Welcome
Guide for Adults
Entryway to lifelong care
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Boston Children’s Hospital
Heart Center
Welcome

We know that getting ready to come to the hospital for cardiac care involves a lot of steps and many questions. As you prepare to travel to the Boston Children’s Hospital Heart Center—whether you are coming from around the corner, across the country or half a world away—we hope that this guide will address some of your immediate concerns and help put you and your family at ease.

Here at Boston Children’s, our doctors, nurses and other staff spend each day getting to know families like yours, especially throughout the vulnerable process of receiving lifelong care. We care for patients—from babies in the womb to adults—with all types of heart conditions, ranging from the most common to the rarest and most serious. We have one of the largest and most experienced heart programs anywhere in the world, and we use the most advanced technology and procedures to give every patient the best possible outcome.

Your care will be coordinated with a team of experts who treat adult congenital heart disease. Above and beyond providing expert medical and surgical care, we are also committed to understanding and addressing important needs for each of our patients and their families—including the need for support, guidance, information and a listening ear.

If you have any questions before, during or after your stay, please don’t hesitate to ask your doctor or a member of your nursing team. You can also contact Boston Children’s Center for Families at 617-355-6279 to learn more about available resources at the hospital and in the community.

You are an essential member of the care team, and we will include you in the process at every step of the way.

Sincerely,
The Boston Children’s Adult Congenital Heart Program
Meet Your Cardiac Care Team

Here at the Boston Children’s Heart Center, you will work closely with a caring team of coordinated experts, including:

**Cardiologists**
Cardiologists, including Adult Congenital Cardiologists, diagnose and manage heart disease. Many specialize in one aspect of heart care, such as catheterization or echocardiography. Boston Children’s has more than 70 cardiologists on staff. You will have a primary cardiologist, but other cardiologists may also be involved in different parts of your treatment plan.

**Cardiac surgeons**
Cardiac surgeons perform operations to treat heart conditions. We have seven heart surgeons on staff at Boston Children’s, making ours one of the world’s largest specialized cardiac surgery programs. We also have a long history in the field: The first operation to correct a pediatric congenital heart defect took place at Boston Children’s back in 1938.

**Cardiovascular nurses**
More than 300 specialized cardiovascular nurses work at Boston Children’s. They assess each patient’s condition and provide direct care, as well as emotional support, information, education and care coordination. A nurse will be responsible for your care at all times.

**Nurse practitioners (NPs)**
NPs have advanced education and specialized skills in cardiac care. They participate in many different parts of the diagnosis, management and care coordination process for patients with heart disease.

**Physician assistants (PA)**
PAs practice medicine under the direct supervision of physicians and surgeons. As part of the cardiac care team at Boston Children’s, PAs focus on the evaluation of new and established patients, diagnostic interpretation of studies, and the implementation of treatment plans for patients with complex congenital heart disease.

**Anesthesiologists**
Our anesthesiologists have special training in the use of anesthesia for cardiac procedures—for patients of all ages. Here at Boston Children’s, we use a wide range of anesthesia techniques during surgery—from light sedation to general anesthesia—to meet the special needs of each patient. We also have pain management specialists who can minimize discomfort from medical procedures and help patients cope with pain while recovering.

**Clinical dietitians**
Clinical dietitians are registered nutrition professionals who will address specific diet concerns. Our dietitians work with you to identify and manage your nutritional needs.

**Patient care coordinators**
Patient care coordinators are nurses who will help you with any special discharge-planning arrangements that may be required. Coordinators will also communicate any important medical information relating to your hospitalization to your insurance company.

**Resource specialists**
Boston Children’s resource specialists are on hand to help you with practical concerns (such as housing and transportation). We recommend that you call us at 617-355-7965 before you come to the hospital so that we can make all the necessary arrangements prior to your arrival.

Did you know?
>>> Boston Children’s has a dedicated team of adult congenital cardiologists.
>>> The Board of Medical Specialties created a new subspecialty, ACHD, to identify physicians who are trained to treat adults with congenital heart defects.

**Psychiatrists, psychologists and counselors**
Psychiatrists, psychologists and counselors from Boston Children’s Department of Psychiatry are available to provide emotional and supportive care for patients and their families. If you would like to work with a mental health professional, your doctor or nurse can help set up an appointment.

