

# Welcome

Dear Patients and Families,

Welcome to the Congenital Heart Center at University of Michigan Health C.S. Mott Children's Hospital. This guidebook was developed in an effort to provide you with valuable information, special resources and practical tools that will help guide and support you throughout your child's journey here in the hospital as well as at home. It is filled with information on people, places, services, policies and amenities throughout the Congenital Heart Center so that you know what to expect along the way. It also contains a wealth of heart specific education material and health management tools related to your child's illness. The team at our center is experienced in the care for all types of pediatric and congenital heart disease – medical care, surgical care, transplant and more. Care is provided to all ages – from prenatal care to adult congenital heart care. There are specialty clinics that address specific needs for particular groups of patients. And we have outreach clinics in many locations so that our pediatric cardiology care can be received closer to home.

This guidebook is an important resource for you and your child's care team. You will refer to it and add to it often. When your child is discharged, please continue to use it and take it with you to your child's doctor appointments and the emergency room. This guidebook should empower you to become an active partner in your child's care and find the support that you and your family need during the various stages of your child's heart journey.

We are here to help you through your child's heart care; please let us know if there is anything that we can do to assist you.

Sincerely,

Congenital Heart Center Team

C.S. Mott Children's Hospital

University of Michigan Health



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# Contacts

<b>Congenital Heart Center Specific Phone Numbers</b>	
<ul style="list-style-type: none"> <li>■ Pediatric Cardiology Clinic: (734) 764-5176</li> <li>■ Pediatric Cardio-Thoracic Intensive Care Unit (PCTU): (734) 232-7000</li> <li>■ 11 West General Care: (734) 763-4387</li> <li>■ Brandon Neonatal Intensive Care Unit: (734) 763-4111</li> <li>■ Pediatric Cardiothoracic Surgery: (734) 936-4978</li> <li>■ Ronald McDonald House: (734) 994-4442</li> <li>■ Patient and Visitor Accommodations Program: (734) 936-0100 <a href="http://www.med.umich.edu/hotels">www.med.umich.edu/hotels</a></li> <li>■ Call Center: (734) 764-5176 <b>** Please use for questions after Discharge**</b></li> </ul>	
<b>Mailing Addresses</b>	
C.S. Mott Children’s Hospital 11 West, SPC 4248 1540 East Hospital Drive Ann Arbor, MI 48109-4248	Congenital Heart Center Pediatric Cardiology C.S. Mott Children’s Hospital 1540 East Hospital Drive Ann Arbor, MI 48109-4284
Pediatric Cardio-Thoracic Intensive Care Unit (PCTU) C & W 10 West 10-321 1540 East Hospital Drive, SPC 4288 Ann Arbor, MI 48109-4288	

# Websites

## Michigan Medicine Web Pages

- Congenital Heart Center, C.S. Mott Children’s Hospital
  - [www.mottchildren.org/congenital](http://www.mottchildren.org/congenital)
- Michigan Medicine Patient Portal
  - (families are encouraged to register patients, the portal is a secure way to manage important health information)
  - To register: [www.myuofmhealth.org](http://www.myuofmhealth.org)
  - For more information: <https://www.uofmhealth.org/patient-visitor-guide/patient-portal>
- What is Congenital Heart Disease?
  - [www.mottchildren.org/conditions-treatments/ped-heart/chd](http://www.mottchildren.org/conditions-treatments/ped-heart/chd)
- Pediatric Cardiac Surgery
  - [www.medicine.umich.edu/dept/cardiac-surgery/patient-information/pediatric-cardiac-surgery](http://www.medicine.umich.edu/dept/cardiac-surgery/patient-information/pediatric-cardiac-surgery)
- Pediatric Cardiology
  - [www.medicine.umich.edu/dept/pediatrics/divisions/pediatric-cardiology](http://www.medicine.umich.edu/dept/pediatrics/divisions/pediatric-cardiology)
- Adult Congenital Heart
  - [www.umcvc.org/conditions-treatments/congenital-heart-disease](http://www.umcvc.org/conditions-treatments/congenital-heart-disease)
- Congenital Heart Center – Outcomes Report
  - <https://www.mottchildren.org/conditions-treatments/ped-heart/outcomes-highlights-report>
- Heart Guidebook
  - **An electronic version of this binder is included on the “Resources for Patients” page on the Congenital Heart Center webpage**  
<https://www.mottchildren.org/conditions-treatments/ped-heart/resources-congenital-heart-patients>

## Patient and Family Social/Emotional Support, Planning and Advocacy

- Please see the support section of this guidebook for a listing of support sites.

# Your Address Book

## Cardiologist:

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Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Primary Care Doctor:

\_\_\_\_\_

Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Cardiology Nurse Practitioner:

\_\_\_\_\_

Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Inpatient Social Worker:

\_\_\_\_\_

Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Cardiovascular (C-V) Surgeon:

\_\_\_\_\_

Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Outpatient Social Worker:

\_\_\_\_\_

Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## C-V Nurse Practitioner:

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Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Medical Equipment Supplier:

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Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

# Your Address Book

## Medical Equipment Supplier:

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Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Compounding Pharmacy:

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Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Home Care Agency: \_\_\_\_\_

Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Other: \_\_\_\_\_

Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

## Home Pharmacy: \_\_\_\_\_

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## Other: \_\_\_\_\_

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## Home Pharmacy: \_\_\_\_\_

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Email: \_\_\_\_\_

## Other: \_\_\_\_\_

Number: \_\_\_\_\_

Fax: \_\_\_\_\_

Email: \_\_\_\_\_

# Wayfinding

## Visitor Restrictions:

Please see the Mott website for current visitor restrictions.

<https://www.mottchildren.org/mott-patient-visitor-guide/family-visitors>



## Parking for Mott Children's Hospital:

**Self-parking:** There are two options for self-parking at the hospital: Parking Structure P2 or P4.

From P4, take the parking elevator to level 3 to enter the children's hospital via the pedestrian bridge on Level 3. The main hospital elevators are straight ahead.

From P2, enter the hospital on the 2<sup>nd</sup> floor, turn left, walk to the greeting desk near the Big Bird statue and enter C.S. Mott Children's Hospital. The main hospital elevator bank will be on the left after the chapel.

Bring your parking ticket to the security welcome desk to have it stamped for discounted parking at a rate of \$2 for every 24 hours.

**Valet Parking:** This service is available in the valet circle in front of C.S. Mott Hospital for \$10 per day.

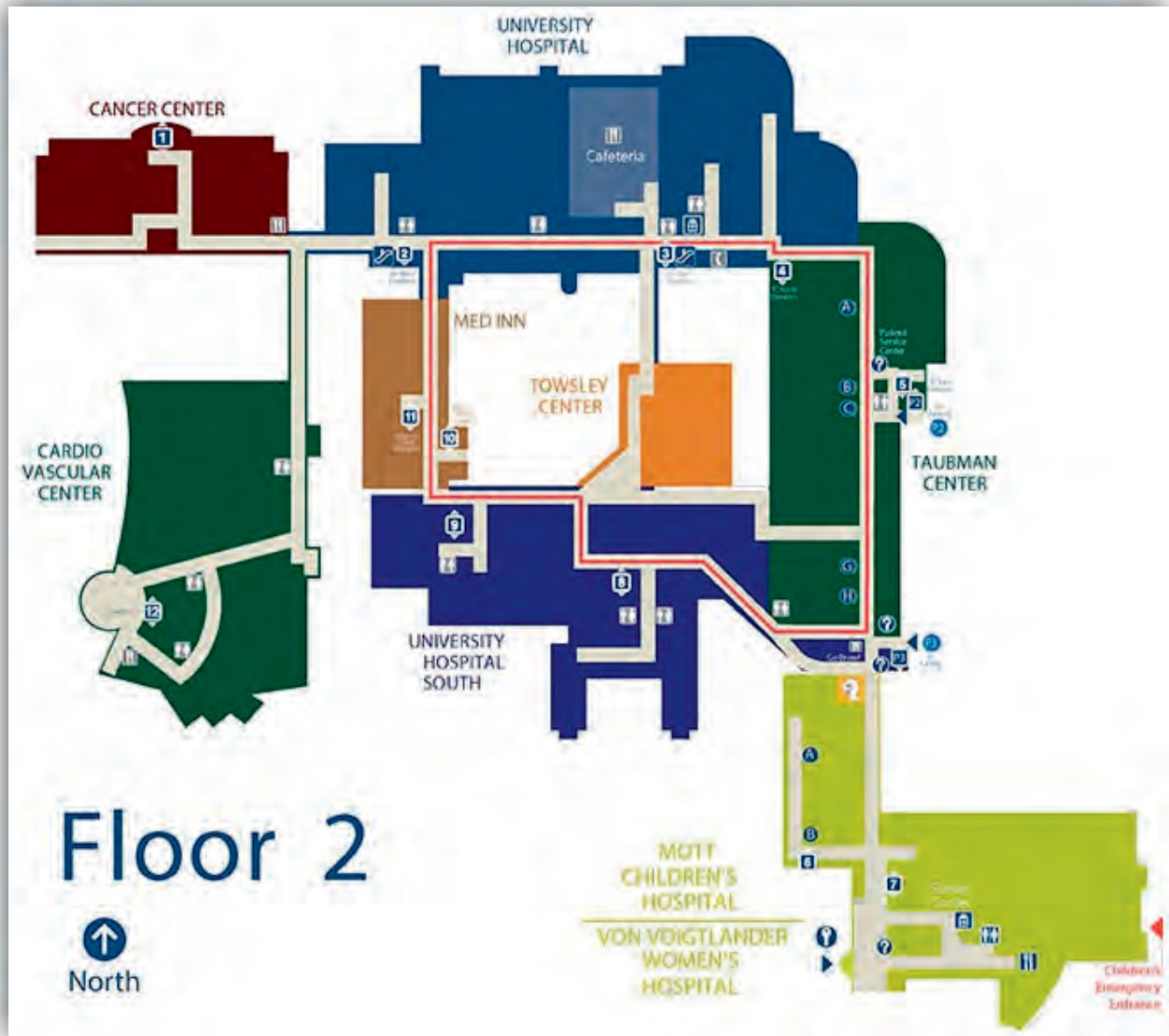


# Wayfinding

## Visitor Restrictions:

Please see the Mott website for current visitor restrictions.

