

# Getting the support you need

When you, your baby or child is diagnosed with a congenital heart condition you will be looked after by a network of clinicians who work together to form the South West and South Wales congenital heart disease service. This means that you or your child will be looked after by the local hospital team but may also meet specialist clinicians at our specialist cardiac centre in Cardiff (Welsh patients only) and/or the specialist surgical centre for the network in Bristol.

A congenital heart condition is a life long journey of care, and it is important to know where you can get support at the times you need it. This leaflet contains information about the support that is available to you and your family, and how to access it.

You can find out more about the South Wales and South West CHD network and the range of support available to you on the South West and South Wales congenital heart disease (SWSWCHD) website: [swswchd.co.uk](http://swswchd.co.uk)

## What will my or my child's pathway of treatment and care look like?

On the website, you will find our visual pathways for different groups: babies and children, young people, parents and adults. These pathway documents explain the things that are likely to happen when you need outpatient or inpatient care, or if you/your child requires cardiac surgery or a cardiac catheter.

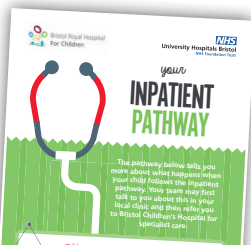
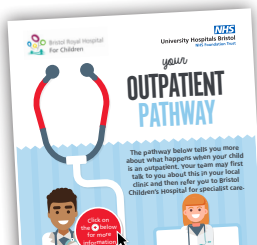
The documents have interactive links that give you more information about particular steps in the pathway.

For example, what will happen before and after an admission for surgery, and what type of health professionals you are likely to meet along the way.

## How do I find out more about support?

You and/or your child may have a number of emotional needs due to having a congenital heart condition or because of an event occurring, such as needing to have surgery. We recognise that these things can be worrying, and that it is helpful to be able to find trusted information, to know where to turn to in times of need, or to know how to find others who have been through similar experiences. In order to help you navigate your journey, we have put together a range of support 'digibooks', which are tailored for children, young people, parents and adults. In these interactive 'digibooks' you will find information about the areas our patients and families have told us are the most challenging to manage. These include things like: coping with a diagnosis, being prepared for surgery, how to manage school or work when you have a congenital heart condition.

If the support you need is not within our specialist expertise, the information in the 'digibooks' will point you in the direction of local or national resources that might better suit your needs. We have included different types of support including online information, specialist clinical teams and specialist non-clinical support (e.g. marriage support). These can be found on the SWSWCHD website, under the 'Getting Support' section: [swswchd.co.uk/en/page/getting-support](http://swswchd.co.uk/en/page/getting-support)



There are three levels of support detailed on the website:

**Level one: if you want to find out more.**

You will find information here about many online resources that you can access, whenever and wherever you need to.

**Level two support: if you need to talk to someone.**

The 'digibooks' direct you to a range of local support groups and organisations that you can approach if you feel you would like to speak to someone about your worries or concerns, either in person or by telephone.

**Level three support: specialist clinical support.**

You can find out more about how you can access specialist support through our clinical teams. This may be through your consultant or cardiac nurse specialist, who may be able to answer your questions or refer you on to our specialist psychology team.

**Toolkits to help you cope with some key issues:**

We also have a number of toolkits that describe a range of tools and techniques you can use to help you with issues that we are often asked about. For example, what to do if you or your child is feeling low, or how to prepare for coming into hospital. Our toolkits contain information, ideas and strategies to help with questions and worries you may have.

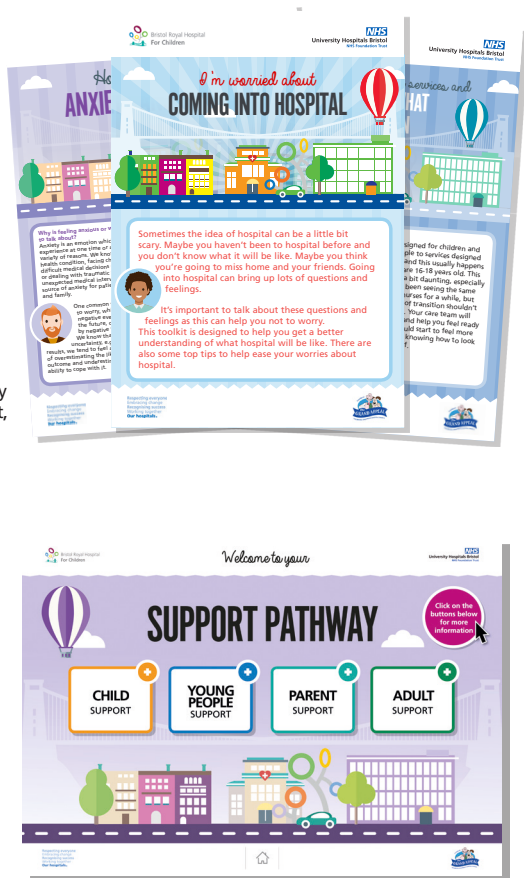
Your clinical teams are also available to talk to you about your pathways of care and support. Please talk to our clinical nurse specialist teams about questions that you have on:

Bristol paediatric team **01173428286**

Cardiff paediatric team **07813922441 / 0781197136**

Bristol adult team **0117 342 6599**

Cardiff adult team **029 2074 4580**



For access to other patient leaflets and information please go to the following address:  
[www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients](http://www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients)

Hospital switchboard: 0117 934 9869 | Minicom: 0117 934 9869 | [www.uhbristol.nhs.uk](http://www.uhbristol.nhs.uk)

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