



HASSENFELD
**CHILDREN'S
HOSPITAL**
AT NYU LANGONE

Preparing for
**Your Child's
Heart Surgery**



Front cover: Jennifer and son Nate, age 4; Nate has been cared for by his mom and the cardiac surgery team at Hassenfeld Children’s Hospital. Jennifer is also a Senior Family Advisor. As such, she hosts Family to Family Hours and shares her perspective on safety and quality committees.

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Created in partnership with families and expertise from our Sala Institute for Child and Family Centered Care

Welcome

Welcome to Hassenfeld Children's Hospital at NYU Langone. While here, your child and family will be cared for by a dedicated team of world-class doctors, nurse practitioners, and medical support staff. You are our most important partner in the care of your child. Your perspectives, knowledge about your child, questions and concerns are very important to your child's care. At Hassenfeld Children's Hospital, we strive to create partnerships with our young patients and families in a compassionate and safe environment.

This guide provides information to help you prepare for your child's heart surgery. Inside, you will find helpful tips from families who have gone through our cardiac care program. It includes planning for surgery and hospital stays, what to expect during the hospitalization, and finally, returning home to recover. All team members will be happy to assist you by providing additional information or helping you with anything your family needs.

We are proud to partner with you to provide excellent care to your child. Thank you for choosing Hassenfeld Children's Hospital.

Sincerely,

**The Staff of Hassenfeld Children's Hospital
at NYU Langone**



Dr. Ralph Mosca
meets with a
patient

Starting the Journey: Meeting the Surgeon and Team

The Pediatric and Congenital Heart Program, part of Hassenfeld Children's Hospital at NYU Langone, provides high-quality, compassionate medical care for known or suspected heart problems in babies developing in the womb, as well as infants, children, and adults.

We treat each patient with the utmost care, focusing on safety and comfort. Our specialized team provides the very best care for people of all ages with congenital heart disease, using minimally invasive procedures when possible.

Our cardiac surgeons treat patients of all ages who have inherited and acquired heart defects, performing about 250 cardiac surgeries per year for congenital heart defects. Our surgeons have extensive experience performing successful cardiac reconstructive procedures on patients with complex cardiovascular disorders including transposition of the great arteries, hypoplastic left heart syndrome, truncus arteriosus, and the entire spectrum of congenital heart defects. Our surgical results rank among the best in the nation, thanks to the outstanding work of our skilled, experienced team.

Under the leadership of Dr. Ralph Mosca, George E. Reed Professor of Cardiac Surgery, Department of Cardiothoracic Surgery, and Professor, Department of Pediatrics, our cardiac surgical team meets with parents and families to discuss surgical options, provide tours of the cardiac unit, and answer questions.

To schedule a consultation with our cardiac surgical team, please call 212.263.5989.



"Here at NYU Langone, your family becomes our family. We are with you every step of the way."

Dr. Ralph Mosca

George E. Reed Professor of Cardiac Surgery,
Department of Cardiothoracic Surgery

One Month Ahead: Planning for Hospitalization and Surgery

Preparing for your child's surgery can be stressful for you. We want to provide you with the support you need.

The month prior to your child's surgery, please consider the following:

Work and Childcare Coverage

You may be juggling many responsibilities, including work and other children at home. Because your presence will be so important to your child during and following surgery, we encourage you to make arrangements for work and childcare (for other children) so you can be focused on your child's recovery. Our social worker will be able to help you complete any required paperwork to ensure that time off from work is secured, arrange for accommodations if coming from out of town and suggest appropriate childcare options.

Because important issues may come up during surgery, we ask that a parent or legal guardian be available at all times during the day of surgery. We welcome one parent to stay with your child throughout the hospitalization. We are sorry that we cannot accommodate more than one parent at a time. The typical hospital stay is between three and ten days and recovery time at home is typically three to four weeks.

