

Preparing for your child's heart surgery

Information for patients, families and carers



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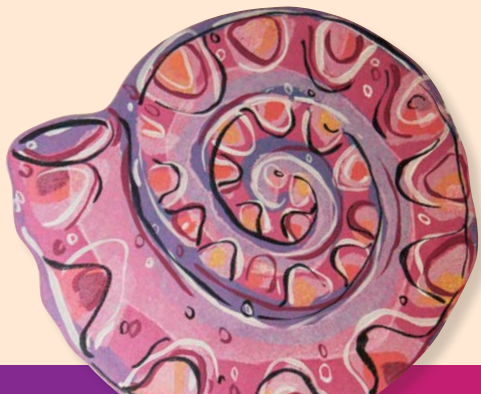
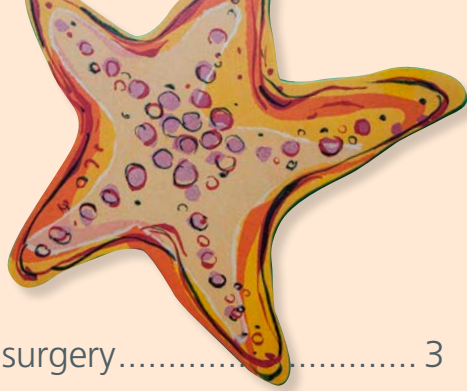
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Preparing for your child's heart surgery

Following the results of a recent investigation, your child's cardiologist (heart doctor) feels your child may benefit from having heart surgery and has placed them on the congenital heart surgery referral pathway at Southampton Children's Hospital.

This booklet explains what happens next and contains some useful advice and tips to help you prepare for your child's heart surgery and their stay in hospital. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please speak to a member of our team.



What is the congenital heart surgery referral pathway?

When a cardiologist feels a child may benefit from having heart surgery, they place them on the congenital heart surgery referral pathway. We have outlined the different stages of the pathway below:

1

Your child's case will be presented at the next cardiac multidisciplinary team (MDT) meeting. At this meeting, a team of healthcare professionals specialising in managing and treating heart conditions will review and discuss your child's recent investigation results. This will help them to decide on the best treatment plan for your child.

2

After the cardiac MDT meeting, your child's cardiologist will inform you of the recommended treatment plan for your child. This may be in writing or during an outpatient appointment.

3

Your child's cardiologist will then refer your child to the care of our cardiac surgery team. A cardiac surgery secretary will call you approximately 10 to 14 days before the next available surgical clinic to arrange an appointment for your child. These clinics run once a month. When you receive this call will depend on the urgency of your child's condition. Please be aware that it may be several months after the cardiac MDT meeting before you receive this call.

At your child's appointment, a cardiac surgeon will explain why the procedure is needed and explain the benefits and risks of the procedure to you. This appointment is a good opportunity for you to ask any questions you may have.

If you think of any questions after your appointment, you can contact our children's cardiac nurse specialist team on 023 8120 4659 (Monday to Friday, 8am to 5pm).

4

After this appointment, we will add your child to the surgical waiting list. Where we place them on the waiting list will depend on the urgency of their condition.

5

When a date is available for your child's procedure, we will contact you to arrange your child's hospital admission. We will try our best to give you around a week's notice of a procedure date, but this isn't always possible (for example, if we get a last-minute cancellation).

Due to emergency cases and limited availability of intensive care beds, we sometimes need to cancel procedures at short notice (this can be days or hours before a procedure). We know that this can be a difficult experience for families, and we will try to give you as much notice as possible if we need to cancel your child's procedure.

Who should I contact if I am worried about my child while they are on the surgical waiting list?

If you are concerned about your child's symptoms while they are on the surgical waiting list, please contact the relevant team below for advice.

For children cared for by an Oxford cardiologist:

Children's cardiac nurse specialist team (Oxford)

Telephone: **01865 234985** or via switchboard on **0300 304 7777** bleep **4170** (Monday to Friday, 9am to 5pm)

If the team are unable to answer your call, please leave a message with your name and telephone number. Messages will be checked throughout the day and a member of the team will call you back.