<https://www.mottchildren.org/mott-patient-visitor-guide/family-visitors>



## Navigating throughout the entire hospital system:

Floor 2 is the connector floor between all of the hospitals and centers.

Please note these areas on the map above which you may need to visit during your stay:

- Med Inn
- Cardio Vascular Center
- Main Hospital Cafeteria
- Mott Children's Hospital



# Key Places at Mott

## 2<sup>nd</sup> Floor:

- **Security Check-In:** At our main entrances, you will be asked why you are here and how you are feeling to screen for any contagious illness. Children with severe colds, flu or any other contagious illnesses will not be allowed to visit. You will receive a visitor's sticker. Use the main elevator bank (#7) to get to all floors.
- **Getaway Cafe:** Featuring Subway, guest restaurants, child friendly food and yummy desserts. Hours of operation: weekday: 6:30 a.m. – 12 a.m., weekend/holiday: 9:00 a.m. – 8:00 p.m.
- **Chapel:** The Mott Children's Hospital chapel is located on the second floor, room 2780. It is open 24 hours a day.
- **Family Center:** Designed by families and health care professionals, the Family Center is a place for inpatients, outpatients and their families to learn, relax and become advocates for their health care.
- **Lab/Blood Draw:** If a blood draw is required for an outpatient visit, it can be done on this floor.

## 3<sup>rd</sup> Floor:

- **Radiology:** If a chest x-ray or radiology test is required for an outpatient visit, the radiology check-in desk is just a few steps from the elevator.

## 4<sup>th</sup> Floor:

- **Frog Desk- Surgery Check-In:** If you are checking in for heart surgery, your first stop will be our Frog Desk. This floor houses our operating rooms, pre-operative bays and surgical recovery unit.

## 8<sup>th</sup> Floor:

- **Neonatal Unit (NICU):** Take the main elevators located to the left of the main desk of the lobby. Once off the elevators, go to the neonatal welcome desk just a few steps from the elevators.
- **Milk Room:** Our unique milk room helps ensure that infants receive optimal nutrition through human milk during their hospitalization. Speak with your nurse to find out more information.
- **Michigan Game Day Experience:** This football themed space is available for children to play 7 days a week; hours vary. Please check with guest services for guidelines.

## 9<sup>th</sup> Floor:

- **Birthing Center:** For parents giving birth at our hospital, our birthing center is located on the 9th floor. To reserve a tour of the birth center, please call 734-763-6295

# Key Places in the Congenital Heart Center

## 10th Floor:

- **Waiting Area:** Families waiting for a loved one undergoing cardiac surgery are asked to wait in the Level 10 Family Waiting Lounge where our staff will provide updates during the procedure. The waiting area is located directly behind the welcome desk on the 10th floor.
- **Pediatric Cardiothoracic Intensive Care Unit (PCTU):** Patients may be cared for in the PCTU after surgery. To locate from the ground floor lobby, take the main elevators (#7), located to the left of the main desk. Take the elevators to the 10th floor. Depending on time of day, Guest Services Specialists provide assistance at the welcome desk near the elevators, or a Clerk provides assistance at the desk inside the unit.
- **Ronald McDonald House:** Located right around the corner of the hospital or inside the hospital on the 10th floor, the Ronald McDonald House provides many of our families lodging. Please speak with your social worker for more information.
- **Inpatient Lockers:** Located in the 10th floor family waiting area.
- **Inpatient Showers:** Located in the bathroom across from the welcome desk on the 10th floor.

## 11th Floor:

- **Pediatric Cardiology Clinic and Cardiac Surgery Office:** For outpatient visits in the clinic, take the main elevators (#7) from the lobby to the 11th floor. There is a welcome desk just a few steps from the elevators. Continue to walk straight down the hallway, and the check in desk will be on your left.
- **11 West Moderate and General Care Inpatient Unit:** To find your way to 11West inpatient area from the lobby, take the main elevators (#7) from the lobby to the 11th floor. Go to the welcome desk, from there, go to the right from the desk and go through the double doors. A clerk will be located at the next desk and will assist you.
- **Laundry:** Washer and dryers are located in the family lounge on both the 10th floor and 11th floor. They are available for patient and family use, free of charge.
- **Inpatient Showers:** Located in each patient room.

*“While my daughter was in the hospital, I used to take time to explore all of the different areas of the hospital. Not only did I learn where everything was, but it was a great way to spend some of the extra time.”*

*-Mom of a heart patient*

# CHC Units

## Pediatric Cardiothoracic Intensive Care Unit (PCTU)



*While tubes, wires, IVs, and monitors are a normal part of the PCTU, so is love and support from family.*

- The PCTU is a 20 bed intensive care unit where your child will recover after surgery or when specialized intensive care is needed. We encourage family to visit at times that are convenient. When you arrive to the PCTU, stop at either the welcome desk or the clerical station to see if you are able to visit at that time. The PCTU clerk will check with your nurse and let you know if it is a good time to visit. **Please call each time before you visit as the unit may be closed to visitors due to sterile surgical procedures which often occur on the unit.**
- Parents and legal guardians are welcome in the PCTU 24 hours a day. Between the hours of 9:00 a.m. and 9:00 p.m., extended family and visitors are welcome with the exception of the time during nursing shift change. We ask that only parents and legal guardians stay during nursing shift change so that visitors will only hear 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.
- Your child's length of stay in the PCTU could last one day 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 staying longer than 2 weeks in the PCTU. These meetings are an opportunity to discuss short and long-term goals, and to discuss current medical status and treatment plan.
- Nursing shift change: 7 a.m. - 8 a.m., 3 p.m. - 4 p.m., 7 p.m. - 8 p.m., and 11 p.m. - 12 a.m.
- Cell phones may be used at the bedside, but we ask that you please place them on silent or vibrate.
- We ask that all family and visitors wash their hands frequently, and always when entering and exiting your child's room.

# CHC Units

## PCTU

### Care After Surgery or During Critical Illness:

Children who undergo a cardiac surgery or need intensive medical care for their heart may be cared for using:

- Mechanical ventilator to provide breathing support
- Medicines to support blood pressure, heart rhythm, and others such as antibiotics for infection prevention
- 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 can be used to pace the heart as necessary with an external pacemaker
- Urinary catheter to monitor the urine output
- Intravenous catheters (IVs) to provide fluids, intravenous nutrition and medications
- Heart, artery and vein catheters for pressure monitoring and blood draws
- Monitors that display the heart rate, heart rhythm, blood pressure, and oxygen saturation



Monitor



Medicine  
Pumps



Ventilator

After surgery, our patients go directly to the PCTU from the operating room without spending any time in a separate recovery area. Because of this, the bed space and nearby bed spaces may be closed for 1-2 hours or longer after your child's return from the operating room. We use this initial time to ensure a safe post-operative recovery, stabilize your child, share medical information, obtain initial tests, and double-check all of the patient's catheters, medications and ventilator settings.

# CHC Units

## PCTU



Rest time with mom

Because the PCTU is a medical AND surgical intensive care unit, various invasive procedures routinely occur at the 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 you may find comforting during your hospital stay. Please label your items with your name to prevent them from being misplaced. Potted plants, flowers, and latex balloons are not permitted.

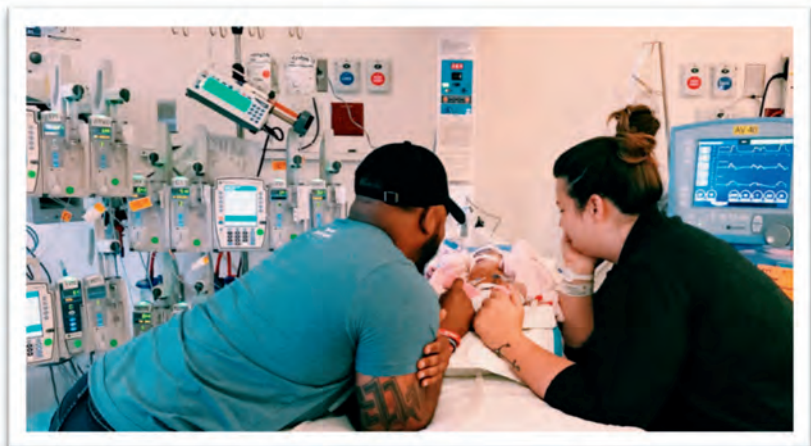
Patient and Family Centered Medical Rounds typically occur between 7:30 - 8:30 a.m. and 5:00 – 6:00 p.m. daily during the week, and 7:30 - 9:00 a.m. on weekends. Team members discuss medical status and form a plan for the day during rounds. Parents or legal guardians are welcome to participate in rounds. If family members are unavailable during rounds, members of the medical team are available to answer questions and discuss the treatment plan throughout the day and evening.

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

The experience you have in the PCTU is important to us and we need to hear from you. Expect a survey concerning your patient and family experience on the PCTU before you transfer to the 11 West.

*"Being there for rounds as much as possible was really important to us. We took notes, which really helped because it is easy to forget all the details later. Whenever we didn't understand what was happening, we asked questions."*

- Heart Parents





# CHC Units

## 11 West-Moderate and General Care



11 West is a 32 bed unit composed of 12 Moderate Care beds and 20 General Care beds, on the 11<sup>th</sup> floor of the hospital. When your child no longer requires ICU care, the remainder of the care will be on 11 West. Moderate care is a step between ICU care and general care. Our goal is to help equip you to take care of your child at home.

Your child's care on 11 West will be managed by a team consisting of pediatric specialists. This team includes Cardiologists, Cardiology Fellows, Residents, Nurse Practitioners, Registered Nurses and many other support services.