William, age 3, a heart surgery patient with his dad Jeremy



Dental Clearance Prior to Surgery

All children five and older need to see their dentists before surgery. The dentist will:

- make sure there are no cavities
- complete any dental work two weeks before surgery
- give your child a letter of clearance for surgery

Please bring this letter with you to pre-admission testing.

Schoolwork During the Recovery Period

You may be concerned about your child missing school during and following surgery. It is important that your child's teachers know about his or her heart condition and what it will mean for school activities. We will prepare this information for your child's school.

To help your child stay on schedule with schoolwork, you may want to ask teachers for lesson plans and homework assignments. It can be helpful to ask friends or teachers for notes, request a reduced amount of homework, or email assignments to and from the teacher.

Stay Healthy

It is important for your child to be in the best possible health on the day of surgery. You can help your child stay well by making sure he or she:

- stays away from anyone who is sick
- gets a good night's sleep every night
- eats nutritious meals

If your child becomes sick within five days of surgery, visit your pediatrician. After the visit, let us know about the illness.

Vomiting, diarrhea, or a fever higher than 101.5 degrees is especially important, and will most likely delay surgery.



Discuss hospitalization with your teen as soon as it is scheduled. While it may be hard to talk with your child, it's better that he hear this information directly from you than someone else.

Talking with Your Child and Family About Heart Surgery

As a parent, it is natural to feel anxious about your child's surgery and uncertain how to talk to your child about it. This isn't always easy, but learning about the procedure and meeting the team who will care for your child can help. Speaking with other parents who have had similar experiences can be helpful too.

When Do I Tell My Child?

A good rule of thumb is one day prior to admission for each year of age. (In other words, a seven-year-old would do well to be told about the surgery a week ahead of time.) But you know your child best. If you think your child needs more (or less) time to process what you're saying, then trust your instincts.

The following section provides some suggestions for talking to children of different ages about heart surgery.

Infants (1 month to 1 year old)

- Infants pick up on cues from their caregivers. Providing a calm atmosphere for your baby will promote a sense of safety and security.
- You know what comforts your baby. Bring a favorite comfort item, such as a blanket or pacifier. Favorite music, DVDs, and books will also be soothing. Similar items will be available for you at the hospital, but it's nice to bring what is familiar and comforting for your baby.

Toddlers/Preschool (1 year to 5 years old)

- Because your child might be very active, we encourage you or another adult family member to stay with your child at all times. Your presence is so important.
- We encourage you to talk to your child about what will happen in simple, honest terms. For example, "The doctor is going to fix your heart, here (and point to the area)." Meetings with the surgical team and tours of the hospital will be helpful to both you and your child.
- Children of this age have concrete thinking. It's best to avoid using the term "put to sleep" when talking about anesthesia. Instead, it's helpful to say, "The doctor will help you fall asleep with special medicine. This is different from sleeping at night or at nap time."
- Read books to your child about going to the hospital.
- Let your child know surgery/hospitalization is not a punishment for something he or she may have done.



School age (5 years to 12 years old)

- We encourage you to tell your child about the surgery in terms he or she will understand. For example, you might say: "The doctors need to fix your heart so you can go to the playground."
- Explain what will happen, step-by-step, in terms of what he or she will see and hear. Be sure to focus on the bandages and tubes that will be connected when waking after the surgery. Ask him or her to explain it back to you to correct any misconceptions.
- Let your child know how it might feel after surgery: "You may feel sore, but the nurses will give you medicine to help you feel better." Avoid telling your child "it won't hurt" when you know it might. Honest, comforting information is best.
- Sometimes it helps to tell your child that they have an important job or role: "Your job can be to tell mom, dad, or the nurse if something hurts or scares you."
- Help friends and family stay in touch by phone, text, and email. Children enjoy getting cards from their class. Consider displaying family photos, cards, and artwork around the room to remind your child of all the people who love him or her.