**Licensed clinical social workers**
Social workers are experts in helping patients adjust to the emotional impact of an illness and hospitalization. Because every patient and situation is different, a social worker will be available to help determine your specific needs and assist you with them.

**Interpreters**
Boston Children’s interpreters speak more than 35 languages, including American Sign Language. Spanish-speaking interpreters and social workers are available 24 hours a day, and other interpreters are available on an as-needed basis.

If you will require an interpreter, please call our Interpreter Services at 617-355-7198 prior to coming to the hospital so we can be ready for you when you arrive.
The Pre-Op Clinic

Before having any type of heart surgery at Boston Children’s Hospital, you will spend six to eight hours in our Cardiac Pre-Operative (“Pre-Op”) Clinic. This visit will cover all of the testing and other evaluations required before the main procedure.

Here’s what to plan for and expect:
• Please plan to arrive at our registration area — located on the second floor of the Farley Building and labeled “Cardiac Pre-Op” — promptly at the scheduled appointment time.
• Please plan to spend the day with us so all of your pre-op testing can be accomplished.
• Due to space constraints, we ask that you please limit the number of people accompanying the patient to two.
• Please bring your appointment letter with you.
• After you register, any tests ordered by your cardiologist—such as ECHOs, EKGs, chest X-rays or bloodwork—will be performed.
• You will also have the opportunity to meet with other members of your care team, including nurse practitioners, cardiac surgeons, anesthesiologists and social workers.
• If you would like, you may tour our Cardiac Intensive Care Unit and Cardiac Inpatient Unit at this time.
• At the end of your visit, you will receive written instructions about when to arrive for surgery on the day of the operation and which eating and drinking guidelines to follow.

Questions? Call our Pre-Op Clinic staff at 617-355-6095.

What to do before your surgery

- Ensure your primary care providers are aware of your procedure
- Decrease negative habits
  • Stop tobacco use, including cigarettes, pipes, cigars
- Make healthy eating choices
  • Maintain appropriate blood sugar
- Identify needed support group
  • Create health care power of attorney
  • Update guardianship papers
  • Inform family and friends about your hospital stay
- Develop a pain control plan
- Visualize positive outcomes
Where you may receive care

The Boston Children’s Hospital Heart Center cares for patients in several locations within the hospital. All are conveniently located here on the main hospital campus in downtown Boston.

Cardic Pre-Op/Heart Clinic—2nd floor of the Farley Building
Before any type of surgery, you will spend six to eight hours in this clinic. The visit will cover all of the testing and other evaluations required before the main procedure.

Adult Program Cardiology Clinic—2nd floor of the Farley Building
Many tests for hospitalized patients—such as electrocardiograms (EKGs) and echocardiograms (ECHOs)—are performed in our Cardiology Clinic.

Operating Rooms (also called the “Surgical Suites”)—3rd floor of the Main Building
Three of the hospital’s surgical suites are reserved specifically for our cardiac patients.

Cardiac Catheterization Laboratory (also known as “6 South”)—6th floor of the Main Building
Our Cardiac Catheterization Laboratory includes four high-tech suites and a 10-bed recovery room.

Cardiac Intensive Care Unit (also called “CICU” or “8 South”)—8th floor of the Main Building
After having heart surgery, patients are cared for on 8 South, our 29-bed Cardiac Intensive Care Unit.

Inpatient Unit (also known as “8 East”)—8th floor of the Main Building
8 East is a 42-bed unit where our patients stay if they need to be in the hospital overnight (for example, if they are admitted for a cardiac catheterization). Sometimes, patients are also transferred here after being discharged from the Cardiac Intensive Care Unit.

