affects your life
- how you are feeling
- what is going well for you and what is not going so well

We might ask if it is ok to speak with other people in your life, like teachers. Things you tell us during appointments will be kept private. This is unless we are really worried about you or someone else because of what you tell us.

What might happen next?

After our first appointment, we can decide together what to do next:

- We might agree on some goals for working together. We would arrange to meet for further appointments, either by video, telephone, or face to face
- You or your family might prefer help from a different service. We might also tell you about another service that would be a better fit for you. This can be because it is closer to where you live, or because your problems are not the kind of thing we can help with. We will talk to you about this at the assessment so that you understand why.
- You or your family might decide that you do not need to see us again

Appointments might involve us working with you on your own, sessions just with a parent or carer, or sometimes families together as a group. We may also work together with other people such as doctors and nurses. You may be offered a small group intervention; these could be for young people or parents. We will discuss with you what the best option for you is available after your assessment.

Contact details

Paediatric Psychology Service, Artemis House, Westcotes House Site, Westcotes Drive, Leicester, LE3 0QU.

0116 295 2959 between 9am and 5pm Monday to Friday.

Outside of these hours, you can leave a message. This will be listened to on the next working day. This is not an urgent response service. If you are worried about someone's safety and need urgent advice, please contact your GP or 111. You should ring 999 if someone is in immediate danger and/or needs urgent help.

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة 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

જે કુર્મીં ઇચ જાજવારી વિમે હેર જામ્મા વિચ ચાહુંદે હે, ઝાં વિરખા વરવે હેઠાં હિંતે ગાદે નંબર 'હે ટેલીફોન વરે।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

Previous reference:

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