For children cared for by a Southampton cardiologist:

Children's cardiac nurse specialist team (Southampton)

Telephone: **023 8120 4659** (Monday to Friday, 8am to 5pm)

If we're unable to answer your call, please leave a message with your name and telephone number. Messages will be checked throughout the day and a member of our team will call you back.

If you have any urgent concerns outside of these hours, please call Ocean ward for advice on **023 8120 6470**.

In an emergency, call **999** or visit your nearest emergency department.



How should I prepare my child for their heart surgery?



Waiting for heart surgery can be a very stressful time for children and your child may have a lot of questions. Knowing what to expect and having their questions answered can help your child to feel more in control of the situation and feel less anxious about what is to come.

To be able to confidently answer your child's questions, it is important that you understand as much as possible about their procedure. If you are unsure about anything, please contact us and we will be happy to answer any questions you may have.

We've included some tips below that you may find helpful when preparing your child for coming into hospital for their procedure.

Talk to your child

When talking to your child about their procedure, it is important that you:

- choose a quiet time to talk to them
- use a calm and relaxed tone

- stay positive (children can usually sense how you feel, so will pick up on any anxiety you have)
- begin the conversation by asking them what they know or think about hospitals (start with the issues your child thinks are the most important)
- use honest and simple explanations for what will happen to them when they go into hospital (for example, if your child is having a general anaesthetic, you may want to explain to them that they will not see, hear or feel anything during the procedure as they will be asleep - try to avoid using the phrase 'put to sleep' when talking to your child as this may frighten them)
- use words your child will understand such as 'uncomfortable' or 'scratch' (especially when talking about procedures or tests that may be painful)
- try not to make any promises you can't keep (for example, saying that things won't hurt or that they won't have any blood tests)



Discuss your child's wishes

Before your child's procedure, you may find it helpful to discuss your child's wishes regarding tests and treatment. For example, before having a blood test or having a cannula (a small flexible plastic tube) inserted into a vein, you may want to ask them the questions below:

- Would they like to look or look away?
- Would they like to sit on your lap or next to you?
- Would they like to see the equipment involved?
- Would they like to say 'ready'?

Include hospital-related toys and books into your child's day-to-day life

Reading your child hospital-related stories and encouraging them to play with hospital-related toys before their procedure will help to give them a chance to explore hospital in a non-threatening way.

Playing with these sorts of toys and activities during your child's stay in hospital is also a good way of taking their mind off things, which will help them to relax into their surroundings.

- reassure them during your conversation that you think this procedure is the best thing to do (where possible, give yourself time to absorb the information first before talking to your child)
- tell your child about any plans for an overnight stay at the hospital and let them know that you will be sleeping there with them (encourage your child to bring their favourite teddy or toy with them to make them feel more relaxed)
- mention any scars your child may have after their procedure
- check they have understood what you've told them during your conversation by asking them some questions (anxiety makes it difficult for children to retain information, so please be prepared to repeat what you have said a few times)

You may also find it helps your child to jointly write down or draw what you have talked about.



Encourage your child to ask questions

Once you have spoken to your child about their procedure, let them know that they can ask you questions any time. Open communication can really help to manage any anxiety your child may have.

It is also important that you let your child know that they can ask their doctors and nurses questions if they want to at any point before, during or after their procedure. If they are too scared to ask questions, let them know that you can ask their questions for them.

Children, particularly younger children, will often ask questions when they are involved in an activity or while they are playing. This can understandably catch parents or guardians off-guard, and it can be difficult to know how to answer certain questions. We recommend having a stock phrase to use when you're not best sure how to answer, for example, 'That is a really good question. I'm going to have a think about it and then we can talk together about it. Is that ok?'. This allows you some time to think about it or gives you the chance to contact us for advice first.

How can I support my child during this time?

We've included some different ways you can support and comfort your child while they wait for their procedure below:

Involve siblings

If your child has any siblings, it is important to involve them in the preparation for your child's stay in hospital. They may have their own questions and worries about what is happening to their sibling.

Plan together

Involving your child in the planning process will help to build their confidence and reduce any anxiety associated with a hospital stay. It may also help to involve them in organising and packing a few things for their hospital stay, such as toys and games, to occupy them while they wait. When talking about their stay in hospital, let them know that they will be able to

talk to and see friends and family while in hospital via video calls.