Teens (12 years to 18 years old)

- Open, honest communication usually works best with teens. Talk to your teen about his or her hospitalization as soon as it is scheduled.
- Welcome your teen to take part in planning the course of care as much as possible with the medical team. Some teens want to remain in the room during medical planning and informational meetings with the staff, and some want to step out. Make a list with your teen or encourage him or her to write down questions before surgery or hospitalization.
- Support your teen to have private time with the nurse or doctor without you present.
- Encourage friends to visit when it is medically appropriate or stay in contact during recovery by sending pictures and videos or by video chatting.

Pre-Admission Testing Day

We will call you to schedule your child for pre-admission testing. This full-day appointment is scheduled within a week of surgery.

This can be a long day for you and your child. For your child's comfort and your convenience, here are some items that we suggest you bring:

- Snacks and drinks, including breast milk or formula for infants (enough for the day)
- Diapers for infants (enough for the day)
- Change of clothes for infants
- Small toys or games
- iPad or portable DVD player

It can help to have another adult along who can care for your child while you learn about the upcoming surgery.



"Ask any and all the questions you would like about surgery while at the appointment. I found it useful to make a list of questions that I carried with me."

-Mother of a heart surgery patient

What Tests Will My Child Have and Where Do We Go?

Blood Tests and Swab Screening

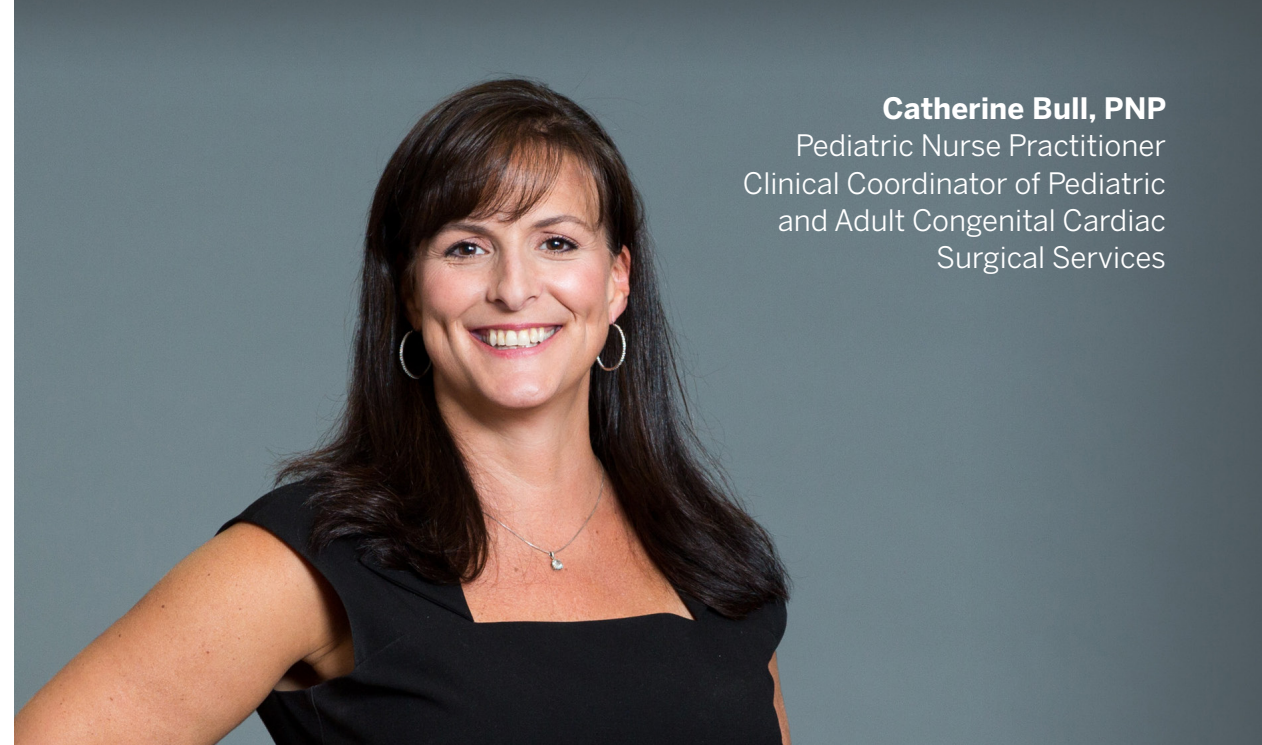
Your child's blood will be drawn and nose will be swabbed for routine testing at the Fink Children's Ambulatory Care Center located at 160 East 32nd Street, Medical Level (L3). When you get off the elevator, enter the door to the left of the fish tank.

