

## POST-TRANSPLANT

### The Operation

Most heart transplant procedures are four to five hours long, but some may take much longer, especially if other steps in the operation must be performed prior to the implant. A family member may accompany the candidate to the operation room. Then they will be directed to the Pediatric Cardio-Thoracic Unit (PCTU) waiting room on the 10th floor. Family members may wish to get something to eat or drink in the cafeteria. Periodic updates will be provided by the surgical team.



During the first hour in the operation room, the candidate will be prepared for surgery. Intravenous lines for administering fluids and medications, as well as monitoring lines, will be placed and antibiotics will be administered. After the candidate is put to sleep, an endotracheal tube will be placed in the windpipe to facilitate breathing. It will then be connected to a breathing machine called a ventilator. Next, the chest will be scrubbed with disinfectant and catheters will be placed in the bladder and stomach. The recipient incision is made prior to arrival of the donor heart. Recipients with prior open heart surgery may have their incision made several hours before the arrival of the donor heart.

A heart-lung, or cardiopulmonary bypass, machine is utilized to maintain blood flow to the body during the implant procedure. Surgeons then remove the sick heart, leaving portions of the left atrium, superior vena cava, inferior vena cava and pulmonary artery. Then the donor heart is sewn into place. When the surgeons remove the old heart, several of the nerves in the chest will be cut. Research is now finding that because nerves do not always grow back, the candidate will be less capable of feeling pain in the chest after a heart transplant. These nerves also help to regulate the heart rate. More information regarding heart rate after transplant can be found on Page 4 of the Complications and Long-term Care section.

Once the new heart begins the job of pumping blood, the heart-lung machine is disconnected. Temporary pacemaker wires are placed on the heart for use if needed in the early period following the operation. A pulmonary artery pressure monitoring line may also be placed.

After the operation, the candidate will be taken to the Intensive Care Unit. The transplant surgeon will meet with the family in the waiting room.

Since the candidate will go directly to the PCTU from the operating room, the nurses and doctors will need some time to get them ready for visitors, which usually takes 1 to 1.5 hours. The PCTU is kept as open as possible for families to visit. It is requested that not more than two people visit at a time. They will not be asked to wear gloves, gowns, or masks. Visitors need to wash their hands upon arrival. We ask that only visitors who are healthy visit during hospital stays.

## **Pediatric Cardiothoracic Intensive Care Unit (PCTU)**

The PCTU is a 30-bed intensive care unit where your child will recover following surgery. We want to encourage you to visit your child at times that are convenient for you. When you arrive to the PCTU, at the welcome desk, please have the clerk or volunteer call to see if you are able to visit at that time. The PCTU clerk will check with your nurse and tell you if it is a good time to visit. We request that you call each time before you visit as the unit may be closed to visitors unexpectedly.

Parents and legal guardians are welcome in the PCTU 24 hours a day. Between the hours of 9 a.m. and 9 p.m. extended family and visitors are welcome with the exception of the time necessary for nursing shift change. We ask that only parents and legal guardians remain present during nursing shift change so that visitors will only receive your child's medical information when you elect to share it with them. A parent or legal guardian may sleep at the bedside during your child's stay.

Nursing shift change: 7 to 8 a.m., 3 to 4 p.m., 7 to 8 p.m., and 11 p.m. to 12 a.m.

Your family and friends can reach you at the hospital by calling you on the public phones in the waiting room or by cell phone. Cell phones may be used at the bedside, but we ask that you please place them on silent or vibrate.

The patient's length of stay in the PCTU could last a few days to many weeks depending on the complexity of the medical condition and possible interventions. A team meeting, including the medical team and the family, is planned for patients exceeding a two-week admission in the PCTU. These meetings will serve as an opportunity to discuss the patient's short- and long-term goals, and to discuss the patient's current medical status and treatment plan. These team meetings will continue on a bi-weekly schedule until the patient is transferred out of the PCTU.

## What to Expect

If the patient undergoes an operation during the hospital stay, he/she will likely return to the PCTU with some or all of the following:

- Mechanical ventilator to provide breathing support
- Medicines to support the patient's blood pressure
- Pain and sedation medications to provide comfort
- Chest tubes to drain any fluid that could collect around the heart or lungs
- External pacer wires that provide an opportunity to pace the heart as necessary
- Urinary catheter to monitor the urine output
- Intravenous catheters for medications and blood draws
- Intra-cardiac and intra-arterial catheters for pressure monitoring
- Monitors that display the heart rate, heart rhythm, blood pressure and oxygen saturation

When a patient returns to the PCTU from the operating room, the patient's bed space and any adjacent bed spaces will be unavailable for visitation for approximately one hour or longer if that patient requires additional stabilization. Our patients come back directly to the intensive care unit from the operating room without spending any time in the recovery room. In order to ensure patient safety, we require this initial time to get reports, stabilize the patient, obtain initial tests, and double-check all of the indwelling catheters, medications and ventilator settings.

Because the PCTU is a medical AND surgical intensive care unit, various invasive procedures routinely occur at the patient's bedside. Most of these procedures require sterility and in some cases may be urgent. In order to provide the highest quality and safest care for our patients, families may be asked to step out of the unit during procedures.