What to bring with you to the hospital

- List of current medications
- Name and contact information for your physician
- Insurance card
- Name and phone number for preferred pharmacy near your home
- Name and contact information of people you can ask for help while you are in the hospital
- Books/magazines
- DVD and DVD player
- Music MP3/iPod
- Laptop computer
- Slip-on shoes
- Comfortable outfit to return home in
- Pictures of your family/support members for your bedside/room
- Comfortable, loose clothing for your hospital stay

To clarify issues or ask questions prior to your visit, please call your primary cardiologist.
Driving to the Hospital

From the north
Via Routes 1, 93 and 28
• Follow the signs for Storrow Drive.
• After the Copley Square/Massachusetts Avenue sign, take the left exit off Storrow Drive marked Fenway, Route 1.
• Take the right fork marked Boylston Street, Outbound.
• At the major intersection, go straight onto Brookline Avenue, past Beth-Israel Deaconess Medical Center-East Campus to Longwood Avenue intersection.
• At this major intersection, turn left onto Longwood Avenue.
• Boston Children’s Hospital main entrance is two blocks down on the right.
• Boston Children’s Parking Garage is on the left.

From the south
Via Routes 1, 28 and 138
• From Route 1, continue to the Jamaicaway.
• From Routes 28 or 138, proceed via Morton Street and the Arborway to the Jamaicaway.
• Continue on the Jamaicaway as it turns into the Riverway.
• At the Brookline Avenue traffic light, turn right onto Brookline Avenue.
• Continue to the third traffic light and turn right onto Longwood Avenue.
• Boston Children’s main entrance is two blocks down on the right.
• Boston Children’s Parking Garage is on the left.

From Logan Airport
• Take the Sumner Tunnel to Storrow Drive.
• Follow the “From the North” directions above.

Alternative route on Red Sox game days
• Exit 18 on Mass Pike (Allston/Brighton toll).
• Merge onto Cambridge Street.
• Take left onto Harvard Avenue.
• Pass through Brookline’s Coolidge Corner.
• Take left on Longwood Avenue.
• Cross over the Riverway.
• Boston Children’s main entrance is four blocks down on the right.
• Boston Children’s Parking Garage is on the left.
Parking

Valet parking
Valet parking is available 24 hours a day for an additional fee above the regular parking garage fee. (This fee is waived for cars with handicap plates/placards.)

Handicapped parking
- Handicapped parking is available at the Main Entrance for patient families and visitors.
- There is no additional fee for valet service for vehicles with handicap plates.

Boston Children’s Parking Garage
Open 24 hours a day, the parking garage is located across the street from the hospital’s Main Entrance at the corner of Blackfan Circle and Longwood Avenue. For parking rates and information.

Validated parking
- Be sure to have your parking ticket validated before leaving the hospital.
- Parking tickets for the Boston Children’s Parking Garage can be validated for a reduced rate at the following locations:

For more information about parking, call 617-355-4168 between 6 a.m. and 8:30 p.m.

Main Lobby Reception Desk
Monday through Friday, 6 a.m. to 11 p.m., Saturdays, Sundays and holidays, 7 a.m. to 10 p.m.

Parking Office, Boston Children’s Hospital Garage, 1st Floor
Monday through Friday, 7 a.m. to 4:30 p.m.

Public Transportation

Boston Children’s Hospital is easily accessible with the Massachusetts Bay Transit Authority (MBTA), the official public transportation system for Boston and surrounding areas. Visit mbta.com or call 617-222-3200 for maps and schedules.

Here are some of the different MBTA services you can use to travel to and from the hospital:

Subway
- Take the Green Line “D” train to the Longwood stop.
- Walk across the Riverway and follow Longwood Avenue four blocks to the hospital, which will be on your right, OR
- Take the Green Line “E” train to the Longwood Medical Area stop.
- Walk down Longwood Avenue two blocks to the hospital, which will be on your left.

Commuter rail
- Providing a great alternative to driving into Boston, the commuter rail is accessible from numerous cities and towns—even those as far away as Newburyport and Worcester, Massachusetts, and Providence, Rhode Island.

Accessible services/special needs transportation
The MBTA’s paratransit program, THE RIDE, provides transportation for people with physical or mental disabilities who are unable to use public transportation.

Operated in compliance with the federal Americans with Disabilities Act, THE RIDE is a shared-ride service, which means you will be traveling with other people.

The service uses lift-equipped vans for persons with disabilities, including those who use wheelchairs and scooters.

To apply for THE RIDE, please call 617-222-5123.
Accommodations

If you require additional help with housing arrangements, please call our Patient Family Housing Program at 617-919-3450. If you have an iPhone or Android smartphone, you can also download the free Boston Children’s MyWay mobile app to access information about where to stay and how to get there.