Echocardiogram and Electrocardiogram

If needed, your child will have a heart ultrasound and heart rhythm analysis completed in the Fink Children's Ambulatory Care Center, which is also located at 160 East 32nd Street, Medical Level (L3). Enter the door to the left of the fish tank.

Chest X-ray

We will need an up-to-date X-ray of your child's chest. Please visit Outpatient Radiology, at the main NYU Langone Medical Center entrance. Take the Schwartz West Elevators (Green Pathway) to the 2nd floor.



Catherine Bull, PNP

Pediatric Nurse Practitioner
Clinical Coordinator of Pediatric
and Adult Congenital Cardiac
Surgical Services

Visit with Cardiac Surgery Nurse Practitioner

After all the testing is complete, a Cardiac Surgery Nurse Practitioner will examine your child and discuss your child's surgery with you. The Nurse Practitioner will provide educational materials and specific surgical instructions. This will be a valuable time to share questions and concerns.

This will take place in the Cardiothoracic Surgery Office at 530 First Avenue, Suite 9V. Enter the main NYU Langone Medical Center entrance and take the Silverstein Elevators (Green Pathway) to the 9th floor.

Tour the Unit

We will provide you with a tour of the Congenital Cardiovascular Care Unit (CCVCU) located on the east wing of the 15th floor of Tisch Hospital. We will introduce your family to the unit's staff, who will care for your child. A nurse practitioner will explain the surgery, the equipment used in the unit, and what to expect in the postoperative period.



Pre-admission testing can seem like a long day. Many parents suggest you bring:

- Food and drinks for you and your child
- Toys, books, and a tablet for your child

Neighborhood Map



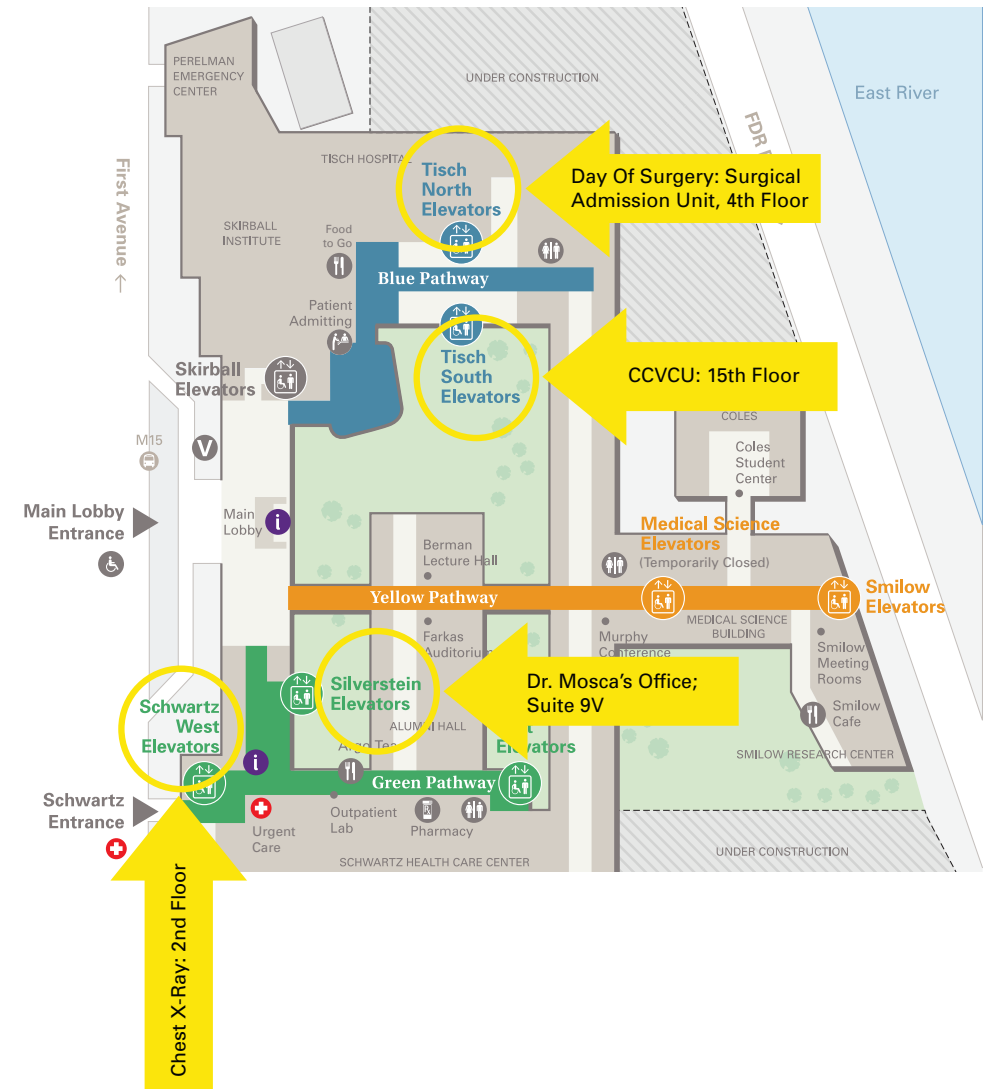
1 Fink Children's Ambulatory Center
160 E 32nd St

