


Preparing for your child's heart surgery

Tips for parents from the psychology service



This book is designed as a brief guide to support parents to prepare for their child's heart surgery. It includes ideas and tips from the Paediatric Cardiology Psychology Service that might be helpful for you.

Every child and parent will have a different experience of cardiac surgery. Our hope is that this guide will give you some ideas for how to support your child, but you know them better than anyone else so please choose the tips that are most relevant to you.



Part One

Supporting your child

Tips for parents from the psychology service

The first part of this guide focuses on helping you to support your child to prepare for their heart surgery.

It is designed to be a workbook with prompts for you to complete to help to personalise our tips and advice to your individual child.

This workbook for parents is designed to be used alongside the workbook for children, which can be accessed using this QR code:



There are also a range of additional resources that can be accessed which are mentioned throughout this booklet. The QR code to access this resource page is included here and at the bottom of each of the relevant pages.



Starting with yourself

When you find out your child needs heart surgery, there can be an overwhelming amount of information to process. The emotional impact of this information is also likely to make it more difficult for you to process than usual. Some people might want to avoid thinking, talking, or reading about surgery, whilst others might want to analyse and absorb every detail. Try to pace yourself as it is often better to process this information in small, buildable chunks, and to give yourself time to process in-between.

Before you explain surgery to your child, you might want to improve your own understanding to help you to explain it in simple and child-friendly language. The British Heart Foundation has a helpful series of guides called "Understanding my child's heart condition" that can be accessed using the below QR code. You can also access videos from the Bristol Cardiac Nurse Specialist team that summarise the surgery process.

You might want to briefly summarise your understanding here to help you to plan how you will explain it to your child.

You will also probably have your own questions about your child's heart condition and surgery. It might be helpful to make a list of them below so you can ask your child's Cardiologist or Cardiac Nurse Specialist.



More resources to help you to understand your child's heart condition and the surgery process can be accessed by scanning this QR code and looking at the "Parents" or "Bristol" sections

Managing your own worries

Most families feel worried about their child having cardiac surgery. This is a very understandable and normal response. However, to enable you to explain to your child in a calm and reassuring way it is helpful if you have some ways of managing these worries.

You might find it helpful to write your worries in the space below

Problem solving



Can you problem solve about any of these worries?

Step 1: Summarise the problem in the space below – try to be specific

e.g. I'm worried about the risks of surgery

Step 2: Write down potential solutions in the space below – include any potential solutions and try to be as creative as possible with your ideas

*e.g. I could google this information – but it might be unreliable
I could talk to my child's Cardiologist or surgeon*

Step 3: Choose the best solution from your above list of ideas

e.g. I will ask my child's cardiologist about the risks during our next appointment

Managing your own worries

You might have some worries that you're not able to problem solve. Instead, it might be helpful to think about strategies to manage worry and anxiety. Below are some ideas that you might want to try.



5-4-3-2-1 Grounding

Look around and describe in detail:

5 things you can see

4 things you can hear

3 things you can feel in contact with your body

2 things you can smell

1 thing you can taste

Progressive Muscle Relaxation

Start by focusing on your arms. Clench your fists as tightly as you can. Tense your arms. Hold this tension for 10 seconds.

Release the tension and let your arms go floppy. Notice how this feels.

Next, focus on your legs. Clench your toes. Tense your legs. Hold this for 10 seconds.

Release the tension and let your legs go floppy. Notice how this feels. Repeat this process again.

Deep breathing

Step 1 - Get into a comfortable position

Step 2 - Put your hands on your stomach. Take a slow, deep breath in for 4 seconds. Notice your stomach rising.

Step 3: Hold your breath for 4 seconds.

Step 4: Breathe out slowly and gently for 4 seconds.

Repeat

Guided Imagery

Sit comfortably with your eyes closed.

Think about a place that makes you feel calm. It might be a beach or a Forrest or by a river, or somewhere else. Try to picture this place really clearly in your mind.

Describe this place to yourself in detail. What can you see? What can you hear? What can you smell? What can you feel in contact with your body? How do you feel?

Hold onto this image for 10 seconds, or for as long as you would like to.

More skills for managing worries can be found in the "Parent well-being" section of the resources page. You can access this page by scanning this QR code.



Talking to your child about surgery

It is important to talk to your child about cardiac surgery so they know what to expect and understand why they are going into hospital. This can help them to feel more in control and to reduce some of their worries.

A four step process for talking about surgery:

1. **Check their understanding** – Start by asking them about what they know about their heart and about hospitals.
2. **Explain to them about surgery** – Use honest and simple explanations about what will happen and why they are having it. Use words that your child understands.
3. **Check their understanding again** – Afterwards, ask them some questions to check that they haven't mis-understood anything you've said.
4. **Encourage them to ask questions** – they might want to write these down so you can answer them or problem solve about them together.