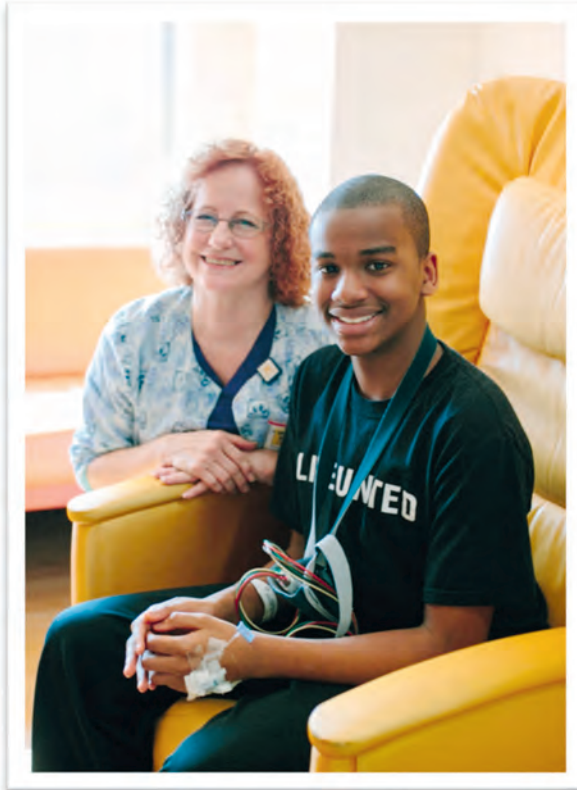
You will receive a tour upon your child's admission or transfer to the unit. On 11 West, you will find nutrition rooms where patients can help themselves to water, juice and various snacks. A central family lounge includes a play room, a laundry room, and a Child Life room. There is also a pumping room for breastfeeding mothers.

Visiting hours are 9:00 a.m. – 9:00 p.m. Parents and guardians are not considered visitors and are encouraged to stay with their child. We ask that all family and visitors wash their hands frequently. \*Please note\* Children who are sick or have been exposed to infectious illness are not permitted to visit. During Flu season, if a patient is in isolation precautions, visitors under 12 years are not permitted.



# CHC Units

## 11 West-Moderate and General Care



Two people, 18 years and older, can stay at the bedside overnight. Each patient room includes a bathroom with shower, personal refrigerator, reclining chair, couch that folds into bed, TV and Internet. Your child's stay on 11 West may last days to weeks, depending on your needs.

- Nursing shift changes are from:
  - 7:00 a.m. – 7:30 a.m.
  - 3:00 p.m. – 3:30 p.m.
  - 7:00 p.m. – 7:30 p.m.
  - 11:00 p.m. – 11:30 p.m.
- Team rounding typically occurs from:
  - 8:30 a.m. – 11:00 a.m.

We encourage you to be a part of shift changes and present for team rounding, your input is important to your child's care.

While on 11 West, your specialized team will work with you to prepare and equip you to provide care for your child at home. The multidisciplinary team partners with you and your child to provide individualized education. Staff will work with you until you feel comfortable and competent in providing all care necessary.

*"Never be afraid to ask!  
No question is silly!"*

*- Parent of a  
heart patient*





# Neurodevelopmental Rounds

Our congenital heart center performs Neurodevelopmental rounds weekly in the Pediatric Cardiothoracic Intensive care unit and the 11 West - moderate care and general care areas. Neurodevelopmental rounds are designed to follow newborns to 3 month old patients after surgery with the goal of reducing developmental delays.



Included in the rounding team are cardiac surgery nurse practitioners, clinical care coordinators, physical therapist, occupational therapist, speech language pathologist, child life specialist, bedside nursing, and families. These rounds discuss the patient’s environment, comfort/pain, gross motor skills, fine motor skills, feeding, family, therapies and discharge planning including home therapy needs. Information on developmental positioning and developmental care goals specific to the individual infant are posted in the patient room for parents and staff.

## Notes & Questions

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# Care Team

The Congenital Heart Center has many healthcare professionals working as a team to ensure your child receives the best medical care possible. The roles of the healthcare team are described below. Those with an asterisk are members who participate in daily rounds often.

Care Team Member	Role
<b>*Care Manager</b>	A registered nurse who works with you and the medical team to ensure a smooth transition from hospital to home. They solve problems that may delay a patient's discharge, and arrange for visiting nurses and equipment once your child is home.
<b>Cath Lab Technician</b>	A specially trained technician that assist the doctor in the heart catheterization procedure.
<b>*Child Life Specialist</b>	Child life specialists support children and siblings during stressful hospital experiences. This is done largely through play and other fun activities.
<b>*Clinical Care Coordinator (CCC)</b>	A clinical care coordinator (CCC) is a nurse specialized in the care of cardiothoracic surgery patients. They provide discharge education and procedural assistance.
<b>*Clinician Assistants</b>	Healthcare professionals, who assist the rounding team and provide helpful information to families throughout their stay in the PCTU.
<b>Education Specialist</b>	An education professional who supports and advocates for school engagement and academic progress for patients, and can help families communicate with their child's school.
<b>Electrocardiogram (EKG) Technician</b>	A specially trained technician that monitors and tests cardiovascular performance using EKG equipment, using electrodes to record the electrical signals of the heart.
<b>EP Technician</b>	A specially trained technician that assists the doctor in electrophysiology tests and procedure, as needed due to abnormal heart rhythm.
<b>*Family</b>	People who know the patient best and provide information about the patient's history and current condition. Family takes on many forms and can include: parents, grandparents, aunts, uncles, foster family, guardians, members of the community, and many others.
<b>Genetic Counselor</b>	Professional with specialized genetic training who provides information and guidance to patients and families and to the care team about risk for inherited conditions.
<b>Guest Service Specialists and Unit Hosts</b>	They may be located at welcome desks. They can assist you with questions, directions, checking in visitors, and parking validation.
<b>Medical Assistant</b>	A trained healthcare assistant who supports the work of physicians, nurses and other health providers, and who supports patient experience.

Care Team Member	Role
<b>*Medical Social Worker</b>	Medical social workers help support children and families during stressful hospital experiences. They offer counseling, assist with lodging and insurance, and link children / families with resources near home. They also provide services on an outpatient basis.
<b>Medical Student</b>	A student in the midst of medical school.
<b>Nursing Student</b>	A student in the midst of nursing school.
<b>Occupational Therapist (OT)</b>	Members of the patient's rehabilitation team who help maximize the patient's independence in order to support improving, maintaining or restoring skills for activities of daily living.
<b>*Pediatric Cardiac Surgeons</b>	Cardiac surgeons are the leaders of the surgical team, and perform heart surgery. They work closely with the cardiologists and doctors in training.
<b>*Pediatric Cardiology Attending</b>	Pediatric cardiologists are the leaders of the medical team. They work with cardiac surgeons and other doctors-in-training such as pediatric cardiology fellows and pediatric residents. They diagnose and treat congenital and pediatric heart diseases, perform heart catheterizations, decide with the surgeon about heart surgery, and provide care before and after heart surgery. One of these doctors may be your child's primary cardiologist.
<b>*Pediatric Cardiology Fellow</b>	Doctors who are completing a training to specialize in pediatric cardiology.
<b>*Pediatric Nurse</b>	Pediatric nurses are registered nurses who provide expert nursing care to children and families. They provide care in our clinic, procedure areas, intensive care and general care units. They are specially trained eyes and ears available 24 hours a day, 7 days a week.
<b>*Pediatric Nurse Practitioner (NP)</b>	Pediatric nurse practitioners are masters or PhD prepared nurses who provide advanced nursing care. Pediatric nurse practitioners work closely with the attending doctors. They jointly manage the care that is provided in the acute or critical care units after heart surgery as well as your child's ongoing cardiovascular care.
<b>Pediatric Psychologist</b>	Pediatric psychologists have PhD training and support the interplay between development, behavior and health. They work together with the medical team to evaluate and provide treatment to promote mental health, coping and development.
<b>*Pediatric Residents</b>	Doctors who completed medical school and are training to specialize in the care of children.
<b>*Pediatric Surgical Fellows</b>	Surgeons in training to become pediatric cardio / thoracic surgeons. They complete a two-year training program to specialize in pediatric cardiovascular surgery.
<b>Phlebotomist</b>	Phlebotomist is personnel that specialize in drawing blood from patient.

Care Team Member	Role
<b>*Pharmacist</b>	A clinical professional with a doctorate in pharmacy who has education, training, and experience in the use of cardiovascular medications including appropriate dosing, side effects, and drug interactions.
<b>Physical Therapist (PT)</b>	Treats injury or dysfunction with exercises and other physical treatments to improve movement function.
<b>*Physician's Assistant (PA)</b>	A healthcare professional who has specialized training to provide healthcare to patients under the supervision of a doctor.
<b>*Registered Dietitian</b>	Registered dietitians assess the dietary needs of children with heart problems and suggest diet changes. They help with infant formulas, tube feedings, and suggest diets for children with obesity, high cholesterol, hypertension (high blood pressure), and high calorie needs.
<b>Research Personnel</b>	Research is how medical teams learn about the best treatment for diseases and conditions such as congenital or acquired heart disease in children. You and/or your child may have the opportunity to participate in a research study. You may be approached by one of our research investigators, a research coordinator, or a research nurse, all of whom have specialized training in research practice and protocols to assure that research is safe and consistent.
<b>Resident Assistant</b>	Assists the medical team with ordering tests / procedures, and for insurance for medication.
<b>*Respiratory Therapist</b>	A clinical professional with specialized education in airway and ventilator management of infants, children, adolescents and adults to assist with breathing.
<b>Sonographer</b>	A specially trained technician that performs echocardiograms (Echos) and ultrasounds. Pediatric Cardiologists look at the images from Echos to diagnose medical conditions and monitor heart function.
<b>Speech &amp; Language Pathologist</b>	Members of the patient's rehabilitation team who commonly assist children who have feeding problems. They can help with skills needed to eat by mouth – swallowing, sucking, and mouth movements.
<b>Spiritual Care Providers</b>	Clinically trained clergy/religious leaders who specialize in offering spiritual and emotional care and support to patients and their families and hospital caregivers.
<b>Technicians (Techs)</b>	Specially trained individuals that assist the nurses, doctors and families.
<b>Volunteers</b>	Volunteers are lay people that come to the hospital to entertain and play with patients, hold them, rock them when needed.
<b>X-Ray Technician</b>	A specially trained individual that take x-rays and other radiology diagnostic tests.