Medical procedures performed here:
Blood work
Echocardiogram
EKG

2 NYU Langone Medical Center Main Campus
530-550 First Ave

Medical procedures performed here:
Chest X-ray
History and physical
Consultation with surgeon and nurse practitioner

Main Campus Map



Blue Pathway

- Tisch North Elevators
- Tisch South Elevators
- Patient Admitting

Green Pathway

- Schwartz West Elevators
- Silverstein Elevators
- Urgent Care
- Pharmacy

Packing for the Hospital

It can be difficult to know what to pack for your child's surgery. The most important items are those that will make you and your child more comfortable. The hospital will provide basic items like diapers, formula, pacifiers, bottles, and hospital gowns. Bring essential items for yourself, but avoid bringing valuables. Please label all personal items.

Following surgery, parents are welcome to be with their child at anytime. One parent is encouraged and welcome to stay overnight in your child's room.

For Admissions

- Insurance cards and identification
- List of all your child's medications and dosages
- List of any allergies

William, age 3 and sister Caroline, with their parents Jeremy and Jennie. William has been cared for by his family and the cardiac surgery team. Jeremy and Jennie are also Senior Family Advisors.



Pack your child's favorite comfort item, toy, smartphone, DVDs, or books. This will help to make the environment more familiar.

For Your Child

- Things from home: Stuffed animals, blankets, pillows, toys, books, and activities for after surgery
- Pajamas: A two piece with front buttons or a onesie that closes in front
- Clothing: A comfortable sweatshirt, sweatpants, bathrobe, and underwear
- Slippers and socks: Hospital socks are provided, but often children prefer to wear their own. They will be up and walking soon after surgery, so foot comfort is important.
- Any preferred personal hygiene items
- Photos from home
- iPads, smartphones, laptops, and DVDs
- Names and phone numbers of all doctors involved in your child's care
- Name and phone number of child's pharmacy
- For teen girls, a soft bra is *necessary* as part of after-surgery care. Please let us know if you don't have one, and we will provide it.
- For teen girls, please note that it is normal to have a period following cardiac surgery. We supply hospital maxi pads, but your daughter may prefer a specific brand.

IMPORTANT NOTE: Since your child can be susceptible to germs, please wash any cloth items you plan to bring from home.

