

The Heart Transplant



Original Artwork by a young heart transplant recipient

How Do We Prepare for the Heart Operation?

Preparing for the Hospital Stay

Children coming to the hospital usually have many questions and concerns, even if they do not know how to express them. Before your child comes to the hospital, give them as much honest information about their condition as you think they can understand. You will find a list of recommended books in the resources section of this manual. Most are easily bought online. Your child might also find it helpful to read about the experiences of another child with a transplant.

Encourage your child to trust the medical staff. It is important children believe they are on the same team as their doctors. A counselor can help if your child is very anxious about the surgery.

Don't be afraid to ask your transplant team for help or for a referral to someone who might be able to provide extra support to your family.

Some transplant programs include checks for stress, depression and anxiety in the overall transplant assessment and routinely have older children needing a transplant talk to a psychiatrist or a doctor in adolescent medicine.

Tips for Talking to Your Child About Their Transplant Surgery

- Be honest and use age appropriate language when talking to your child.
- Tell your child what their incision (opening for surgery) or scar will look like.
- Draw a picture of an incision on a doll or on their chest.
- Tell your child they may have some pain but that they can ask for medicine to make it feel better. A child often is anxious about surgery because of their fear of the pain.
- Tell them the doctors and nurses are on their side and helping to make them better.
- Check that your child understands what will happen by asking them to explain in their own words what they think will happen or what could happen.

Many hospitals prepare children for surgery using age-appropriate materials such as soft cloth dolls, puppets, medical equipment, photographs, books and other materials. These materials not only help to teach your child about hospital stays and procedures but also give them a chance to express their feelings in a non-threatening way and address any misunderstandings. When children feel prepared, they are usually less afraid and feel more in control.

Fears and Concerns About Surgery and Recovery

It is normal to be overwhelmed by the thought of transplantation and its effect on your life, your family and your future. Some people become very emotional and experience confusing or overwhelming feelings. This is normal; these feelings should pass with time.

Maintaining Routine During Hospital Stays

The hospital stay can be very upsetting for children. Their daily routine and sleep patterns change. They will also face strange and sometimes painful tests and meet many new people. It is normal for them to be irritable and bad-tempered after this experience, especially if their stay in the hospital has been a long one.

The experience can be particularly hard for younger children, who particularly benefit from a regular routine. Try to keep to familiar routines as much as possible during your child's treatment. Bedtime routines are especially important for good sleep.

When your child leaves the hospital after surgery, it may take some time for things to get back to "normal."

What Happens on the Day of Surgery?

When a donor organ becomes available for your child, it will be a day filled with overwhelming emotions. You and your child may feel nervous, anxious, excited or scared. At this time it is very important for you and your child to ask any questions you feel have not yet been answered.

In the next few pages, you will have a glimpse into what you and your child can expect on the day of transplant.

Finding out About a Donor Heart

A member of the transplant team will call you to say a donor heart is available for your child. They will give you specific instructions about when to come to the hospital and where to go when you arrive. The transplant team member will also ask you some questions about any recent symptoms that would cause concern for infection.

Note: It is very important your child does not eat or drink anything once you have been called. Please follow any instructions carefully. Not following instructions could result in delayed or cancelled surgery.

Arriving at the Hospital

Once your child arrives at the hospital, a nurse will examine them and take vital signs (such as their heart rate, blood pressure and temperature). They will review the information they have on file about your child's allergies or medications and update your child's medical history with you.

To prepare for transplant, your child will need to have blood tests and have an IV inserted into their arm or back of their hand. Your child will also have an x-ray of their chest. All these tests help us make sure your child is ready and safe for transplant.

Many people will see you and your child before the surgery and can answer questions. A transplant surgeon will have you sign a consent form for the surgery and answer any other remaining questions. An anesthesiologist (the doctor who gives your child the anesthesia, or sleep medicine for surgery) will also meet you, examine your child and have you sign a consent form.

Your child is now ready to go to the operating room (OR). A member of the OR team will tell your child's nurse they are ready, and the nurse will then escort you and your child to the OR waiting area. The nurse or a member of the surgical team will discuss how and when they will give you medical updates during your child's surgery. You will be told where to wait to receive these updates.

If My Child Is Called for Transplant, is the Donor Heart Healthy and Ready to be Used?

When a suitable heart is offered for your child, the doctors will accept it, let you know about the quality of the heart and prepare your child for the transplant.

Preparations for the transplant take place even before the doctors have inspected the donor heart.

When the doctors actually see the donor heart, sometimes it is too damaged to be used. In these situations, the transplant must be called off. Usually this happens when you and your child are already at the hospital but before the operation has started. We call this a “dry run.” If this happens, the team will tell you to wait for another organ to become available.

This can be very disappointing, but it is more important to make sure your child receives a healthy donor heart than to take risks because a heart is available.

What Happens in the Operating Room?

Assuming the donor heart is healthy, the transplant operation involves removing the failing heart from your child’s body and attaching the new heart. This takes about four to eight hours. For children with complex congenital heart disease, the operation is more complicated.

Several members from the surgical team (nurse, surgeon and other doctors and staff) will be with your child during surgery. The surgical team will describe your child’s operation to you in detail.

Preparing for Surgery

When your child enters the operating room, they lie on the special operating room bed while the nurse attaches ECG stickers to their chest, an oxygen saturation probe to their finger and forehead and a blood pressure cuff to one of their arms. These devices are all designed to help the team monitor your child’s condition during the surgery.

