

Psychological wellbeing in congenital heart disease

- Important information for patients with congenital heart disease.

Introduction

The purpose of this booklet is to explain the types of psychological difficulties and distress that you may be experiencing with congenital heart disease.

Why is there a psychologist at a heart clinic?

Having congenital heart disease can be unpredictable. You might want to do things with your life (e.g. start a family, travel the world) but are told that this may be tricky because of your heart condition. You may struggle because you want to be like your friends, but your condition gets in the way. You might also find it difficult to cope with the different treatments you're having.

A certain amount of distress is common, especially when there are changes to your condition, or when you have to make big decisions. Many people with congenital heart disease experience distress. Distress can affect your everyday life. It may mean you are:

- Struggling to cope with your condition
- Feeling down, depressed or hopeless
- Stressed out
- Unable to relax, feeling nervous, anxious or on edge
- Having difficulty falling or staying asleep, or sleeping too much
- Feeling bad about yourself.

If you regularly feel this way, we may be able to help you.

How do I know if I need help?

If you are struggling because of your heart condition, you may be:

- struggling to come to terms with your condition as your life changes;
- struggling to understand difficult information you've been told and what it means for you;
- not coping with your heart condition;
- angry because of your heart condition and what it is stopping you from doing;
- fed up of having to take medication and come to appointments;
- not taking your medication or coming to appointments because it reminds you of your heart condition;
- worried about the need for more surgery or interventions;
- struggling to cope after a stay in hospital;
- unable to stop focusing on your heart; or
- forgetting appointments and conversations.

Or you might feel that you're just not quite right. You may be:

- feeling like you have let yourself or others down;
- no longer enjoying activities or struggling to find things interesting;
- unable to stop worrying about your health, finances or family's wellbeing;
- easily annoyed, angry or irritable;
- feeling you "can't be bothered";
- feeling your relationships are a challenge or struggle;
- avoiding situations because you are scared of what might happen;
- having trouble focusing on things, e.g. reading the newspaper or watching TV;
- drinking alcohol or taking drugs to help you cope.

These are just a few examples of how your heart condition can have a negative impact on your mental health and wellbeing.

If you feel that you are stuck or have reached a crisis point meeting with us may help.

What do clinical psychologists do?

We are trained to use talking therapies. Talking through problems can help you put them into perspective. It can also help you come up with different ways of dealing with these problems.

You can discuss things that you find difficult to talk about with family and friends. We can talk to you about your memory, attention and language. We can offer advice on any difficulties you may have in these areas.

We do not wear white coats. We won't ask you to sit on a couch. We do not prescribe medication.

What should I expect?

Your first appointment will last about one hour. Further appointments will be about 45 minutes long. You will have a chance to talk about the impact your heart condition is having on you, unhelpful thoughts and feelings that show up and how they get in the way of everyday life.

We will usually ask about other aspects of your life and personal experiences. This will help us understand you as a person, and not just the symptoms you are experiencing.

You may find it helpful to write down any questions you want to ask beforehand.

What will happen next?

After the first few appointments, we will come up with a plan about how to approach your problems. We will work together to help you live well with your heart condition.

This may involve seeing you by yourself or with your partner or a family member. We will ask you to complete some forms about your problems as we work together, to see if our work is helping.

Between appointments, you may be asked to work on some goals we have agreed, practice new skills and test things out.

In some situations, we may suggest you speak to another person or organisation as they may be better able to help you.

Appointments

The number of appointments will depend on the plan we agree. We can see you at NHS Golden Jubilee in person or we can offer appointments using video calls or over the telephone, which means you don't need to travel.

How do I make an appointment?

If you feel you would benefit from a clinical psychology appointment, please speak to any of the healthcare professionals within the Scottish Adult Congenital Cardiac Service (SACCS) team, who will pass us your details. We will then contact you to offer you an appointment as soon as we can.

Notes

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Notes

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