For Parents

- Comfortable clothes, socks, slippers, or slip-on shoes. For your own privacy, and since staff enter your child's room at night, it's helpful to bring your own modest overnight clothes, toiletries, medications, and supplements.
- Hobbies and personal devices such as a laptop, smartphone, and books
- Cash for incidentals, such as parking and food
- Contact numbers for friends and relatives

The Night Before Surgery

The day before your child's surgery, you will need to get yourself, your child, and the rest of the family ready and organized. Below are things to do before you come to the hospital.

Make Sure Your Child Is Well

If your child is sick, please let us know right away. **Please call our Cardiac Surgery Office at 212.263.5989 if your child has:**

- Cold symptoms such as fever, runny nose, or cough
- Vomiting, diarrhea, or fever
- Been near anyone with flu-like symptoms, measles, mumps, or chickenpox
- Any change in usual health



"My message would be to keep your head up even during the most difficult times, know that your love for your child is the greatest love of all and very powerful."

-parent of a heart surgery patient

Prevent Infection

We want your child to be safe from infections. You are an important part of this process.

- We will give you antiseptic cloths and ask that you wash your child with them the night before and the morning of surgery. Please follow the instruction sheet provided with the cloths. This will help reduce risk of skin infection.
- Remove any nail polish, synthetic nails, jewelry (including any jewelry in piercings), and makeup that your child is wearing. Take out your child's contacts and bring his/her glasses with you to the hospital.
- Handwashing prevents infections. Please wash your hands with soap and water or using an alcohol-based hand sanitizer before touching your child. We promise to do the same.



Encourage friends and family to send photos and videos to your child. Video chats are also helpful.

Medications

Unless otherwise instructed, you may give your child's scheduled medications the night before surgery. Please **do not** give them the morning of surgery.

Eating and Drinking Restrictions

To keep your child safe the day of surgery, please follow the instructions below. Not doing so may delay the surgery. **If you have any questions about your child's eating and drinking restrictions, call the Cardiac Surgery Office at 212.263.5989.**

Infants

- No infant formula, cow's milk, or baby food may be given **after MIDNIGHT**
- Breast milk and Pedialyte may be given **before 4:00 A.M.**
- Nothing at all should be given by mouth **after 4:00 A.M.**

Children

- No food or milk after **MIDNIGHT**
- Clear liquids such as water or apple juice may be given **before 4:00 A.M.**
- Nothing at all should be given by mouth **after 4:00 A.M.** (including water and chewing gum)



After Surgery

When Will I See My Child?

After surgery, we know you will be very eager to see your child. Your child will be brought to the Congenital Cardiovascular Care Unit (CCVCU), where specially trained doctors, nurse practitioners, nurses, and technicians provide around-the-clock care. You will be reunited with your child in the CCVCU as soon as possible following surgery. You will be able to see your child after the necessary postoperative tests are completed.

When you first see your child, you may notice some extra swelling. This is common, as extra IV fluid is given in the operating room. The swelling will gradually go away. Some of the equipment used during surgery will still be attached to your child. The tubes and wires will be removed gradually as your child recovers. Slowly, your child will be able to start drinking and eating.



Because of allergies, please ask friends not to send balloons, flowers or plants to the hospital.



“My son has hypoplastic right heart syndrome and is doing amazing. I was told by a doctor when I was pregnant that there was a chance Nate would never survive. Now he is two years old and very advanced for his age.”

-Jennifer, mother of Nate, age 4

How Can I Help My Child?

It is natural to be nervous about touching or talking to your child. It is okay to stroke, touch, and kiss your child; talk to your child’s nurse about how and when to do this. If the breathing tube is still in place, your child will not be able to talk to you and should be supported in not trying to talk. Your voice and those of other family members, however, will mean the world to your child. They make your child feel secure.