Although bedside space is limited, we encourage you to bring in favorite stuffed animals, blankets, music boxes or pictures that your child may find comforting during his/her hospitalization. Please label all personal property with the patient's name to prevent items from being misplaced. Potted plants, flowers and latex balloons are not permitted.

Medical rounds typically occur between 7 to 8:30 a.m. and 5 to 6 p.m. daily during the week, and 7 to 9 a.m. on weekends. Parents or legal guardians are welcome to be present during rounds. It is during this time that team members discuss the patient's medical status and form a treatment plan for the day. Parents or family attending rounds are asked to make note of their questions and after rounds are completed on all patients, these questions will be addressed. If family members are unavailable during rounds, members of the medical

team will be available to answer questions and discuss the treatment plan throughout the day and evening. While the medical team will make every effort to provide families with timely updates and daily treatment plans, please recognize that there may be rapid changes in a patient's clinical status which could alter the original plan. To protect patient privacy, parents at adjacent bed spaces will be asked to step into the hall during rounds.

When your child's condition has improved they will then be transferred to 11 West. In order to be well enough to transfer out of the PCTU, the patient needs to be off the ventilator, off blood pressure medications and have stable vital signs.

## 11 West

11 West is a 32-bed unit. It is where the patients are transferred after the intensive care unit, but before patients go home. Patients on the floor are continuing to progress toward going home, but might continue to require monitoring or oxygen therapy. Patients on the floor are able to walk around and play in the playroom.

While on 11 West, patients are now monitored by pediatric residents, pediatric nurse practitioners, cardiology fellows and attending cardiologists. There is always a doctor or nurse practitioner available.

A nurse will care for your child 24 hours a day through physical assessments, vital signs, medication administration, weights and other treatments. We try to promote uninterrupted rest periods but will need to assess and observe your child at various times including during the night. Please let staff know if you have any questions or concerns.

When you arrive at 11 West, our unit hosts or other patient staff members will provide you with a tour of our unit including the nutrition rooms, bathrooms, laundry room and family waiting room, all available for your use.

Parents and primary caregivers are not considered visitors and are encouraged to stay with their child. Our nurses support the presence of parents at the bedside and consider them vital participants in caring for their child. Our staff will work closely with you to assist and teach you information and care you will need to know before you go home.

Siblings and other visitors may visit between the hours of 9 a.m. and 9 p.m. Since space is limited at the bedside we encourage you to use the family waiting room. Children who are sick or have been exposed to infectious illnesses are NOT permitted to visit.

We do ask that all visitors and caregivers wash their hands when they arrive on the unit.

At each bedside there is a family wardrobe to store personal items. To assist our housekeepers we ask that you do not store any belongings on the floor.

We have space for two caregivers to spend the night at the bedside on 11 West. We will work with families to provide them with the best option to meet their needs as well as their child's during the night hours.

The patient entertainment system (TV) is available in all rooms and can be used for patient/family entertainment as well as education. Internet access is available through this system as well as a wireless internet connection for personal laptops.



## Discomfort

Any chest pain the recipient may feel after the transplant will be due to the natural mending of the chest wall; it is not the heart. Nerves that normally signal the heart to pain are cut during the transplant operation, so it is impossible for transplant recipients to feel any pain from the new heart.

When turning over during sleep, it may be possible for the recipient to feel a prickly pain. As the weeks go by, this pain may actually get worse before it gets better. Pain is a natural part of the healing process – it does not signal a “heart attack” of any kind.

Be sure to discuss any pain or discomfort experienced by the recipient with the medical team.

## Discharge/Going Home

### *Going Home*

Preparing for discharge after a heart transplant really begins the first day after surgery. The nursing staff will start to teach you about your child's care, medications and how to care for him/her after you leave the hospital. The transplant coordinator will have you start to review this education book before leaving. Before being discharged, the transplant coordinator will meet with you and your family members to discuss the immediate and long-term care needs of having a transplant child at home.

Most pediatric heart transplant patients are in the hospital approximately 14 days after transplant. Younger children and infants often require a longer hospital stay due to their nutritional and health requirements. Your child will not be sent home until he/she is physically able to leave the hospital and you have been taught all of the necessary care needs for your child.

### *Discharge Planning*

Discharge planning is a team approach. You, as the parent, are an important part of this team. Before discharging your child from the hospital, there is much planning and teaching that needs to be completed. As a member of the team, it is your responsibility to actively participate in discharge planning so that you can learn how to maintain a healthy lifestyle for your child and care for the transplanted heart. We are here to support you and answer any questions you have. We want you to feel confident and comfortable managing your child's health care needs when you leave the hospital.

### *Discharge Education for the Transplant Patient and Family Members*

The transplant nurse coordinator will coordinate the following discharge information:

- Frequency of routine clinic visits and lab studies
- Review instructions for transplant medicines, including how to order refills
- Provide a personalized medicine schedule for home
- Arrange home care nursing at parents request
- Review short- and long-term complications after transplant
- Review basic health practices
- Transplant dietitian to review diet, formula and supplement as indicated
- School liaison/educational specialist will review school planning needs for school-age patients