# Cardiologists



Dr. Ranjit Aiyagari



Dr. Sowmya  
Balasubramanian



Dr. Katherine Bates



Dr. David Bradley



Dr. John Charpie



Dr. Clinton Cochran



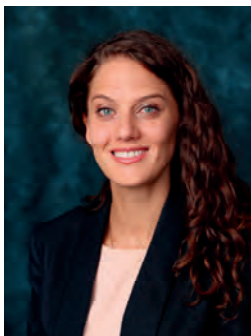
Dr. Tim Cotts



Dr. Nancy Cutler



Dr. Michael DiMaria



Dr. Katherine "Kate" DeWeert



Dr. Adam Dorfman



Dr. Daniel Ehrmann



Dr. Greg Ensing



Dr. Carly Fifer



# Cardiologists



Dr. Sarah Gelehrter



Dr. Caren Goldberg



Dr. Ron Grifka



Dr. Ryan Green



Dr. Jonathan Hagel



Dr. Jesse Hansen



Dr. Micheal Joynt



Dr. Martin LaPage



Dr. Heang Lim



Dr. Jimmy Lu



Dr. Dan McAree



Dr. Scott Maurer



Dr. Amanda McCormick



Dr. Katie Mowers



Dr. Mark Norris

# Cardiologists



Dr. Mary Kay Olive



Dr. Gabe Owens



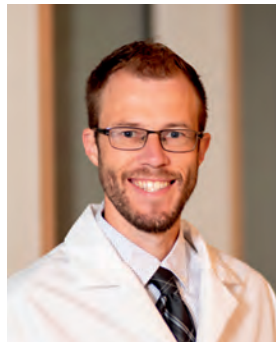
Dr. Sonal Owens



Dr. Sara Pasquali



Dr. David Peng



Dr. James Reinhart



Dr. Al Rocchini



Dr. Mark Russell



Dr. Sara Sadat-Hosseiny



Dr. Kurt Schumacher



Dr. Todd Sower



Dr. Courtney Strohacker



# Cardiologists



Dr. Nate Sznycer-Taub



Dr. Thor Thorsson



Dr. Daniel Turner



Dr. Mary van der Velde



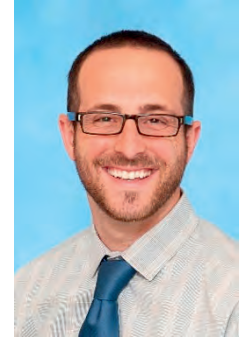
Dr. Alyssa Vermeulen



Dr. Carolyn Vitale



Dr. Wendy Whiteside



Dr. Jeff Zampi

# Dietitians



Asha Shanti



Jessica Stoscup

# Cardiac Surgeons



Dr. Tim Lancaster



Dr. Jiyong Moon



Dr. Richard Ohye



Dr. Jennifer Romano



Dr. Vikram Sood

# Clinical Care Coordinators (CCC)



Holli Clewis, RN



Amy Herrema, RN



Sarah Mikola, RN



Katie Nolan, RN



Megan Parker, RN

# Psychologist



Catherine Dusing, PhD



Melissa Cousino, PhD

# Cardiac Surgery Advanced Practice Providers (APPs)

NP = Nurse Practitioner



Samantha Adams, NP



Louise Callow, NP



Izzy Debarbaro, NP



Michelle Dwyer, NP



Kim DiMaria, NP



Kim Kellogg, NP



Ally Longnecker, NP



Beth Norton, NP



Alissa Scheffer, NP



Jordan Shifman, NP



Julianne Stieber, NP



Kate Sweeney, NP



Kate Thornsberry, NP



Becky Tompkins, NP



Anna Van Riper, NP



# Cardiology

## Advanced Practice Providers (APPs)

NP = Nurse Practitioner  
PA = Physician's Assistant



Becky Chambers, NP



Andrea Craven, NP



Brynn Dechert-Crooks, NP



Kristin Evans, NP



Bethany Giacobbe, NP



Nikki Grennell, NP



Bethany Largent, NP



Cathy Miller, NP



Emily Miller, NP



Morgan Redies, PA



Natalie Sinicropi, NP



Elizabeth Stalder, NP



Alicia Valentini, NP



Meg Zamberlan, NP



Veronica Zitterman, NP

# Pharmacists



Bronwyn Crandall, Pharm D, BCPPS



Ashley Huebschman, Pharm D, BCPPS

# COPA Nurses (Comprehensive Outpatient Pre-Surgical Analysis)



Becky Bail, RN



Jenny Sherrer RN

# Clinician's Assistants



Adrian Dantzer

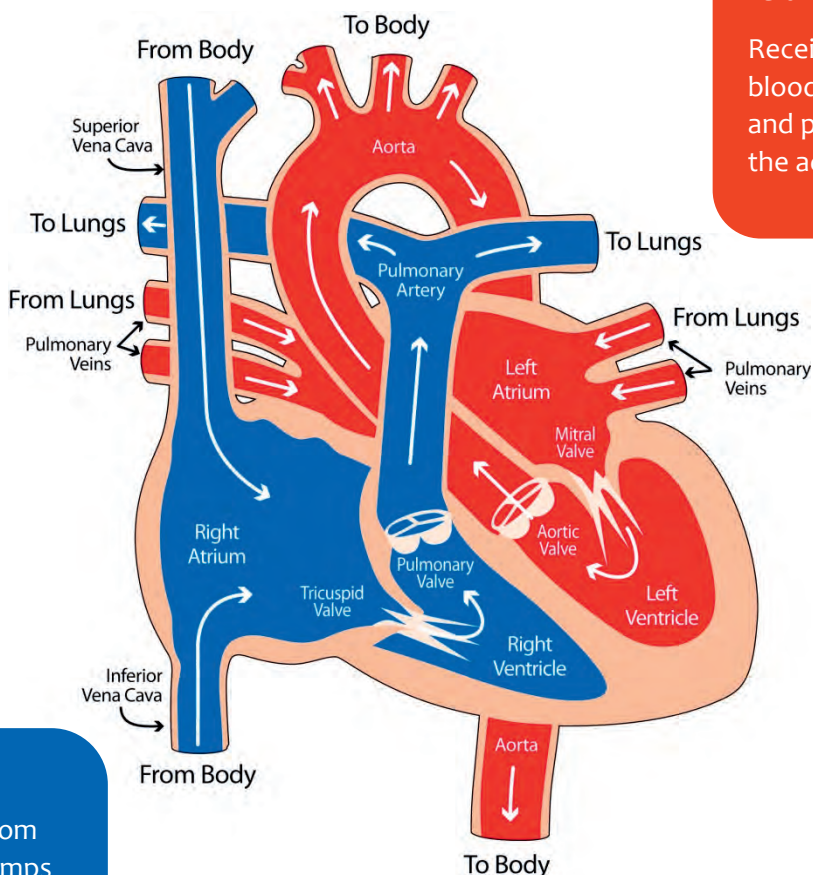


LeKetra Holland

# Heart Education: Diagrams

## The Normal Heart:

The heart has 4 chambers; 2 top chambers called atria which collect blood returning to the heart and 2 bottom chambers called ventricles which pump blood out of the heart. The right atrium collects blood returning from the body after delivering nutrients and oxygen to the body tissues. The blood then moves to the right ventricle which pumps this blood to the lungs. In the lungs, the blood gets rid of a waste gas (carbon dioxide) and picks up a fresh supply of oxygen. The oxygen-rich blood returns back to the heart and collects in the left atrium before draining into the left ventricle where it is then pumped into the aorta (large blood vessel) which carries blood to the rest of the body.



### Left Heart

Receives oxygen-full blood from your lungs and pumps it through the aorta to the body

### Right Heart

Receives blood from your body and pumps it through the pulmonary artery to the lungs where it picks up oxygen

# Heart Education:

## Definitions

ABG (Blood Gas): A blood test used to gather information about oxygen and carbon dioxide in the blood to provide information about the function of the lungs and delivery of oxygen to the body.

Angiogram: An x-ray of blood vessels that require injection of a contrast agent.

Antibiotics: Medications to stop the growth of bacteria in the body (commonly used are amoxicillin, vancomycin, and gentamicin).

Arrhythmia: An abnormal heart rhythm. An electrocardiogram (EKG) provides information about abnormal heart rhythms.

Arterial (art or a) line: Tube placed in the patient's artery to monitor blood pressure and draw blood.

Artery: A vessel that carries blood from the heart to the other parts of the body.

Atrium: One of the heart's two upper chambers where blood collects before going to the ventricles.

Balloon Valvuloplasty: A procedure which involves inserting a balloon-tipped catheter into the opening of a narrowed heart valve. The balloon is inflated, the valve is stretched open, and the catheter is removed.

Blood Pressure: The pressure of the blood in the arteries.

Cardiac Catheterization: This procedure involves inserting a catheter into a vein or artery and guiding it into the heart. It's done to obtain diagnostic information by sampling oxygen content of blood, measuring pressures and evaluating the structural components of the heart. Cardiac cath can also be used for treatment of some types of disorders.

Cardiology: The study of the heart and its functions in health and disease.

Cardiomyopathy: A type of heart disease in which the heart is abnormally enlarged or thickened, which causes the heart to pump blood less efficiently.

CT scan or Computerized Tomography Scan: A specialized radiology procedure that provides more detailed images than a regular x-ray.

Central venous line (CVP or CVC): An IV tube placed in a large vein so the tip is near the heart ("central") to measure pressures, give medications and fluids, and to draw blood samples.

Chest Tube: A tube placed in the space around the lungs or the heart to drain fluid.

Congenital Heart Defect: Part of the heart or its major blood vessels that isn't formed properly and doesn't work as it should at birth. The term congenital heart disease is sometimes used when talking about the scope of heart defects.

Congestive Heart Failure: A condition in which the heart's ability to pump is impaired.

Cyanosis: A bluish discoloration of the skin due to a shortage of oxygen in the blood.



# Heart Education:

## Definitions

Diuretic: A medication that increases urine output (commonly used are diuril (chlorothiazide), lasix (furosemide), aldactone (spironolactone)).

Echocardiogram (ECHO): An ultrasound of the heart. A way to look at the heart and see the structures of the heart and how the blood travels through the heart.

ECMO (Extracorporeal Membrane Oxygenation): An advanced technology that acts as a person's heart and lungs to support a person who is recovering from surgery or disease, or during a surgical procedure.

Edema: Swelling or puffiness.

Electrocardiogram (EKG /ECG): A picture of electrical impulses produced by the heart.

Extubate: To remove the breathing tube from the trachea (airway).

Foley catheter: A tube inserted into the urethra with the tip resting in the bladder used to collect and measure urine output.

Hybrid procedure: A heart procedure using both surgery and cardiac catheterization techniques.

I and O: Intake and output of fluid.

Intra-cardiac line: A tube placed inside the heart to monitor pressures and possibly used to give medication.

Inotropic Agents: Medications to help support heart function and blood pressure (Eg: dopamine, epinephrine, milrinone).