In the CCVCU, you are welcome to be with your child at any time. One parent is encouraged and welcome to stay overnight in your child’s room. Many of the couches and chairs pull out into beds. Feel free to stay overnight or sleep during the day whenever you wish. Ask your nurse for bed linens, blankets, and pillows. We also have kitchen and shower accommodations for parents on the 9th floor.

When Can I Hold My Child?

You will be able to hold your child when the medical team is certain that it is safe to do so. Generally this is when your child’s breathing tube and certain IVs have been removed.

How Is My Child’s Pain Managed?

Surgery can cause discomfort and pain. It is hard to see your child go through anything that causes distress. Your child will continue to receive different pain medications depending on the level of pain. In partnering with you and your child, we will determine the type and dose of pain medication. It is important that your child receive enough pain medication to support rest and healing.



As a parent or family caregiver you know better than anyone how your child copes. You can help the healthcare team know how to support your child. There are many ways you can comfort your child. Research says that your presence, voice, touch, and calm manner decrease pain. Distraction can also help. You can distract your baby with singing, bubbles, and light-up toys or your older child with an iPad, tablet, breathing exercises, brainteasers, music, books, and imagery (“think of your favorite place”).

Wi-Fi service is available at the CCVCU.

Who Else Cares for My Child and Family?

In addition to the doctors and nurses who are taking care of your child, we have many other professionals who also partner with you to support you and your child.

- Social Workers
- Child Life Specialists
- Speech and Occupational Therapists
- Integrative Health Specialists
- Care Managers
- Dieticians
- Physical Therapists
- Pastoral Care



Our son is doing incredibly well. When people find out that he has a serious heart condition, they can't believe it!

- Jennie, mother of William, Age 3

When Can My Child's Family and Friends Come to the CCVCU?

You are your child's most important caregiver. We welcome parents/guardians to be with their child in the CCVCU 24 hours a day, 7 days a week.

Brothers and sisters, extended family members and friends can be a source of great support to your child. Your child's nurse will have specific guidance regarding sibling and guest visits to the CCVCU. Our child life specialists can talk with you prior to your other children visiting their brother or sister.

Will My Child Move to Another Unit?

Each child is unique and the CCVCU tailors its care to each child. Most children will go home from the CCVCU, but your child may be transferred to an intermediate care unit when he/she:

- Can breathe without the breathing machine
- Has a strong blood pressure without the need for continuous medication infusions
- Has a stable heart rhythm

When your child leaves the CCVCU, this means you are one step closer to going home. When your child is ready to be transferred, it means he or she is stable enough to require less monitoring. Once out of the CCVCU, you will likely feel more comfortable caring for your child on your own and will learn everything you need to know before going home.



Pack your child's favorite comfort item, toy, smartphone, DVDs, or books. This will help to make the environment more familiar.

Leaving the Hospital

It is natural to be eager to take your child home. Most children spend three to ten days in the hospital after cardiac surgery depending on the type of surgery and how they are doing.

Discharge Planning

Our Social Workers and Care Managers will work closely with you, the nurses, and medical staff to ensure that your child is prepared for discharge home. They will assess your child's medical needs, your personal needs, and your insurance coverage. They can assist you in obtaining:

- Medications
- Transportation home or to follow-up appointments
- Access to formula and food for your child through programs such as Women, Infants, Children (WIC)
- Medical equipment
- Home care nursing
- Community resources, such as Early Intervention
- Counseling

Follow-up Appointments

Follow-up appointments will be with your primary cardiologist within two weeks of discharge from the hospital. We will schedule the cardiology follow-up appointment before your family leaves. If you have any concerns before your follow-up appointment, call the Cardiac Surgery Nurse Practitioner in the CCVCU at 212.263.3200.



Follow-up medical visits are medically important, but they are also helpful in giving parents confidence that their baby is healing well.

Medications

It is important to have all of your child's prescriptions filled prior to going home. You can fill prescriptions at a pharmacy of your choice, or we will coordinate the delivery of the medications directly to the hospital. Your nurse will teach you how to administer the medications to your child.