Special housing options

- **Hospitality Homes** For the past 29 years, this program has provided temporary housing in volunteer host homes for families of patients receiving care at Boston Children’s and other area medical centers.

  Families may apply for the program regardless of income or nationality or the patient’s age or diagnosis.

  888-595-4678 | hosp.org

- **Yawkey Family Inn and the House at 21 Autumn Street** Located just blocks from the hospital, the Inn and House double the amount of affordable housing available to Boston Children’s families.

  Featuring bedrooms, shared private bathrooms, a fully equipped kitchen, common areas and more, these facilities offer all of the comforts of home to families during their stay in Boston.

  617-919-3450 | familyhousing@childrens.harvard.edu

Hotels

Some hotels offer discounted rates for our patients and their families. Be sure to ask for the medical rate or preferred rate for Boston Children’s Hospital patients and families when you call any of the hotels below to make reservations. Please note that special rates are not guaranteed, and are based upon availability.

- **Best Western – The Inn at Longwood** (.01 miles from Boston Children’s)
  342 Longwood Avenue, Boston | 617-731-4700

- **Holiday Inn Brookline (.75 miles)**
  1200 Beacon Street, Brookline | 617-277-1200

- **Howard Johnson Fenway (.82 miles)**
  1271 Boylston Street, Boston | 617-267-8300

- **Marriott Courtyard Brookline (1 mile)**
  40 Webster Street, Brookline | 617-734-1393

- **Hotel Commonwealth (1.08 miles)**
  500 Commonwealth Avenue, Boston | 617-933-5000

- **Hotel Buckminster (1.1 miles)**
  645 Beacon Street, Boston | 617-236-7050

- **Sheraton Boston Hotel (1.5 miles)**
  39 Dalton Street, Boston | 617-236-2000

- **The Colonnade Hotel (1.5 miles)**
  120 Huntington Avenue, Boston | 800-962-3030

Inns

Please call inns directly for rates and reservations.

- **Longwood Inn (.25 miles from Boston Children’s)**
  123 Longwood Avenue, Brookline | 617-566-8615

- **The Bertram Inn (.73 miles)**
  92 Sewall Avenue, Brookline | 617-566-2234

- **Samuel Sewall Inn (.74 miles)**
  143 Saint Paul Street, Brookline | 617-713-0123

- **Beech Tree Inn (.75 miles)**
  83 Longwood Avenue, Brookline | 617-277-1620

- **Anthony’s Town House (.9 miles)**
  1085 Beacon Street, Brookline | 617-566-3972

- **Beacon Inn (1 mile)**
  1087 and 1750 Beacon Street, Brookline | 617-566-0088

- **Oasis Guest House (1.5 miles)**
  22 Edgerly Road, Boston | 617-267-2262
Here are some popular Boston spots to visit during time away from the hospital:

- **Fenway Park, home of the Boston Red Sox Major League Baseball team**
  4 Yawkey Way (Kenmore or Fenway stops on MBTA Green Line subway), Boston | 1-877-REDSOX9 | boston.redsox.mlb.com
  Tours of Fenway Park take place hourly, seven days a week, from 9 a.m. to 4 p.m.

- **Isabella Stewart Gardner Museum**
  280 Fenway (Museum stop on MBTA Green Line “E” subway), Boston | 617-566-1401 | gardnermuseum.org
  Open Wednesday to Monday, 11 a.m. to 5 p.m.; Closed Tuesdays.

- **Museum of Fine Arts Boston**
  465 Huntington Avenue (Museum stop on MBTA Green Line “E” subway), Boston | 617-267-9300 | mfa.org
  Call for hours and admission fees.
  Bring your yellow Boston Children’s ID badge to receive $2 off adult general admission. Children under 17 are admitted free.

- **Museum of Science**
  Science Park (Lechmere stop on MBTA Green Line subway), Boston | 617-723-2500 | mos.org
  Open Saturday to Thursday, 9 a.m. to 5 p.m.; Friday, 9 a.m. to 9 p.m.
  Please note that hours change per season.