Intubate: To place a breathing tube through the nose or mouth into the trachea (airway) to assist with breathing. It can be connected to a ventilator.

Lipids: Nutrients that are fats and, in proper preparation, can be given as IV nutrition.

Narcotics: Pain medication (commonly used are morphine, fentanyl, diuladid, and oxycodone).

Nasogastric (NG) / Feeding Tube: a tube that is inserted into the nose and down the esophagus (food pipe) and into the stomach to deliver breastmilk or formula for nutritional support for patients who are not able to eat enough on their own.

NPO: Nothing by mouth – no drinking liquids or eating food.

Oxygen saturation (sat): Percentage of oxygen in the blood.

Pacemaker: An electrical device that regulates the rate of the heart.

PIV or IV:. A peripheral intravenous (IV) line that is used to give intravenous hydration and medications. Typically seen in veins of the hands, arms or feet.

Stent: A device that is placed in the heart or blood vessels to open an area to allow blood to flow through more easily. A cardiac catheterization is typically used to place a stent.

TPN: Total parenteral nutrition – a way to give nutrition by IV. Regular IV fluid is simply fluid with sugar and salts (electrolytes) while TPN provides proteins and other nutrients for someone who is unable to eat for a longer period of time.

Vein: A vessel that carries blood from other parts of the body back to the heart.

# Heart Education:

## Definitions

Ventricular Assist Devices (VADs): Electrically powered pump designed to increase the amount of blood the heart is able to pump through the body. Most VADs are surgically implanted in the chest in the area around the heart, and connected to the ventricle that needs help pumping blood.

Ventilator: Breathing machine.

Ventricle: One of the heart's two lower chambers. They are the muscular chambers that contract to pump blood.

Vital signs (Vitals): Temperature, blood pressure, heart rate (how many beats per minute) and respiratory rate (how many breaths per minute).



## Notes and Questions:

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# More About Hearts:

## Congestive Heart Failure

### What is Congestive Heart Failure?

CHF occurs when the heart does not pump as well as it should and is not able to meet the demands of the body. Congestive heart failure (CHF) does not mean the heart is going to suddenly fail or stop working. When the heart cannot pump enough blood to the kidneys, they cannot filter extra fluids out of the body and into the urine. This fluid can build up in the lungs and the rest of the body, causing difficult breathing and swelling.

Children born with certain types of heart problems are at risk for developing CHF. Not all children with heart defects will have CHF.

CHF can occur gradually. If your child has CHF, you will notice some signs and symptoms that happen over a period of time. The type and number of symptoms are different in each child.

### What are symptoms of Congestive Heart Failure?

- **Persistent fast breathing:** If you are caring for a child with CHF, the best time to observe their breathing is while they are sleeping. Children naturally breathe faster when awake or crying.
- **Hard breathing:** You may see muscle pulling or “sucking in” between and below the ribs or the breast bone (retractions). You may see some widening of the nostrils when breathing in, or hear a grunting or wheezing sound with breathing. Some children with CHF may have more trouble breathing when they are lying down.
- **Cough and congestion:** It may be difficult to tell if these symptoms are related to CHF or a respiratory illness. A fever and nose drainage are generally symptoms of a respiratory illness, not congestive heart failure.
- **Changes in skin color:** Look for a grayish, mottled (lacy or net-like patches) color or paleness.
- **Sweatiness:** Look for cool, clammy skin or sweat on the forehead. This may happen when active, feeding or at rest.
- **Decreased amount of urine:** For babies, this may mean they have fewer wet diapers (less than 6-8 a day)



# More About Hearts:

## Congestive Heart Failure (continued)

### Symptoms of Congestive Heart Failure:

- **Swelling or edema:** Look for puffiness in your child's hands and feet and around their eyes. For adults, puffiness in their legs or feet.
- **Changes in activity:** Look for a decrease in activity, an increase in time spent sleeping or tiring more easily.
- **Feeding difficulties and poor weight gain:** For babies, this may mean taking longer to finish bottles or eating less than usual.
- **Irritability or restlessness**
- **Fatigue**

### How is Congestive Heart Failure treated?

Congestive heart failure is treated by finding and removing the cause or by giving medicines to help the heart work more easily. Some common medications that are usually given are:

- **Diuretics:** These medications help remove extra fluid from the body tissues. Expect to urinate more frequently. Common diuretics used are Lasix® (Furosemide), Diuril® (Chlorothiazide) and Aldactone® (Spironolactone).
- **Captopril or Enalapril:** These medications lower your child's blood pressure and makes it easier for the heart to pump blood out to the body.
- **Carvedilol or Metoprolol:** These medications help to slow down the heart rate so that it can pump better.

### Other things that you can do to support recovery:

- Provide quiet areas for rest
- Avoid extreme hot or cold temperatures
- Avoid people who are obviously sick



# More About Hearts:

## Immunizations & Infection Prevention

### **Can children with heart disease receive immunizations?**

- Immunizations are given to infants and children to protect them from serious illnesses such as diphtheria, hepatitis, whooping cough, polio and others. It is recommended that children with CHD receive routine vaccinations according to pediatric guidelines unless otherwise noted by their pediatric cardiologist.

### **Immunizations before or after heart surgery:**

- Children who are having heart surgery should not receive routine immunizations 2 weeks before surgery and it is best to avoid routine immunizations for 2 weeks after heart surgery (this does not include Influenza , RSV and Pneumococcal vaccines).

### **Influenza (Flu) vaccine:**

- Children and adults with some heart problems are at increased risk for severe illness with influenza, which may require hospitalization. They should receive the influenza vaccine each year. Children 6 months to 12 years of age need two shots, unless they have had an influenza vaccine before. In this case, only one shot may be necessary. Please discuss immunizations with your primary doctor or pediatrician. Pneumococcal vaccines.

Please discuss immunizations with your primary doctor or pediatrician.

### **Pneumococcal and respiratory syncytial virus (RSV) vaccines:**

- Talk with your doctor or nurse about your child's individual needs.

### **Synagis® - a medication used to protect against respiratory syncytial virus (RSV)**

- Talk with your doctor or nurse about your child's individual needs.

# More About Hearts:

## Endocarditis and Antibiotic Guidelines for Children with Congenital Heart Disorders

**All children should have dental cleanings every six months once their teeth come in.**

### **What is endocarditis?**

Endocarditis (also referred to as subacute bacterial endocarditis or SBE, bacterial endocarditis or infective endocarditis) is an invasive infection of the inner lining of the heart and the heart valves. It is a serious condition that can cause major damage to the heart tissue. Early diagnosis can be very helpful. Treatment requires weeks of IV antibiotics and may require a long hospital stay and sometimes even surgery.

Some routine daily activities such as chewing, brushing teeth or flossing can allow small amounts of bacteria to enter the bloodstream. For most people, this isn't a problem. A healthy immune system prevents these bacteria from causing harm, but people with some heart conditions have a higher risk for developing endocarditis and need to take special precautions to prevent it. Having good dental hygiene is helpful in reducing the chance of getting endocarditis.

Symptoms of endocarditis can include:

- Persistent fever
- Chills
- Aching
- Night sweats
- Feeling generally unwell

Consult with your doctor if your child is having these symptoms. Ask if blood cultures or other tests should be done.

### **How can I prevent endocarditis?**

One way to prevent endocarditis is by taking antibiotics before having certain procedures, such as dental work. These procedures may increase the likelihood that bacteria could enter the bloodstream and cause an infection. Taking antibiotics for the purpose of preventing endocarditis is called prophylaxis (or SBE prophylaxis). While endocarditis is not very common, talk with your doctor about the steps you need to take in order to reduce your child's risk for developing endocarditis.

### **Who needs to take antibiotics to prevent endocarditis?**

- Individuals with many forms of unrepaired congenital heart disease, especially those that result in lower than normal oxygen saturations (cyanosis).
- Individuals with artificial heart valves or shunts.
- Individuals with patches or devices in their heart for at least 6 months after the procedure. This may be longer if there is a leak close to the patch or device.
- People who develop heart valve disease after a heart transplant (valvulopathy).
- Any person with a history of endocarditis, even if they do not have any other heart diseases or conditions.

# More About Hearts:

## Endocarditis and Antibiotic Guidelines for Children with Congenital Heart Disorders (continued)

### **If my child has been advised to have endocarditis prophylaxis, when is it recommended?**

Any person in the list above for who needs prophylaxis will need to take antibiotics before any of the following procedures:

- Dental procedures around the gum area, or procedures that may cause bleeding such as tooth extractions, cleaning and drilling.
- Any surgical procedures that involve the mucus lining of the respiratory organs in the nose, neck and lungs. These include tonsillectomy, adenoidectomy, bronchoscopy with biopsy and more. It is not necessary for endotracheal intubation or myringotomy with tube insertion.
- Incision and drainage of infected tissue.

To learn more about recommendations on infective endocarditis prophylaxis and infective endocarditis, visit the American Heart Association's page on infective endocarditis at [www.heart.org/endocarditis](http://www.heart.org/endocarditis).

### **Take the next step:**

Talk with your U-M pediatric cardiologist about your child's risk of endocarditis and whether endocarditis prophylaxis may be recommended. To contact your doctor, call the Congenital Heart Center at (734) 764-5176.

## Travel: Can my child travel?

There are no reasons not to travel if your child has a congenital heart defect.

- Children should always be in an age-appropriate safety seat while traveling. Do not add extra padding across the chest area. Restraining straps need to be tight enough to restrain the child.
- Make sure that you travel with important phone numbers, including your Pediatric Cardiologist.
- Pack enough medication for a couple extra doses in case travel plans change at the last minute.
- Knowing where the closest major children's hospital is located may be helpful.
- Children with cyanotic heart defects should **never** fly in a non-pressurized plane. Additionally, oxygen must always be used on airplane flights while in the air.
- Take a recent letter from your cardiologist in case of an emergency.
- See the next page for travel data form.



# More About Hearts:

## Travel: Emergency Treatment Information for Outside Institution Health Care Providers

**PARENTS: This form should be taken on all travel, vacations and trips to Emergency Departments**

This patient, \_\_\_\_\_ has a complex congenital heart defect and is under care at the C.S. Mott Children's Hospital, Michigan Medicine.