Jackie Fuller, RN, BSN, CPN, Nurse Manager and
Sujata Chkravarti, MD, Medical Director, CCVCU



Transportation Home

When your child is ready to go home, we recommend that you have an appropriate car seat or vehicle restraint device. Because your child has had heart surgery, any sudden bumps or stops may cause injury to your child's healing chest bone.

Although New York State law does not require that you use a car seat when traveling in a taxi or on a bus while in New York City, we recommend that you use an appropriate child restraint system at all times. If you do not have a car seat and are unable to purchase one, please let us know ahead of time so we can assist in making arrangements for your child's safe discharge home.

Recovery at Home


What Should I Have at Home for My Child?

Your child will probably be able to eat a normal diet, so you may want to buy a few of your child's favorite foods. When your child comes home from the hospital, you will be busy helping with his/her recovery. Allow family and friends to help prepare meals and stock up on a few items, such as:

- Soup
- Popsicles
- Clear liquids, such as apple juice, Gatorade

Call your Cardiology Office if:

- Your child has a fever of 101 degrees or higher orally or rectally or has chills
- The incision is painful, opens up, has cloudy yellow/green drainage, or has a bad smell
- Your child has trouble breathing or has color changes (gray, pale, or blue) of the skin, lips, or fingernails
- Your child has vomiting and/or diarrhea, or an upset stomach
- Your child has trouble eating, tires easily while eating, or is not interested in eating at all
- Your child has signs of dehydration: dry mouth, no tears, little or no urine output
- You have any questions about medications



Zoe, age 3, and her family. Her mom Alex is a member of our Family Advisory Council.

When Can My Child Resume Normal Activities?

Most children are able to resume all their previous activities within two to four weeks after the heart operation. While it can be very difficult for a child to have limitations, it is important to the healing process. Limitations include:

Infants

- No daycare until after the first follow-up visit
- Make sure all visitors and family members wash their hands prior to coming in contact with your child
- No contact with visitors or family members with flu-like or cold symptoms
- Do not lift your child from under the arms for four weeks; rather, scoop from his or her bottom and back

Children

- No daycare/school or until after the first follow-up visit
- May swim in:
 - Private pool: after two weeks
 - Public pool/lake/ocean: after four weeks
- No gym class, playground, or bike riding for six weeks
- No lifting items greater than five pounds for four weeks
- Do not lift your child using his/her underarms for four weeks; rather, scoop from his or her bottom and back

Young Adults

- No school or work until after the first follow-up visit
- No driving for six weeks
- No gym class or competitive sports for a minimum of six weeks. Beyond six weeks this is under the direction of your child's cardiologist.
 - Examples of such activities include baseball, basketball, football, soccer, hockey, swimming, tennis, and bike riding
- No lifting items greater than 10 pounds including backpacks for six weeks



“Take advantage of community support organizations for congenital heart defects. Connecting with others who have dealt with similar circumstances helps you not feel isolated.”

- Parent of a heart surgery patient

Important Phone Numbers and Addresses

**The Fink Children's
Ambulatory Care Center
Department of Cardiology**
160 East 32nd Street, Level 3
New York, NY 10016
tel: 212.263.5940
fax: 212.263.5808

**Congenital Cardiovascular
Care Unit (CCVCU)**
550 First Avenue – 15 East
New York, NY 10016
tel: 212.263.3200
fax: 646.501.6803

Sujata Chakravarti, MD
Medical Director

Jacquelyn Fuller, RN, BSN, CPN
Nurse Manager

Debra Lederman, RN, BSN, CLC
Assistant Nurse Manager

Social Work
Deborah Dore, LCSW
Congenital Cardiovascular
Care Services
deborah.dore@nyumc.org
212.263.8070 x72726

Blood Donation
317 East 34th Street, 8th Floor
212.263.5440

Child Life
212.263.5585

Nutrition/Food Services
212.263.5171

Pastoral Care
Chaplain's Office: 212.263.5903
Nights or weekends: 212.397.9330
and enter ID #26903



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