

Clinical psychology - adult congenital heart disease

Patient information sheet

The experience of having congenital heart disease (CHD) will feel different for each person. There may be times when you have questions, worries or concerns. This is quite understandable.

Some of the things you may experience when you have a congenital heart condition might include:

- Worries about your heart condition and the impact it is having on your day to day activities.
- Adjusting to managing your condition as an adult.
- Adjusting to late diagnosis of previously unknown CHD.
- Coping with changes in your health which may need further medical treatments or interventions (e.g. MRI, CT scan, ICD implantation, catheter, cardiac surgery, possible future heart transplant).
- Preparing for surgery or other interventions.
- Coping with being in hospital for a long time.
- Specific needle or other hospital related phobia.
- Worries that you may have trauma symptoms associated with past, current and future medical treatments and interventions.
- Difficulties with following advice and sticking with long term medication and other treatments.
- Having difficulties coping with advice about the risks of pregnancy due to your heart condition.
- Having a learning disability or neurodevelopmental disorder and needing additional support regarding your CHD.

- Adjusting to more limited treatment options, including a palliative pathway towards the end of life.

As well as your consultant and specialist nurses, your hospital ACHD team also has a clinical psychologist who can help with different aspects of your care.

Clinical psychologists have training in a variety of psychological approaches that can help when people are having difficult thoughts or feelings affecting their wellbeing. Sometimes these challenges also make it harder for patients to manage their medical condition and do the things they want to do in life.

Clinical psychologists use an understanding of how people think, feel and behave, together with an understanding of the psychological impact of living with long term medical conditions, to help individuals with CHD cope with the kind of difficulties described above.

Clinical psychologists do not prescribe medication (such as anti-depressants) but instead use therapeutic skills to support progress. Sometimes this therapy might be provided alongside medication for your mood, prescribed by your GP.

Therapy is a collaborative process, which means that you will be asked to think about what is important for you to gain from the sessions. Therapy can help you find ways to manage difficult thoughts and feelings, develop better relationships, learn strategies to help you to manage personal problems, and develop ways to live a meaningful and valued life with CHD.

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Large print copies and alternative language versions of this leaflet can be made available on request.

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How do I arrange to see a clinical psychologist?

The psychological medicine department at the Royal Papworth Hospital has a part-time psychologist specifically for ACHD patients. You can discuss consideration for a referral with your specialist ACHD clinical team.

Once consideration for referral is made, the case is discussed in a team meeting and a decision is made about how best to proceed.

If the referral is not accepted, a plan will be made for signposting or referral to the most appropriate alternative source of support.

If the referral is accepted, you will usually be assessed face to face at Papworth within a few weeks. The waiting time for a first appointment varies, as we have limited resources, but everyone accepted for assessment will be seen at the earliest opportunity. If your situation is considered urgent (due to upcoming surgery for example) you will be prioritised as far as possible.

The outcome of the assessment will lead to one or more of the following options:

- A better understanding of your situation and what will help you
- Provision of self help resources
- Signposting or referral to a suitable service
- A brief therapy intervention at Royal Papworth Hospital.
- A more in-depth therapy intervention at Royal Papworth Hospital.

Please note, we are not able to offer crisis interventions.

If you are experiencing a mental health crisis, then you can make an urgent GP appointment to gain support.

You can also ring NHS 111 option 2 or go to your local A&E.

In addition, you can ring Samaritans any time on 116 123.

Scan the QR code to find out more about the ACHD service at Royal Papworth Hospital via our website:



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