

How can I support my child's siblings during this time?

When a child has surgery, their brothers and sisters may also feel worried or confused. They may hear or see things that they do not understand. They may have to cope with being away from one or both parents. Here are some ways that you can support siblings before and during the hospital admission.

- **Include siblings in conversations** about their brother or sister's surgery. **Use simple explanations** that they will understand.
- It can be common for siblings to think that their thoughts or actions caused their brother or sister to become unwell, or worry that they will become sick themselves. **Reassure them that it is not their fault** and that they can't 'catch' a heart condition.
- Siblings may worry about being left alone or their needs not being met. **Let them know who will be caring for them** while you are at the hospital and that you will come back as soon as you can. **Leave a special item** that they associate with you to provide comfort.
- **Try to keep routines** such as naps, meals and bedtimes as **close to normal** as possible. If they attend school or childcare, let their teacher know what is happening so that they can provide support and watch for any changes in mood or behaviour.
- Siblings may feel jealous of all the attention their brother or sister is getting. **Try to set aside some one-on-one time** for them if possible so that they don't feel left out.
- Siblings may miss their brother or sister. **Encourage them to make something for their sibling** like a drawing or card. Provide them with the choice of visiting and if they choose to, explain what to expect (for example what they will see or hear).
- **Provide opportunities to play away from the bedside** to help siblings cope with spending time at the hospital. There is a playroom on Edgar Stephens ward which siblings can visit along with the Starlight Room on Level 2. The Volunteers department also run Sibling Care where, for a small fee, families can drop their children off to play. The George Gregan playground is on level one, as is the Book Bunker.

What supports are available?

- **Child Life Therapy** – Child Life Therapists use play to help children understand and cope with their hospital experience. They can support you to prepare your child using a number of tools including books, photos, videos, medical play with dolls and equipment, and tours of the hospital environment. They can also help your child learn ways to cope with potentially stressful procedures such as blood tests. If you wish to book a Pre-Admission visit with a Child Life Therapist, please call **(02) 9845 3717**.
- **Family Support Team** – This team specialises in providing emotional care for babies and children with heart disease and their families. It includes psychologists, social workers, clinical nurse consultants and nurse practitioners. They can help by providing parents with opportunities to talk about their worries, experiences and questions in relation to their child's heart condition and surgery. If you would like to talk to a member of the family support team, or to make an appointment to meet, please call **(02) 9845 0088**.

Useful resources and links

- Bourgeois, P. (2000). Franklin goes to hospital.
- Winkel, M., Holzheimer, L. and Hensshellwood, F. (2000). Sarah's Story. Available from Kids Health Bookshop.
- My visit to the preadmission clinic and My heart operation – heartcentreforchildren.com.au/surgery.html
- schn.health.nsw.gov.au – search for virtual tour and kids and teenagers
- Procedural preparation videos – rch.org.au/be-positive
- Medical play videos – whatwhychildreninhospital.org.uk/play-videos



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Talking with your child about their heart operation

A guide for families and carers

Why is preparation important?

Talking with your child before surgery can help them to cope with the experience by knowing what to expect. The hospital environment has many unfamiliar sights, sounds, smells, people and procedures, and these can feel confusing or worrying for a child. If not provided with honest, accurate and age appropriate information, a child may invent their own explanations or scenarios which may be more frightening for them than the reality.

Research has shown that children who receive preparation and support that is sensitive and appropriate for their age and stage display lower levels of anxiety, show an increased trust in healthcare staff, have a faster recovery post-operatively and exhibit fewer emotional difficulties after discharge, such as separation anxiety and sleep disturbances.

What should I do before talking with my child?

- Learn as much as possible from the Heart Centre for Children team about what your child will experience before and after surgery. Once you have these details, it will be easier to explain and answer any questions that may arise. If your child asks a question you aren't sure how to answer, it is ok to say you don't know but will find out.
- Seek support in talking through your own fears and anxieties. Children are very good at noticing feelings so if you feel worried, they are likely to worry too. It can be helpful to talk to someone you trust, such as a family member or friend. It's best to do this away from your child, so that you can be open and honest about your own feelings and then model being calm when preparing them. You might also like to meet with one of our psychologists or social workers at the Heart Centre for Children, who have experience supporting parents as they support their child.

How do I talk to my child about surgery?

- Be honest about what will happen. **Use simple explanations** that your child can understand to tell them about what they may see, hear and feel. If you are unsure what to say or how much to tell your child, please contact the Child Life Therapy department (details on the back).
- **Help your child understand** why they need surgery. It is common for young children to think they have said or done something wrong to cause their heart condition or need for surgery. Reassure them that it is not their fault and that they are not in trouble.
- Try to **use the least frightening language** possible. For example, you could say 'make a small opening' instead of 'cut' or a 'special medicine that will make you sleep' instead of 'gas' or 'anaesthetic.'
- **Explain** to your child they will not see, hear or feel anything during surgery because of a special sleep medicine. Provide reassurance that they will only wake up after the operation is finished.
- **Reassure** them that if something hurts, they will be given medicine to help with the pain.
- **Emphasise that the doctors and nurses are there to help not to hurt them** to establish a sense of trust.
- Let your child know that you will be able to **stay with them** in hospital.
- **Read age-appropriate books** or watch videos about visiting the hospital (see list on the back).
- Provide opportunities for **medical play**. Toy doctors kits, dress-ups, dolls and stuffed animals are a great way of supporting children to become more familiar with medical equipment and procedures whilst also allowing them to work through any anxieties or worries they may have. Let your child lead the play and discussion, validating any feelings they express. Provide simple explanations and correct any misconceptions as they arise.
- **Involve your child** in packing his or her bag including any favourite toys, books, games, music, movies and photos that will serve as comforters.
- Do not make promises that you cannot keep such as there will be no needles. Instead, tell your child that you will **find ways to cope together** with any fears that may arise.



For many parents, the thought of talking with their child about surgery can be overwhelming.

Some families may feel it is best to avoid telling their child the truth about what is happening so as not to worry or frighten them. Some families may feel uncertain about how much to tell their child and what to say. Others may find it hard to talk to their child if they are feeling worried themselves. These are all common responses.

At the Heart Centre for Children, we are committed to supporting families to have these conversations so that children can better understand and cope with their hospital experience.