Tips for explaining surgery:

- **Use child-friendly language** – For example, “You are going to have surgery for your heart so that it will work better to help you to be able to run around more.”
- **Explain the things that will happen** – For example, “we will go to Bristol to a special hospital where children go to have surgery for their heart like yours”.
- **Use storybooks and videos** – Try using storybooks and videos to help you to explain and to help them know what to expect. We recommend scanning the QR code below to access a range of videos that explain the heart and the process of heart surgery in A child-friendly way.
- **Using play** – Imaginative play can be another helpful way of preparing your child for surgery. You might want to set up a hospital for a teddy bear or toy. Your child could practice taking their temperature and listening to their heart with a toy stethoscope to help them to get familiar with what happens in hospital. You could use toy medical kits, hospitals, ambulances, dressing up outfits, or puppets.
- **Be honest** – Try not to promise things that might not be true. For example, instead of saying it won't hurt, say that you and the doctors and nurses will try to make it hurt less.
- **Reassure them** – It is important to be honest with children, but we also want to reassure them about hospital and surgery. It can be helpful to let them know that they will be looked after by doctors and nurses who focus just on helping children with their heart.



A range of videos, story books and guidance for talking to your child about surgery are on the “Younger children” and “teenagers” sections of the resources page. You can access this page by scanning this QR code.

Conversation Planner



This is a space for you to write your own plan for talking to your child about their cardiac surgery.

When will I talk to them about surgery?

It is best to find a quiet and relaxed time to talk.

Generally, younger children benefit from knowing a week before their pre-assessment clinic appointment, whilst older children might benefit from knowing weeks or even a couple of months before. You know your child better than anyone else, so use your own judgement about how long they will need to process and prepare for surgery.

How often will I talk to them?

Often a gradual, continued and gentle approach can help to ensure your child doesn't feel overwhelmed. In the lead up to the surgery, you might want to allocate a specific time where you spend half an hour talking about surgery.

Will I talk to them on my own or with someone else?

How will I involve their siblings in this conversation (if relevant)?

It is likely that they will have their own worries and questions as well.

Managing your child's worries

Children might feel a range of different feelings about having surgery. Some children might feel relief or excitement as they are hoping they will feel better afterwards. Most children also feel worried, angry, scared or sad about surgery. This is a really understandable response and it can be helpful to allow them to feel this. An upset stomach, trouble concentrating, problems with sleeping, not wanting to talk about their heart or hospital, asking lots of questions, or not wanting to go to hospital can all be signs of worry.

It can be helpful if you are able to support your child to identify how they are feeling, for example, "Your face looks like you might be upset. How do you feel?" and then validate how they are feeling by saying "I can see how that would feel..." or "That makes sense that you feel like...". Try to reassure your child that most children get upset, scared, or worried about surgery and that is an understandable way to feel. It can also be helpful to ask if they have any worries so you can problem solve about them together.

Worry time

You could try allocating an agreed "worry time" for 30 minutes every day. You can agree a certain time and set a timer where you will talk about their worries. Your child might want to write their worries and put them in a special jar, box or bag ready to talk about during worry time.

Managing the wait

Some children find the wait for a date for surgery difficult. Try to reassure them that this is an understandable way to feel and focus on what is within their control e.g. what they pack. We appreciate this wait can also be very frustrating for parents. It can be helpful to continue to have gradual and gentle conversations about surgery to keep preparing your child for when they are given a surgery date.

The workbook for children (accessed via the QR code on page 2) includes ways of talking about worries and skills to help manage them.

My packing list



Use this space to make a list of things to pack for hospital

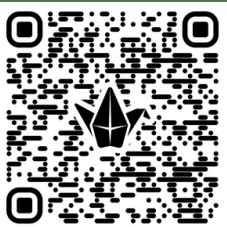
- | | | | | | | | | | |
|---|---|-------------------------------------------------------------|--|--|--|--|--|--|--|
| ▶ | ✓ | Things to keep my child busy e.g. colouring, drawing, games | | | | | | | |
| | ✓ | Things to keep myself busy during the surgery | | | | | | | |
| ▶ | ✓ | Comfortable clothes, phone charger, toiletries | | | | | | | |
| | ✓ | My child's medication and any medical equipment they need | | | | | | | |
| ▶ | ✓ | | | | | | | | |
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My preparation checklist



This is designed to be a checklist to aid your conversations with your child about surgery:

- Does my child understand why they are having surgery?
- Do they understand what will happen?
- Do they know where we are going? (Scan the QR code below to access videos of Bristol Children's Hospital)
- Do they know who will be with them in hospital?
- Do they know what we will do in hospital whilst they are having surgery?
- Do they know who will visit them in hospital, or phone or video call with them?
- Have we talked about anaesthetic? Resources included on QR code below.
- Have we talked about how they will have a scar so they know what to expect (if relevant)?
- Have we watched some videos about hospital and/or surgery? (scan QR code below to see some)
- Have they had a chance to ask questions about surgery?
- Have we talked about their worries?
- Have we tried worry time, and/or other skills to manage their worries? See children's workbook for more ideas.
- Have we involved their siblings (if relevant)?
- Have their siblings had a chance to ask questions and talk about worries?
- Have we planned something for them to do with their siblings in hospital?
- Have we planned things to keep them busy in hospital?
- Have we planned something for them to look forward to for afterwards?
- Have we made a packing list for myself and my child?
- Have I spoken to my child about their recovery after surgery?
- Have I spoken to them about missing school and how we will manage this?
- Do they want their class in school to know or not? Who do they want to know?
- Have I made a plan for what I will do during the surgery?
- Have I made a plan for looking after my own well-being (see part two of this booklet for ideas)?



Scan this QR code to access more resources about preparing for surgery.

Returning home

Returning home after cardiac surgery can be both an exciting time, and also a difficult time for families. Often people like being back in their own homes, but it can be a big adjustment after being in hospital and having constant access to doctors and nurses, as well as monitoring equipment.

Here are some of our tips for managing the return home after surgery:

- **Allow yourself time to adjust as a family** – you might feel more anxious with the reduced monitoring and this is completely normal. Even though leaving hospital is seen as a positive change for many families, it is still a change and it takes time to adjust to that change.
- **Create a routine** – It is likely that your child will still be recovering when you return home. It can be helpful to create a routine to support them with this adjustment.
- **Plan nice activities** – plan some nice things together to do as a family as part of their recovery and return home from hospital.
- **Creating their own storybook** – Your child might find it helpful to create a book of their cardiac surgery story, which might include drawings or photographs to share with other members of their family, or to show their friends when they return to school. For younger children, you might want to use the same methods of play or activities that you used to prepare them for surgery to help them to share how they are feeling after surgery.
- **Changes in behaviour** – You might notice changes in your child's behaviour. This is completely normal after being in hospital. Give them time to return to their normal selves, which usually takes up to six weeks.
- **Managing worries** – Continue to talk to them about surgery and use the skills that they find helpful to manage their worries.



Part Two

Looking after yourself

Tips for parents from the Psychology service

Before and during your child's stay in hospital, you might feel a mixture of different feelings. This might include anxiety, sadness, relief, pride, or anger. Often, parents tell us they feel understandably overwhelmed. As you are required to prioritise your child's needs, it is likely that your own well-being might not be a priority for you. However, caring for your child requires you to also be the best version of yourself that you can be in this difficult situation and environment. It is therefore important to pay some attention to your own well-being as well.

This workbook has five ways of looking after yourself before, during and after your child's hospital stay: Checking-in, Connection, Control, Cortisol, and Compassion. It is designed to be a workbook with prompts to help you to apply our tips to yourself.

There are also a range of additional resources that can be accessed which are mentioned throughout this booklet. The QR code to access this resource page is included here and at the bottom of each of the relevant pages.



Checking-in

Often, parents understandably describe being in “survival mode” when they are in hospital. Our minds are often good at jumping to the worst case scenario, and between things that have happened in the past or that might happen in the future.

If you can, try to take things one day at a time, and focus on being present in the moment where possible. It can often be helpful to try to develop a routine for hospital that considers your own needs for support, nutrition, rest, exercise, and emotional support.

One way of looking after your own needs can be to try to regularly check-in with yourself by asking yourself the following questions:

- How am I feeling right now? *e.g. I am feeling anxious*

- Where can I feel this in my body? *e.g. I can feel tension in my shoulders*

- What do I need right now? *e.g. I need food and a break from the ward*

- How can I look after myself right now? *e.g. Eating and going for a five minute walk*

Three-minute Body Scan

You might also find the below three-minute exercise helpful to bring you back to the present moment:

- Sit in a comfortable position and close your eyes.
- Focus on your feet. Notice how it feels for you feet to be touching the floor. Do they feel warm or cold, tense or relaxed?
- Move your attention up to your legs. How do they feel?
- Notice your back against the chair. Feel the chair supporting your body weight.
- Notice your arms. How do they feel? Is there any tension in your shoulders?
- Move your attention up to your jaw. Does it feel tense or relaxed?

Connection

Your support network during your hospital stay

We know that a hospital admission can often be a stressful experience for most families. Support from your family, friends, and usual support network has been shown to be a protective factor that helps families manage when they are in hospital. Sometimes, we can find it difficult to ask for support, but it can often make a difference when managing a hospital admission.

When thinking about support, it can be helpful to break it down into practical and emotional support. You might find it helpful to complete the below grid to help you to think about who you might need to ask for support.

You do not need a lot of people in each of the below sections, the quality of these support relationships is more important than the number of them.