Talk about feelings and emotions

Let your child know that it is normal to feel many different things before, during and after their procedure. They might feel worried, scared or curious about what will happen to them.

Arrange something for your child to look forward to

Some children like to choose a small reward to look forward to when they return home after a procedure. It may be a good idea to take a photo of the reward with you into hospital to remind them of the special thing they are looking forward to receiving when they go home.



How can we help support you and your child during this time?

Our whole team are here to support you and your child. If you would like additional support in preparing your child for their procedure, please contact us to discuss a referral to our play specialists and/or to our psychology team.

Play and psychology team

The play and psychology team are a small team made up of play specialists, a youth worker and psychologists. The team work alongside our medical team and are often asked to meet with children and their families to prepare them for visits to the hospital. The team are also able to access support from the learning disability and autism team to help children with a diagnosis of autism or a learning disability prepare for their hospital visit.

If you feel your child would benefit from additional support before their procedure, please contact us.

Play specialist team

During your child's stay in hospital, a team of play specialists will provide play activities for children on Ocean ward, either in the playroom or at their bedside. The team can help to prepare children for procedures using play therapy, allowing them to act out their worries and develop ways of coping. The team can also:

- provide pre-admission visits and practice sessions for some medical procedures (if you feel this would be helpful for your child)
- organise visits from dedicated PAT (pets as therapy) dogs (if you feel this would be helpful for your child)



Psychological support for parents

A hospital visit for your child also means a hospital visit for you. During your child's stay in hospital, you may experience a mixture of emotions, so it is important that you look after yourself too. We recommend taking some time to think about how you can look after yourself during your child's stay in hospital. We've included some ideas below to help you get started:

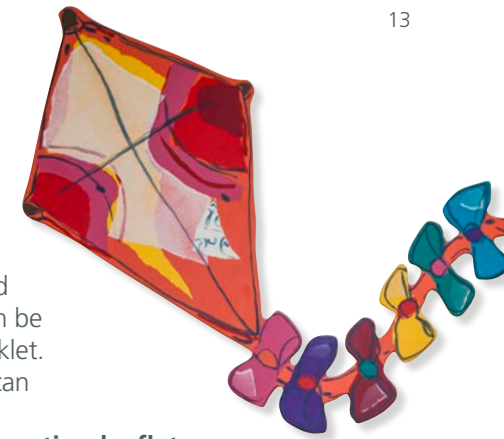
- practise some simple breathing and relaxation exercises to use when your child is having their procedure



- arrange to call a supportive family member or friend while your child is having their procedure
- make sure you eat, drink and get some fresh air during your child's stay in hospital

Our psychology team are available to support you too when you are in hospital. Please let a member of our team know if you would like to access this service.

Useful links



More information about staying on Ocean ward and your child's recovery from heart surgery can be found in the 'Welcome to E1 Ocean ward' booklet. We will give you a copy of this booklet or you can download a copy from our website:

www.uhs.nhs.uk/for-patients/patient-information-leaflets

When you talk to your child about their procedure, it is important that you explain why they need to go into hospital in a way they can understand.

The following resources from national support groups may help with this:

Little Hearts Matter: Preparation for hospital

www.lhm.org.uk/preparation-for-hospital

British Heart Foundation: Sammy's Heart Operation (aimed at 7 to 11 year olds)

www.bhf.org.uk/information-support/publications/children-and-young-people/sammys-heart-operation

British Heart Foundation: My Heart Op (aimed at 13 to 19 year olds)

www.bhf.org.uk/information-support/publications/children-and-young-people/my-heart-op

One of the main worries children have about coming into hospital is having an anaesthetic or blood tests. We recommend watching the two videos below with your child before coming into hospital to help with these worries:

A Little Deep Sleep - a family guide to anaesthetics

www.youtube.com/watch?v=NIV2zLkOqjI

Preparing your child for blood tests

www.uhs.nhs.uk/for-visitors/southampton-childrens-hospital/childrens-services/childrens-outpatient-department/childrens-blood-tests

Contact us

If you have any questions or concerns about preparing your child for their procedure, please contact us.

Children's cardiac nurse specialist team

Telephone: **023 8120 4659** (Monday to Friday, 8am to 5pm)

If you need to rearrange the date of your child's procedure, please contact our congenital cardiac coordinator team on **023 8120 5382**.

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**