



**University Hospitals
Bristol and Weston**

NHS Foundation Trust

Patient information service
Psychological Health Services

Preparing you and your child for cardiac surgery admission resources for parents of younger children



Introduction

Telling a child about their cardiac surgery and what it means for them can be a difficult topic to approach. As parents or guardians there is a lot of information to understand, and it can be hard to judge how to explain this to a young person.

Depending on factors such as their age they may have more questions than others. What is hospital going to be like? Why am I different from my friends? Will my scar be there forever? This leaflet, prepared by the paediatric cardiology psychology team, is designed to help.

It brings together a wide range of resources to help you understand the procedures and explain them, support with talking through thoughts and feelings with a child or teenager, and how you as parents and guardians can access support too.

During your child's surgical pathway, you will also meet members of the hospital team who can offer advice or support prior to and during your admission – they include ward teams, play specialists, cardiac nurse specialists, family support workers, music therapists and the chaplaincy team.

In addition to the information you will receive from the ward, the psychology team have developed some resources for preparing your child for an admission:

- Wellbeing toolkits for parents Patient support | University Hospitals Bristol NHS Foundation Trust (uhbristol.nhs.uk) including: 'How do I prepare my child for coming into hospital?', 'How do I talk to my child about their health condition?', 'Helping your child cope with their worries when coming into hospital'
- You can access an online recording of the paediatric cardiology psychology team webinars on 'Supporting your child with coming into hospital' and 'Supporting siblings'. In these webinars, the team talk in more detail about ways you might use some of the resources below
- The South Wales and South West Congenital Heart Disease website www.swswchd.co.uk has information about the team, pathways, support and some advice from the psychology team on preparing for cardiac surgery which you can access using this link www.swswchd.co.uk/en/page/getting-support-cardiac-surgery
- 'Practical ways to help your child prepare for a test or investigation'



Resources for preparing younger children for surgery

It is best for parents to read through the book first, and many choose to read sections at a time whilst asking your child whether they have any questions, or would like to hear more about some of the information.

Books and videos

- **Sammy's Heart** operation book and animation is aimed for children between 6 and 11 years old to help understand who they will meet in hospital, the tests they will have, what will happen on the wards and when they can go home.
 - Book: *Sammy's Heart Operation*
- British Heart Foundation (bhf.org.uk)
 - Video: *Sammy's Heart Operation* - YouTube (QR codes).
- **Zipline** by David Humphreys can be helpful to explain a surgical scar for younger children.
- **A Little Deep Sleep** can be used to explain operations to younger children
 - Video: <http://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/bristol-royal-hospital-for-children/childrens-website/operations-and-tests/going-to-theatre/>



Play

- Play specialist support may be available prior to or during admission. Please ask your cardiac nurse specialist (CNS) team or ward team.
- For younger children, using hospital-based play, including noticing feelings and modelling potential coping strategies may be helpful in preparing for surgical admissions.

- The following link provides some short video examples for preparation for blood tests, cannula, anaesthetics, CT, ECG, EEG, Ultrasound, MRI and X-ray
 - Video: Play - What Why Hospital For Children (whatwhychildreninhospital.org.uk).



Toolkits

- Wellbeing toolkit for children (insert link/QR code) including: 'I'm worried about having a medical procedure', 'I'm worried about coming into hospital', 'How do I talk to my friends about my condition?', 'What can I do if I feel worried or low?'



Looking after your own wellbeing as parents:

- Wellbeing toolkit for parents on 'How do I cope when my child is in hospital?'; Webinars for parents' wellbeing including: 'Managing the impact of a child's cardiac condition', 'and 'Mindfulness'. Recordings are available from:
- The South West and South Wales Congenital Heart Disease Network website has information about patient pathways, supporting yours and your child's wellbeing and patient stories – www.swswhcd.co.uk under 'Patients and families' – 'Getting Support'.



Information about Bristol Royal Children's hospital:

There are video tours of the wards which some families find helpful to watch prior to admission to familiarise themselves with the environment:

- Dolphin ward information and video tour Bristol Royal Hospital for Children - Ward 32 - Cardiac Ward | University Hospitals Bristol NHS Foundation Trust



(uhbristol.nhs.uk)

- Seahorse ward (Paediatric Intensive Care Unit – PICU) information and video tour Bristol Royal Hospital for Children - Paediatric Intensive Care | University Hospitals Bristol NHS Foundation Trust (uhbristol.nhs.uk)



General resources to support living with a heart condition

- Understanding your child's heart: a series of booklets from the British Heart Foundation
 - for parents QR code project CHD Parents v5 190422.pdf (swwchd.co.uk)
 - and for booklets for teenagers QR code project CHD Teenagers posters v5 190422.pdf (swwchd.co.uk)
- Changes to my child's treatment: what now? Advice for parents



Charities

- Charity organisations including Heart Heroes, Little Hearts Matter and Tiny Tickers offer parents and children the opportunity to be linked up with other families with a child with a heart condition and may provide information, support or advice see www.swwchd.co.uk/en/page/charities
- Teen Heart – British Heart Foundation group for people aged 13-18 with a heart condition Teen Heart - support programmes for young people | BHF
- Youth@Heart are a charity linked with the hospital that provide support, awareness and opportunities to engage in events for young people with a congenital heart condition aged between 15-24 years old www.youthatheart.co.uk



- The website Changing Faces has a number of resources for children of all ages and for parents on approaches to supporting children with visible difference including surgical scarring: www.changingfaces.org.uk



- For story books for both the child and their sibling, please see: www.littleparachutes.com.



Please contact your GP if you have concerns about your and/or your child's mental health and wellbeing.

Additionally the NHS urgent mental health 24/7 helpline (England only) – offers mental health support and advice, help to speak to a mental health professional, and can arrange an assessment to help decide on the best course of care Mental Health Helpline for Urgent Help - NHS (www.nhs.uk)



For more general advice on supporting your own and your child's mental health, please see the following resources:

- Every mind matters www.everymindmatters.co.uk
- Hub of hope – enter your post code and select your support need/concern and to see a list of support services local to you <https://hubofhope.co.uk/Youngminds> – includes information resources, young people's text line and parents' helpline, email service and webchat <https://youngminds.org.uk/>
- Childline – includes information resources as well as 24/7 telephone, instant messenger and email support lines for young people



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As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients.

While under our care, you may be invited to take part in research. To find out more please visit: www.uhbw.nhs.uk

Help us prevent the spread of infection in hospital. Please make sure your hands are clean. Wash and dry them thoroughly/use the gel provided. If you have been unwell in the last 48 hours please consider whether your visit is essential.

Smoking is the primary cause of preventable illness and premature death. For support in stopping smoking contact **NHS Smokefree on 0300 123 1044.**

Drinkline is the national alcohol helpline. If you're worried about your own or someone else's drinking, you can call this free helpline in complete confidence. **Drinkline on 0300 123 1110.**

For access all patient leaflets and information please go to the following address:
<http://foi.avon.nhs.uk/>

Bristol switchboard: 0117 923 0000
Weston switchboard: 01934 636 363
www.uhbw.nhs.uk



For an interpreter or signer please contact the telephone number on your appointment letter.



For this leaflet in large print or PDF format, please email patientleaflets@uhbw.nhs.uk.