They have \_\_\_\_\_,

and most recently had surgery on \_\_\_\_/\_\_\_\_/\_\_\_\_. Date of discharge from hospital \_\_\_\_/\_\_\_\_/\_\_\_\_.

Medications: \_\_\_\_\_

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Baseline hemodynamic ranges are below:

HR \_\_\_\_\_ RR \_\_\_\_\_ BP \_\_\_\_\_ / \_\_\_\_\_

O2 sat \_\_\_\_\_ % on Room Air

**Please call 734-936-6267 and ask to speak with the Pediatric Cardiology Fellow-On-Call as soon as the child arrives at your facility.**

**It may be critical to transport this child to Mott Children's Hospital immediately.**

**Chest compressions and defibrillation may be done in the usual manner.**

# Care at Home:

## What Do I Need to Know Before I Go Home After Hospitalization?



In order to be prepared for discharge you will need to learn about your child's needs. Learning this care takes time and patience and we want to make sure you are comfortable before going home. We are here to help you!

To help you feel confident in providing care we encourage you to spend as much time as possible in the hospital with your child.

When you are in the hospital you will see a "Discharge Readiness Checklist" in your room that will help you keep track of your progress.

*"I am a big hands-on learner. Having staff actually show us how to do everything was a big help."*

*-Parent of a heart patient*

### Discharge Readiness Checklist:

#### Watch Videos found on Get Well Network:

- Congestive Heart Failure
  - Your Child's Recovery from Heart Surgery
  - Nasogastric Tube Feedings
  - Developmental Milestones for Little Heart Victors
- <https://www.youtube.com/watch?v=Wp4SSrOTxw>

#### Review Handouts:

- Nutrition
- Medication Info Sheets
- Medication Card: Dose/Times
- RSV
- Home Care After Heart Surgery
- Congestive Heart Failure
- How to Place a Feeding Tube

#### Demonstrate:

##### Infant Care:

- Diapering
- Bathing
- Comfort
- Safe sleep
- Umbilical cord
- Care of circumcision (if applicable)

##### Nutrition:

- Volume and Schedule
- Bottle and/or breast feeding
- Mixing increased calorie formula

\*Checklist is continued on next page.

# Care at Home:

## Goals and Education Checklists for Hospital Discharge

Goals and education checklists for discharge will be provided by your care team to meet the unique needs of your child. Please ask your care team questions as you go through this process. Writing down your questions as you think of them may be helpful when there are many education topics to prepare for discharge.

### Nasogastric Feeds (two caregivers should learn):

- Tube set up
- Administration
- Tube placement

### Medications:

- How to draw up and administer
- What the medication is for
- How much to give and when to give it

### Incision:

- Wound care
- Suture removal

### Attend:

- Emergency Procedure Class

### Complete:

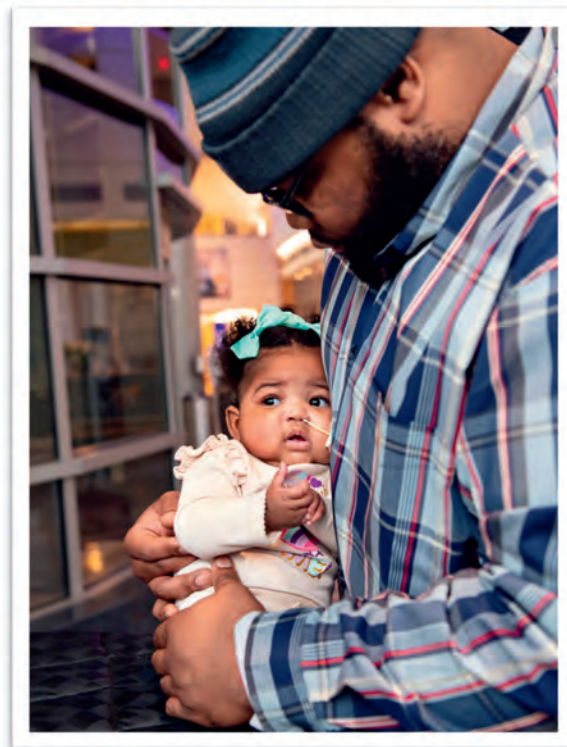
- Buckle Up
- Hearing Screen
- Newborn Screen
- Synagis
- Flu Vaccination

### Identify Resources:

- Home Care Supplies
- Visiting Nurse
- Early On
- Support Groups

### Identify Providers:

- Pediatrician / Primary Doctor
- Cardiologist
- Occupational / Physical Therapy
- Pharmacy
- Neurodevelopmental Clinic
- \_\_\_\_\_
- \_\_\_\_\_
- \_\_\_\_\_



*“The first time we were discharged, my son was on a feeding tube, so it was a little scary. But the training we got from the nurses (making us do it a few times while they coached), and the moral support made things much easier.”*

*-Parent of a heart patient*

# Care at Home:

## Home Care After Surgery



### How do I care for the incision?

- Do not cover the incisions, leave them open to air. If there is no drainage, then no Band-Aids® or dressings are needed.
  - Do not apply any lotion or ointment unless directed, for six weeks.
  - There may be a small amount of clear yellow or dark bloody drainage from any of the incisions, this is normal. A Band-Aid® or light dressing may be used for this. Please remove dressing as soon as there is no more drainage.
  - Wash the incision(s) and chest tube sites daily with soap and water and gently pat dry. Use a clean washcloth and towel each time. Use wash cloth on incisional areas before using on other parts of the body.
  - You can take tub baths, take care to not submerge incision(s) or chest tube sites until completely healed, and no obvious scabs remain. Showering with back to the flow of water is allowed after all tubes and IVs are removed.
  - Clothing should be clean and fit loosely over the incision(s).
- 
- Steri-strips or special tapes placed over the incision should be left alone until they fall off or are removed at the follow-up appointment.
  - If a chest tube stitch is still in place, it should be removed by your local doctor or home care nurse 5 days after the tube(s) are taken out.

### Are there any physical restrictions for children?

Allow your child to play at their own pace. Children are good at limiting their own activity. Children can lay on their stomach or have “tummy time”. You can lift your child under their arms if they are comfortable. We encourage non-contact physical activity such as walking, light elliptical use and stairs.

- Follow these restrictions for **2 weeks after discharge**:
  - Keep your child home from school, day care and crowded areas such as stores and churches.
  - No swimming. After 2 weeks, they may swim in chlorinated water.

# Care at Home:

## Home Care After Surgery

- Follow these restrictions for **6 weeks after discharge**:
  - No physical activity that risks injury such as gym class, contact sports, sledding, roller blading, skiing, bike riding, or using trampolines.
  - No lifting over 10 pounds.
  - Swim in chlorinated water only. After 6 weeks, they may swim in unchlorinated water (ocean, lake, pond).
- Restrictions can vary for each patient. Talk with your doctor or nurse about your child's individual needs.

### How will surgery affect my child's behavior?

A child's surgery is a difficult experience for everyone in the family, and your child may have trouble adjusting once they are home. Your child may temporarily behave differently from normal, with such problems as:

- Sleep pattern changes
- Clingy behavior
- Eating changes
- Hyperactivity
- New fears, such as not wanting to sleep alone or needing a night light
- Acting younger, such as bed-wetting or thumb sucking

This behavior is temporary and normal. Here's how you can help:

- Reassure your child that they are safe and well
- Read books about hospitals and doctors
- Play hospital
- Distract your child with games, toys and music

**For tips on travel, see page 35**



# Care at Home:

## Home Care After Surgery

### **When should I call my doctor? - In Case of Emergency: Call 911**

- Temperature over 101.5° (F)
- Increased tiredness
- New onset of dry cough
- Increased pain
- Vomiting, diarrhea or feeding intolerance
- Change in appearance of incision
  - Cloudy yellow drainage
  - Increased redness or swelling
  - Separation of incision edges
- Shortness of Breath
  - Signs of Congestive Heart Failure

### **When should I schedule a follow-up appointment?**

#### **Pediatrician/Family Doctor:**

- Newborns: within 2-3 days after discharge. Please call the office to schedule an appointment.
- All others: as needed or suggested.

#### **If being followed by a cardiologist at Michigan Congenital Heart Center:**

- Pediatric Cardiac Surgery Clinic:
  - 1-2 weeks after discharge with the Nurse Practitioner. Appointment will be scheduled for you before discharge. This appointment may be done virtually.
  - If scheduled for an in-person visit, please arrive 30 minutes early for a chest x-ray.
- Pediatric Cardiology Clinic:
  - 4-6 weeks after discharge with Cardiologist. Appointment will be scheduled for you before discharge.

#### **If being followed by a referring or outside cardiologist (non-U of M cardiologist)**

- Please call to schedule a follow-up appointment with your referring cardiologist to be seen 1-2 weeks after discharge. We are able to assist with this if needed.

# Care at Home:

## Diet & Nutrition - Breast Milk Guidelines

### Breast Milk Storage Guidelines at Home:

These guidelines are provided to help our moms and babies get the most benefit from breastfeeding once they go home. They will differ slightly from the guidelines used during the hospital stay. Please let our staff know if you have any other concerns or questions.

LOCATION	DURATION	COMMENTS
Countertop, table	6-8 hours	Containers should be covered and kept as cool as possible; covering the container with a cool towel may keep milk cooler.
Insulated Cooler bag	24 hours	Keep ice packs in contact with milk containers at all times, limit opening cooler bag
Refrigerator	2-5 days	Store the milk in the back of the main body of the refrigerator.
Freezer compartment of a refrigerator	2 weeks	Store milk toward the back of the freezer, where the temperature is most constant. Milk stored for longer durations in the ranges listed is safe, but some of the lipids in the milk undergo degradation resulting in lower quality.
Freezer compartment of a refrigerator with separate doors	3-6 months	
Chest or upright deep freezer	6-12 months	

Source: American Academy of Pediatrics (<http://www.aap.org>)

### Use breast milk in the following preferential order:

- 1) Colostrum
- 2) Fresh milk
- 3) Thawed milk (good for 24 hours after being thawed)
- 4) Frozen milk (use the oldest milk first)

A day or two before your child is scheduled to be discharged your nurse will alert the Milk Room to prepare for packing breast milk for transport home. If you have to fly or travel longer than 18 hours, let your nurse know so they can make special packing arrangements.