Your child may be given medication to keep them calm. Then, within a few minutes of entering the OR, they will have anesthesia to send them completely to sleep. A breathing tube, special IV and urine catheters will then be inserted to support your child’s bodily functions during and after surgery.

Removing Your Child’s Heart

The surgical team will open up your child’s chest and start a heart and lung bypass machine, which does the work of the heart and lungs during the operation. The surgical, nursing, anesthesia and perfusion teams monitor your child carefully during the surgery.

Transplanting the New Heart

When the new heart arrives, the surgical team works to safely implant it in your child. When this is done, the heart and lung bypass machine is stopped, and the new heart begins to take over the work.

After the bypass machine is stopped, the teams in the operating room watch the new heart to make sure it is working properly. Often an echocardiogram is done to see how the new heart is working and make sure there is no narrowing where the new heart is attached to your child's blood vessels.

When the surgical team is sure everything is functioning as it should, your child will be prepared to be transferred to the intensive care unit (ICU) for recovery.

Where Do I Wait During My Child's Surgery?

You and your family members will be shown to the surgical waiting room or intensive care waiting room.

What Happens in the Intensive Care Unit?

When your child first arrives in the intensive care unit, they will require a period of “settling in.” This usually takes at least one to two hours. Your child’s nurse will tell you when you can visit.

What to Expect When You First See Your Child

Your child will be attached to many tubes and monitors, which can be an overwhelming sight at first. Your child’s team will explain all the monitors, tubes and IVs to you in detail.

Monitors

Your child will be on a ventilator (breathing machine) until they are ready to breathe on their own. Your child will remain sedated while they are on the breathing machine so they are relaxed and comfortable. This usually takes a day or two for older children and teenagers, but it can sometimes take a bit longer for babies. In addition to the ventilator, several monitors in the room will be used to check your child’s heart rhythm, blood pressure, blood oxygen level and possibly other signs, depending on your child’s specific situation.

Devices and Tubes

Most children return from the operating room with a temporary pacemaker in place. This is an electrical device to control the rate of the heart beat. The pacemaker wires will be attached to your child’s heart and come out through their skin.

Your child will have a bladder catheter, a soft plastic tube, which will continuously drain urine. This tube is inserted during surgery.

A nasogastric tube will also be in place. This tube is inserted through a nostril and then passed down into the stomach.

Your child will also have chest tubes to drain fluids that collect during and after surgery. These tubes will come out through the skin just under your child’s ribs.

As your child will still be asleep or very drowsy at this time, they will get fluid, medications and nutrition through intravenous (IV) drips. These will normally go into your child’s arm or the back of their hand.

Your child’s nurse will be able to explain all monitors and tubes to you. Feel free to ask any questions.

Your Child’s Incision

Your child will have an incision (cut) along the length of their sternum (breastbone). This is called a “sternotomy” and will be covered with a dressing. After two or three days, the dressing will be removed and left off.

Depending on their surgeon's preference, your child may have staples (wire) or a suture (thread stitches) on the incision. Sometimes, a child returns from the OR with the "chest open" because they are more stable that way. In this case, the incision is covered with a cloth or dressing and then closed in the ICU or the OR after a few days, once your child is more stable.

As your child recovers from the surgery, the medical team will reduce their medications and begin to remove the invasive lines and monitors. The breathing machine will do less work as your child is woken up from sedation. When your child is finally disconnected from the breathing machine, they will be able to speak and, in time, be able to drink.

When Does My Child Leave the ICU?

Depending on their condition, a child can stay in the ICU for a few hours, a few days or even a few weeks. When your child no longer needs intensive care, they will be moved to the cardiology ward.

Although most of the monitoring equipment will have been removed, your child may still have chest drains, pacing wires or intravenous infusions. Over the following days, these will be gradually removed as your child's condition improves.

Working With Your Child's Healthcare Team

Once your child is in a ward, the nurse who looks after them regularly will also have other patients to care for, unlike in the ICU. Because of this, you will be encouraged to play a greater role in your child's care.

At this point, too, other transplant team members, such as the physiotherapist, occupational therapist, and dietician, become involved again in your child's care. It is important you and your child follow their recommendations and instructions so your child can begin to experience life with their new heart.

This is also a time when the transplant co-ordinators and pharmacists work closely with you to make sure you are getting ready to care for your child at home.

Your Child's Emotional and Psychological Recovery

The physical recovery from a heart transplant operation is only one part of your child's transplant journey. A heart transplant can be an emotionally challenging experience for your child and the rest of your family.

It is not unusual for children who have received a transplant to experience depression, self-esteem and self-image issues, and/or attention disorders after their surgery. Being aware of the warning signs and providing support and counseling for new issues will help to reduce their impact on your child's life.

The transplant team is prepared to support your or your child's emotional concerns and needs at this time. You can get support from the transplant psychologists, psychiatrists, social workers and child life specialists.

Heart transplant generally improves the overall quality of life for a child and their family. It allows seriously ill children to feel well and take part in age-appropriate activities. It has helped many children get back to the normal routines and tasks involved in growing up. However, a heart transplant is not a cure. Children and their families are trading a life-limiting heart disease for lifelong medications and their side effects, close medical follow-up and invasive procedures.

Going Home after the Transplant

Before you and your child are discharged from the hospital, you will start to learn about life after transplant. The transplant nurse co-ordinator, dietician, pharmacist and other team members will teach you how to keep your child healthy at home.

The next section of this manual has information about things that are important after a heart transplant.

It is important to remember each child's situation is different, and your child may not experience everything mentioned.

Your transplant team will give you much more information after your child has the heart transplant and they have time to observe your child's recovery.