- **New England Aquarium**
  Central Wharf (Aquarium stop on MBTA Blue Line subway), Boston | 617-973-5200 | neaq.org
  Open Monday to Friday, 9 a.m. to 5 p.m.; weekends and most holidays, 9 a.m. to 6 p.m.
  Bring your yellow Boston Children’s ID card and receive $2 off admission.
Heart Glossary

Here are some of the heart-related terms you may hear during your cardiac care:

A

Ablation  Elimination or removal. Also refers to a procedure that eliminates extra electrical pathways within the heart, which can cause fast or irregular heart rhythms.

Angiography  A special X-ray study that uses dye injected into the arteries to study blood circulation.

Angioplasty  A non-surgical procedure for treating narrowed arteries.

Aorta  The largest artery in the body and the primary blood vessel that carries oxygenated blood out of the heart to the rest of the body.

Aortic valve  The valve that regulates blood flow from the heart into the aorta.

Arrhythmia (also called dysrhythmia)  A fast, slow or irregular heartbeat.

Artery  A blood vessel that carries oxygenated blood away from the heart to the body.

Atrium (‘atria’ when plural)  One of two upper chambers in the heart.

B

BACH  Boston Adult Congenital Heart Program

Balloon angioplasty  A procedure usually done in the cardiac catheterization laboratory that uses a catheter (tube) with a balloon in the tip to open up a narrowed valve or blood vessel.

Bicuspid  A valve that has two leaflets.

C

Capillaries  Tiny blood vessels between arteries and veins that distribute oxygen-rich blood to the body.

Cardiac catheterization  A diagnostic procedure in which a tiny, hollow tube (catheter) is inserted into an artery or vein to evaluate the heart and blood vessels.

Carotid artery  The major artery in the neck that supplies blood to the brain.

Cineangiography  Taking moving pictures to show the passage of dye through blood vessels.

Closed heart surgery  An operation that repairs problems with the blood vessels attached to the heart without requiring a heart-lung bypass machine.

Computed tomography scan (CT/CAT scan)  A diagnostic imaging procedure that uses a combination of X-rays and computer technology to produce detailed images of the body.

Congenital heart defect  A heart problem that is present at birth.

Coronary arteries  Two arteries that come from the aorta to provide blood to the heart muscle.

Cyanotic  Appearing blue due to insufficient oxygen in the blood.

D

Diastole  The time during each heartbeat when the ventricles are at rest, filling with blood and not pumping. (See “systole” under “S”)

Doppler ultrasound  A procedure that uses sound waves to evaluate the heart, blood vessels and valves.

Dyspnea  Shortness of breath.

E

Echocardiogram (ECHO)  A procedure that evaluates the structures and function of the heart by using sound waves to produce a moving picture of the heart and heart valves.

Edema  Swelling due to the buildup of fluid.

Effusion  A collection of fluid in a closed body space.

Electrocardiogram (ECG or EKG)  A test that records the electrical activity of the heart, shows abnormal rhythms (arrhythmias or dysrhythmias) and detects heart muscle damage.

Epicardium  The outermost part of the heart.

Exercise electrocardiogram (stress ECG or stress EKG)  A test to assess cardiac rhythm and function by having a patient exercise on a treadmill or bicycle.

F

Fibrillation  Rapid, irregular and weak contractions of the heart muscles.

Fluoroscopy  An X-ray procedure that takes continuous pictures to evaluate the heart and other body structures.

Flutter  Rapid but regular contractions of the heart’s right and left atria.

H

Heart block  Interrupted electrical impulse to the heart muscles.

Heart-lung bypass machine  A machine that performs heart and lung functions during open heart surgery.

Holter monitor  A portable EKG machine worn for a 24-hour period or longer to evaluate irregular, fast or slow heart rhythms during normal activities.

Hypertension  High blood pressure.

Hypotension  Low blood pressure.

Hypoxia  Abnormal oxygen content in the organs and tissues of the body.

I

Inferior vena cava  The large blood vessel (vein) that returns blood from the legs and abdomen to the heart.

Insufficiency  A valve deformity that allows blood to leak backwards when the valve is closed.

Ischemia  Decreased flow of oxygenated blood to an organ due to narrowing in an artery.

L

Left atrium  The upper left chamber of the heart, which receives oxygen-rich ‘red’ blood from the lungs and then sends it to the left ventricle.