People who can give you practical support

People who can give you emotional support

How will you ask them for support?

How will you ask them for support?

Connection

Connecting with your child

It can feel understandably difficult for families to feel connected to their child whilst they are in hospital due to medical equipment and having different healthcare professionals involved. However, we know that it is really important and beneficial for the well-being of both children and parents to feel connected.

If you can, try to remind yourself that despite being in this more challenging setting, there are small ways that you can connect with your child that can also be beneficial for your well-being.

You might find the following ideas helpful to connect with your child:

For younger children, you can connect with your child by talking to them, singing to them, or engaging with them in sensory play. You might also want to use sounds (e.g. a rattle) or touch (e.g. gently tickling them), or sight (e.g. blowing bubbles).

For older children, reading with or to them, watching something together, or playing a game with them (e.g. I spy..) might help you to feel more connected.

Control

During a hospital admission there are likely to be many stressors. There will also be things that you cannot control, which can often result in feeling understandably overwhelmed. As humans we often use control as a strategy to help us to feel safer. It can therefore be helpful to ask yourself that in this difficult situation where many things are out of your control, what can you control and where can you make a difference?

You might find it helpful to look at the circles below and add some of your own ideas about things that are outside and within your control.



Cortisol

It can be helpful to think about our three systems that regulate our emotions - our drive, our threat and our soothing system. For our well-being to be it's best, we want these three systems to be as balanced as possible. Often, when parents are in hospital these three systems will look like this:

Drive system is working really hard to accomplish tasks and organise things.

Parents feel driven and have lots of dopamine, which can make it hard to switch off or rest.

Soothing system is under-activated making it hard to feel safe or content or connected. Less Oxytocin.

Threat system is working really hard to protect their child and manage the threats.

Parent is feeling anxious, scared, shame, anger, and disgust. This is linked with increased levels of cortisol, which can make it hard to switch off or rest.

It is understandable that your three circles might be out of balance before, during, or after your child's hospital stay. It is also helpful that your drive and threat systems are activated during this time to help you to get through. However, sometimes it can feel very uncomfortable when your threat system is working really hard and your body is experiencing increased levels of cortisol.

If possible, it can be helpful to notice this and to see if you can do anything to reduce this stressed or tense feeling. Some people find exercise, such as a fast-paced walk or jumping on the spot a helpful way of managing this. Other people find it helpful to have a cold drink, or cold shower to manage this feeling. You might also find the progressive muscle relaxation exercise on page 5 helpful.

You might also find these movement videos created by Belfast Children's Hospital helpful. Scan this QR code to access them.



Compassion

Our drive (blue) and threat (red) systems are activated by a hard-wired and automatic response that we all have as humans. We therefore do not need to actively try to activate these systems. However, our soothing system, which is just as important, requires us to actively choose to do things to activate it to help to balance out the three circles. Sometimes our soothing system can seem like less of a priority, but all three systems are equally important for us to function at our best.

One important way of activating our soothing system is through self-compassion. This means being more understanding about ourselves and treating ourselves in the same way that we would treat a good friend. It can be helpful to ask yourself, what would you say to a friend who is in your situation? What would you do to look after them? Can you do that for yourself?

Some other ideas of how to activate your soothing system are included below. You might find it helpful to add in some of your own ideas as well.

Focus on your breathing

Have a break

Go for a walk

Have a warm drink

Picture someone who is kind.

What would they say to you right now?

Soothing System

Returning home

Many people find their child being in hospital a difficult experience. Sometimes people might experience the following after the hospital stay:

- Re-experiencing what happened in hospital through nightmares or flashbacks
- Being hyper-alert and aware of any signs of danger. This might be being hyper-alert to any signs of problems with your child's or your own health.
- Not wanting to talk or think about your experiences in hospital, or go to places that remind you of it.
- Changes in your mood, such as, feeling more withdrawn, low in mood, numb, or irritable.

All of these responses are completely understandable and are a normal response to an abnormal situation. Often they can be a consequence of your brain working hard to process what has happened. Usually, these experiences improve over time and it can be helpful to try to reassure yourself that they are an understandable consequence of what you have been through.

Sometimes you or your child might need some professional support to process these experiences. It might therefore be helpful to contact the Psychology service if you think this might be helpful for you. Our contact details are included on the final page of this booklet.

Sharing your story

Research suggests that sharing your hospital story with other trusted people and using your own experiences to help other people struggling with the same challenges can be beneficial for your own well-being. You might therefore also find it helpful to share your story with some people that you trust.



This workbook was created by the South Wales Paediatric Cardiology Psychology team

To help us to improve our resources, we would really appreciate your feedback on this workbook. To share your feedback with us, please scan the below QR code:



A special thank you to all of the healthcare professionals and families who have taken the time to feedback on and help to develop this workbook with us.