# Care at Home:

## Diet and Nutrition



During your hospital stay, you or your child may have spoken with a registered dietitian. Prior to going home, you and your child's dietitian will be working together to create a plan based on your child's specific dietary needs. This education may include receiving breast milk and formula recipes, a home regimen schedule for tube feedings, or education on heart healthy eating habits.

After your discharge from the hospital, you can contact us if you have questions about:

- Diet
- Growth
- Nutrition plan after hospitalization

## Emergency Procedure Class for Parents and Caregivers of children under 1-year old

- The classroom is located in the Mott Respiratory Care Classroom. Your nursing staff can provide you with directions. Class size is limited to 6 participants.
- To register, contact your nurse or unit clerk. Please check with your nurse or clerk for the day and time that the class is offered.
- Class is intended to give basic knowledge of cardiopulmonary resuscitation (CPR), it is not intended to certify parents.
- **We encourage all families to attend this class before discharge.**

## Neurodevelopment clinic

A referral has been placed for each child under 1 year of age to the Neurodevelopmental clinic. This follow up is to evaluate if your child is meeting developmental milestones.

Neurodevelopmental Clinic: [www.mottchildrens.org/cardiacneurodevelop](http://www.mottchildrens.org/cardiacneurodevelop) or call 734-764-5176

# Care at Home:

## Medication

Most children with heart disease will need to be treated with medications after surgery and when discharged home. Medications are available in many different forms including capsules, tablets, and liquids. Most capsules and tablets are available at your local pharmacy. This is not always the case for liquid medications. Many liquid medications must be specially made using a recipe. It is important to check ahead of time with your local pharmacy about how to get all medications so there are not delays.

### It is important to understand the following information for each medication:

- Name of the medicine
  - Medications can have two names: a generic name and a brand name
- Concentration of the medicine if it is a liquid
- Dose of medicine
- How often should the medication be taken
- Reason for giving the medicine

### Medication Lists:

**Anywhere Pharmacy** **Dr. Ernie**  
**Rx# 9898989**

**Big Bird**  
**Take 10 mg (1 mL) by mouth two times a day**

**Furosemide 10 mg/mL** **Quantity: 10 mL**

1. **Name of medication:** Furosemide
2. **Concentration:** 10 mg/mL
3. **Dose:** 10 mg
4. **Volume** to draw up in an oral syringe and give: 1 mL
5. **How often** the medicine should be taken: Two times a day

# Care at Home:

## Medication

Keep a current list of medications. The medication list should include prescription medications, over-the-counter medications, herbal medicines, and supplements. Medicines are changed or adjusted frequently, so it is important to update your list (especially when changes are made between clinic visits).

### Missed Doses of Medication:

- If you miss a dose of medicine, check the medication sheet or call your doctor.

### Storing Medications:

- Keep the medicines tightly capped.
- Store them in a cool, dry place away from direct sunlight.
- Do not store in an area that has too much moisture such as the bathroom.
- Keep all medicines out of the reach of children.
- Do not let the liquid medicines freeze if they require refrigeration.
- Do not store the medicine in the refrigerator unless instructed by the pharmacist.
- Do not crush or cut the tablet, capsules or caplets unless instructed to do so.



### Medication Tips:

- When giving liquid medication, be sure to measure using a syringe or medicine cup.
- Be sure to give your pharmacy at least a one week notice when filling specially made liquid medications.
- Do not use any medicine after the expiration date on the bottle or package.
- If too much medicine is taken by accident call poison control or the doctor.



# Care at Home:

## Medication

### Medication Refills Made Easy:

- Medication refills can be requested via the [myuofmhealth.org](http://myuofmhealth.org) portal or by calling 734-764-5176
- The call center fills medication requests. Please plan ahead - allow at least 3 days for a refill request.
- Waiting until the last minute to order medications or right before a holiday or vacation can be problematic. Pharmacies may have to reorder medications specially for your child if they do not have a large need for that specific medication. That takes time.

### Prior Authorizations

- Some medications require a prior authorization in order to be paid for by the insurance plan. The prior authorization can take 3-7 days or longer to obtain. In order to NOT pay out-of-pocket for your child's medication, you'll want to give staff sufficient time to send in and obtain prior authorization requests.
- Prior authorizations are generally required for compound suspensions that are not commercially made and are used by infants or children who take food and medications through an enteral tube. Examples include Omeprazole, Sildenafil, Enalapril, Aldactone, Nadolol, Propranolol and Flecainide.
- If your child's compounded medication is made here at Michigan Medicine, our pharmacy requires the Attending Physician's signature only. Be aware that if you call in your compounded medication refill request, and your physician is out of town or not available, the prescription will not be filled until a signature is obtained. Please plan ahead.

### Organizing and Tracking Medications

- Depending on how many medicines you will be giving, you can organize them on a chart so that you can easily remember what the medication is, how much you need to give and when you need to give it.
- You will receive a medication schedule to take with you at discharge with your current medications.
- Many different ideas for medicine organization can be found online.
- The After Visit Summary (AVS) will also list your medications including the last time it was given prior to discharge and the next time it is due.

# Care at Home:

## Tips and Advice from other parents

### Medication Organization and Storage:

- A tackle box or clear plastic organization container works well to transport medicines safely.
- Some families fill medication syringes a week at a time and put them in zip lock bags or a wide mouth bottle with the day and time. This also works well for refrigerated medication. Just be sure they are stored and transported safely so they don't get knocked around and accidentally lose medicine.
- If you leave the house you can grab the medication for the amount of time you will be gone.
- Please keep medications away from children and out of reach.

### Medication Schedule:

- Families find it helpful to make a check list on excel with all of the medication and feeding times. We have a 24-hr medication / feed chart available for printing.
- Put the excel sheet on the counter or hang in on the refrigerator.
- After the medication or feeding is done, check it off so all caregivers know what has been done.
- Some families also find it helpful to set an alarm on their cell phone for medication and feeds.

### Medisafe:

- A phone app with a virtual pill box that tells you what medications have been taken and what is coming up. Medisafe has a digital reminder for medication and will alert you if you miss a dose.

### Follow Up Care:

- Families find that a dietitian is helpful with getting enough calories and choosing the right foods.
- Families also think a speech pathologist is helpful with feeding.
- Resources for physical therapy, occupational therapy, and speech therapy.
  - State of Michigan: Early On; [www.1800earlyon.org](http://www.1800earlyon.org); 1-800-327-5966 (1-800-Early On)
  - State of Ohio: Help Me Grow; [www.helpmegrow.org](http://www.helpmegrow.org); 1-800-755-4769 (GROW)

### Support:

- Support comes in many ways for patients and families, both formally through our center and elsewhere! Please refer to the support section for programs and sites. Sometimes the most helpful thing is to ask family to bring meals, do laundry, and grocery shop.
- No question is silly! Never be afraid to ask!

# Notes and Questions:

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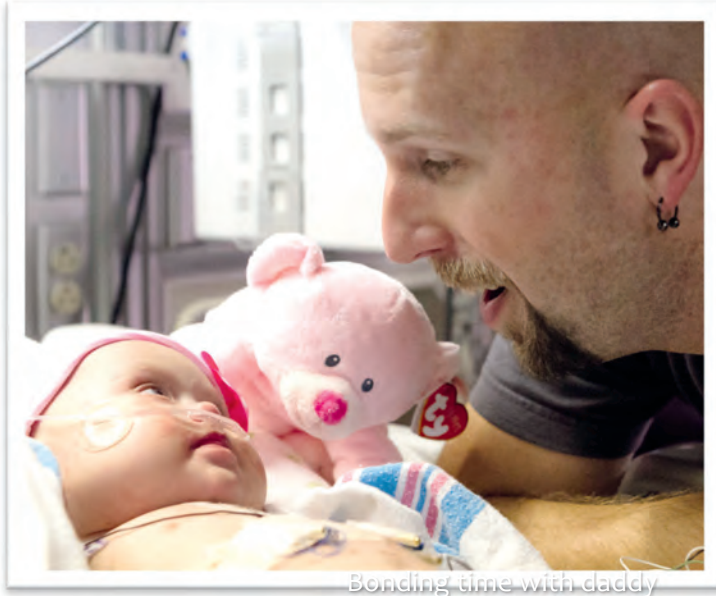
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# Patient & Family Support



*“Strength comes from struggle. When you learn to see your struggles as opportunities to become stronger, better, wiser, then your thinking shifts from I can’t do this to I must do this.”*  
–Toni Sorenson

**This section of the guidebook is designed to honestly acknowledge and address the emotional challenges which sometimes come up during a family’s heart journey. Recognizing these emotional challenges is an important step in coping. The following pages contain information on many resources to help support, inform, engage, and empower your family.**

*“You have the permission to be overwhelmed. . . When it gets overwhelming, take it one hour or one moment at a time.”*

*- Heart Mom*

# Patient & Family Support

## General Information

### A Parent's Guide to Congenital and Acquired Heart Disease:



Learning that your child has congenital or acquired heart disease) can be shocking and overwhelming. This reference was designed by parents of children with congenital heart disease (CHD), in collaboration with mental health and healthcare professionals, to provide information and resources that may be helpful for your family as you prepare for your child's heart journey.

### Feelings

When you learn of your child's diagnosis you may have many feelings. You are not alone. Parents of children with CHD have shared many of the same feelings. Some of these might include:

- Anger
- Helplessness
- Sadness
- Nothing will be ok
- Fear
- Everything is out of control

### Stress

It is normal to be stressed along your child's heart journey. Many families say the most stressful parts of finding out their child has a CHD or acquired heart illness were:

- Seeing their child sick and worrying what was going to happen.
- How their child looked after the operation or procedure—the incision, the medications and tubes are frightening.
- Not being able to feed, hold, or take care of their child.
- Worrying that their child would not know them.
- Being away from other family members and children.

This guide has been adapted from material provided by:





# Patient & Family Support

## Tips

### Coping

Parents cope in different ways. Many parents put themselves second to their child at this time. You need to take care of yourself to be in the best shape to make decisions and to support your child. Coping strategies include:

- Eating and taking care of your own health and hygiene needs.
- Getting a good amount of rest and sleep.
- Eating meals away from the hospital and being physically active.
- Asking for help is okay—lean on friends and family members to help you.
- Talking with family, friends, ministers, people taking care of your child, or other helpful support persons.
- Asking for help with household tasks, child care, or other daily activities.
- Professional mental health care can be helpful for many. For referrals, ask your family doctor, heart center social worker, or insurance company.