Left ventricle  The lower left chamber of the heart. It receives oxygen-rich ‘red’ blood from the left atrium and pumps it into the aorta, which takes the blood to the body.
**M**

**Magnetic Resonance Imaging (MRI)** A diagnostic procedure that uses a combination of large magnets, radiofrequencies and a computer to produce detailed images of organs and structures within the body.

**Mitrval valve** The valve that controls blood flow between the left atrium and left ventricle in the heart.

**Murmur** A blowing or rasping sound heard while listening to the heart. This may or may not indicate problems within the heart or circulatory system.

**Myocarditis** Inflammation of the heart muscles.

**O**

**Open heart surgery** Surgery that involves opening the chest and heart while a heart-lung machine performs cardiac and respiratory functions during the operation.

**P**

**Pacemaker** An electronic device that is surgically placed in the patient’s body and connected to the heart to regulate the heartbeat.

**Palpitation** A sensation of rapid heartbeats.

**Pericardiocentesis** A diagnostic procedure that uses a needle to draw fluid from the pericardium (the sac around the heart.)

**Pericarditis** An inflammation or infection of the pericardium.

**Platelets** Cells found in the blood that assist in clotting.

**Pulmonary artery** The blood vessel connecting the right ventricle to the lungs, allowing oxygen-poor (‘blue’) blood to receive oxygen.

**Pulmonary valve** The heart valve, located between the right ventricle and the pulmonary artery, that controls blood flow to the lungs.

**Pulmonary vein** The vessel that carries oxygenated blood from the lungs to the left side of the heart.

**Pulse oximeter** A device that measures the amount of oxygen in the blood.

**R**

**Regurgitation** Backward flow of blood, caused by a defective heart valve.

**Right atrium** The upper right chamber of the heart, which receives oxygen-poor (‘blue’) blood from the body and sends it to the right ventricle.

**Right ventricle** The lower right chamber of the heart, which receives oxygen-poor (‘blue’) blood from the right atrium and sends it to the pulmonary artery.

**Risk factor** Any condition, element or activity that may negatively affect the heart or circulation.

**S**

**Septum** The muscle wall between the heart’s atria or ventricles.

**Shunt** A connector to allow blood flow between two locations.

**Sinus node** The cells that produce the electrical impulses that cause the heart to contract.

**Stent** A device placed in a blood vessel to help keep it open.

**Stenosis** Narrowing or constriction of a blood vessel or valve in the heart.

**Subclavian** A blood vessel that branches from the aorta and takes oxygen-rich (‘red’) blood to the head and arms.

**Superior vena cava** The large vein that returns blood to the heart from the head and arms.

**Systole** The time during the heartbeat when the ventricles are pumping blood, either to the lungs or to the body.

**T**

**Tachycardia** Rapid heartbeat.

**Tachypnea** Rapid breathing.

**Telemetry unit** A small box with wires attached to EKG patches on the chest, used to transmit information about the heartbeat via radio transmission.

**Thoracotomy** An incision made on the right or left side of the chest between the ribs, in order to access the heart or lungs during surgery.

**Transesophageal echocardiography (TEE)** A diagnostic test that uses a long tube, guided into the mouth, throat and esophagus, to evaluate the structures inside the heart with sound waves.

**Tricuspid valve** The heart valve that controls blood flow from the right atrium into the right ventricle.

**U**

**Ultrasound (sonography)** A diagnostic imaging technique that uses high-frequency sound waves and a computer to create images of blood vessels, tissues and organs.

**V**

**Valves** The “doors” between the chambers of the heart that allow blood to move forward and prevent it from moving backward.

**Vascular** Pertaining to blood vessels.

**Vein** A blood vessel that carries blood from the body back into the heart.

**Ventricle** One of the two pumping chambers of the heart.

**X**

**X-ray** A diagnostic test that uses invisible energy beams to create images of internal tissues, bones and organs on film.
Make a heartfelt connection today

Join the Boston Children’s Hospital Heart Center community on Facebook. facebook.com/heartcenter

Our community includes thousands of patients and family members in different stages of treatment for congenital heart defects. Learn from others who have been where you are—and share your experiences with families just starting down this road.