### Finding Answers

Many parents find that asking a lot of questions helps them learn about their child's current condition and progress.

- Write down questions as you think of them, so you have them when care providers are available.
- Don't be afraid to ask care providers to go over things more than once.
- Ask nurses and doctors to use different words if they don't explain things in a way you understand.
- You know your child best. Partner with your healthcare team to understand all treatment options and participate in decision making.
- It is your right to know what is happening, and the more you know, the more you can help.

### Development

You can develop a connection with your child and help to promote your child's development while in the intensive care unit. Some things you can do might seem small but can make a big difference:

- Ask for ways to hold, touch, and take care of your child.
- Softly talk, sing, or read to your child.
- Hold their hand, or put a hand around their head or feet.
- Leave a cloth in your child's bed that you have worn so it smells like you.
- Bring in photos for around your child's bed.
- Provide breastmilk for your child, if you are able.

This guide has been adapted from material provided by:



**NATIONAL PEDIATRIC CARDIOLOGY**  
*Quality Improvement Collaborative*

# Patient & Family Support

## Tips & Congenital Heart Center Resources

### Support and Education Resources

There are many supports available for patients and families coping with CHD or acquired heart diseases. Please see the following pages for hospital and out-of-hospital information.

#### Books/Apps

- Books for Adults: It's My Heart, HLHS Book of Hope, Single Ventricle Q&A Book
- Talking about congenital heart disease with young children can be difficult. These children's Books might help: My Brother Needs an Operation, Hayden's Heart, Riley's Heart Machine, Zipline, Charlie the Courageous, Jeremiah the CHD Aware Bear.
- There are numerous mindfulness apps (via the Android or Apple app stores) that can help with stress and anxiety. Several members of our community have found the "Calm" app to be helpful (available for free).

This guide has been adapted from material provided by:



## Social Work Team



Madelyn Gardner



Chris Kozel



Alana Oudekerk-Hans



Maria Reale



Kristin Santo

# Patient & Family Support

## Congenital Heart Center (CHC)

### Support and Resources

## Social Work

The Congenital Heart Center patient care team includes social workers who are available to all patients receiving care in the Congenital Heart Center and its offsite clinics. Our social workers focus on the personal and often non-medical questions and needs that can accompany health and illness at any time or stage of life. The social work role is varied and is dependent on the individual needs of each patient and family.

Social workers can be helpful in:

- Providing emotional support and discussing strategies for coping with stressors.
- Preparing for disruptions to the family's routine.
- Addressing questions or concerns about the safety or well-being of the patient.
- Identifying and connecting patients to local resources to meet their specific needs.
- Helping to promote effective communication and information sharing between patients, their support persons, and their care providers.
- Assisting with coordination of travel to the area, locating lodging options during hospitalizations.
- Preparing for discharge from the hospital with our Discharge Planners to ensure a safe and smooth transition home by coordinating needed support and follow up.

## Helpful Information

- Early on (home physical, occupational, & feeding therapy) – 800-327-5966
- Car seat inspections – Buckle Up! Hotline of the Pediatric Trauma Program 734-763-2251
- Deaf Access Program and Interpreter Services – 734-936-7021
- Billing and Insurance Questions: Toll-Free # 855-855-0363; Local # 734-615-0863
- Account/Hospital Registration Information – to update: Toll-Free # 866-452-9896
- Birth Certificates: 734-936-7481
- Lodging:
  - Patient/visitor Hotel Accommodations: 800-544-8684
  - Ronald McDonald House: 734-994-4442
  - Mott House: 734-232-3500
  - Guest Assistance Program: 800-888-9825

<https://www.uofmhealth.org/patient-visitor-guide/guest-assistance-program>

Social workers may contact you as part of the team, and you can request social work at any time.

# Patient & Family Support

## CHC Support and Resources



### Child & Family Life

The Child and Family Life team is made up of trained professionals with expertise in helping reduce the stress and anxiety associated with hospitalization and illness. Team members work together with doctors, nurses, social workers and others throughout the hospital to meet the emotional, developmental and cultural needs of children and their families.

Child life will be available to you throughout the Congenital Heart Center, including cardiology clinic, inpatient 11W and the PCTU. Some of the special services we offer include:

#### **Procedural Support and Preparation:**

What happens during a child's time in the hospital can be new and strange. Our Child Life Specialists can help through providing both preparation and distraction for tests and procedures.

- Teach through books/pictures and medical tools, and medical play
- Tours before surgery
- Coping tips and tools
- Create and practice a coping plan with the child, family and staff

#### **Distraction, Relaxation & Non-Pharmacological Pain Management:**

- Help children find an alternate focus before, during, and after a test or procedure.
- Various non-pharmacological pain management techniques are available, including: guided imagery, deep breathing, and relaxation techniques.

For more information, visit [www.mottchildren.org/childlife](http://www.mottchildren.org/childlife) or ask your nurse to speak with a child life specialist at the hospital.

# Patient & Family Support

## CHC Support and Resources

### Pediatric Psychology



Our pediatric psychologists provide therapy to children, teens and young adults in and out of the hospital setting to address a number of things, including:

- Coping with Illness
- Anxiety or Sad Mood
- Behavioral Challenges
- Adherence to Medical Treatment
- Pill Swallowing and Procedural Preparation
- Patient and Family Impact of Illness

In addition to the psychologists working in the CHC, the Division of Pediatric Psychology at Michigan Medicine offers many specialized clinics to meet the needs of patients and families. Some of these specialty clinics include focus on chronic and acute pain management, weight management, sleep, toileting, and feeding.

For more information on Pediatric Psychology services, visit: [www.mottchildren.org/conditions-treatments/behavioral-health/psychology](http://www.mottchildren.org/conditions-treatments/behavioral-health/psychology)



# Patient & Family Support

## CHC Support and Resources

### Patient and Family Centered Care

Patient & Family Centered Care (PFCC) is a model for providing care that recognizes and respects the uniqueness of each family and encourages and empowers families to partner with health care providers. Family members are viewed as key members of the health care team. This partnership will provide your child with the best opportunity to heal. Patient and Family Centered Care has four Core Concepts: Dignity and Respect, Information Sharing, Collaboration and Participation.

The PFCC program is based on a realization that greater success comes from working together. By assessing patient and family needs, doctors and other care team members work together with families to improve the patient and family experience at the hospital.

There are many opportunities for volunteer involvement in PFCC as an advisor. There are councils and committees that operate throughout the CHC. Volunteers may act as e-advisors, onsite advisors, mentors, and speakers, sharing your story and experience to help us improve care for all.

More information about Patient & Family Centered Care opportunities in the Congenital Heart Center is on our website at: <https://www.mottchildren.org/conditions-treatments/ped-heart/resources-congenital-heart-patients/patient-family-advisor>.

### Patient Family Centered Care During Hospitalization - Patient and Family Centered Rounds

#### What are "rounds" and what does it mean to be family centered?

- While making medical decisions can occur throughout the day, rounds are a reserved time for your medical team to gather, discuss your child's health, and plan for the day.
- "Family centered" means we welcome patient and family involvement in discussion and decision-making to the level they are comfortable, recognizing that you know your child best.
- When you share your observations and questions with the medical team you are:
  - Providing important information that may affect treatment.
  - Ensuring your access to information and transparency in care.
  - Ensuring greater safety and reducing the possibility of error.

#### What do rounds look like in a teaching hospital?

- C. S. Mott is a teaching hospital, so the medical team may discuss different topics regarding general pediatric cardiology that may not be directly related to your child. These discussions are a normal part of the medical education process and do not mean that the team is unsure of how to care for your child. This is how your team shares knowledge so that we can provide the best care.

# Patient & Family Support

## CHC Support and Resources

### Patient and Family Centered Rounds (continued)

#### When do rounds start, and where do they take place?

- Rounds occur in the patient's room unless there is a need for them to take place in the hallway.
- PCTU – Rounds begin daily at 7:30 a.m.
- **General Care - 11 W-** Rounds occur daily for children who have recently had surgery between 8:30 - 11:00 a.m.
- It is difficult to know exactly when rounds will be for your child, as your medical team will be rounding on many patients, and each day the amount of time needed for each patient varies.

#### How can I participate?

##### Before rounds, please tell your nurse or medical team:

- If you would like to participate in rounds.
- If you are available to participate in rounds.
- If you are unable to be at rounds, ask to speak with someone from the team to update you later.
- If you would or would not like to be woken up, if you are asleep when rounds occur.
- If you prefer not to have the medical team meet at the bedside.
- If you think of important questions or concerns throughout the day, write them down in your Heart Guidebook so that you will have them ready for rounds.

##### During rounds:

- Carefully listen as the care team introduces themselves and discusses your child's condition. Write down any questions or concerns you have.
- Introduce yourself and your relationship to the patient. Ask for introductions from anyone that you do not know.
- Because of time constraints, it is important to find out the realistic amount of time you can expect with your team. If you do not have enough time to go over all of your questions, you can ask to speak with someone from your child's care team later in the day.
- Ask for clarification of medical terms with which you are unfamiliar.
- Give feedback about how the treatment plan is working.
- Provide details about your child that may be helpful for making medical decisions.
- Encourage your child (when age appropriate) to take part in rounds by asking questions, contributing to the discussion, and helping to make decisions.

# Patient & Family Support

## CHC Support and Resources

### Caregiver and Patient Mentors

Our parent / caregiver and patient mentors have lived with congenital heart disease and heart illness. They understand the emotional challenges and the toll it can take on the patient and family. All mentors are volunteers at Michigan Medicine who have received training on being a mentor.

#### **Our Heart Mentors:**

- Provide a listening ear and emotional support to parents and patients in the CHC.
- Provide helpful information, guidance, and care management strategies.
- Offer a network of peers to help those experiencing a health issue to not feel alone.
- Host virtual opportunities for connection.

You can connect with a mentor in person or by phone, have a single conversation or more – whatever you find most helpful!

If you would like to connect with a mentor, tell the nurse or social worker you would like to visit with a heart mentor.

### Spiritual Care

Chaplains are clinically trained clergy/religious leaders who specialize in offering spiritual and emotional care and support to patients and their families. Chaplains listen to what is important to each person and remain sensitive to differences in culture, religion and lifestyles. Mott chaplains represent a variety of religions and faith traditions. They have a list of local congregations and can arrange a visit from a religious leader of your choosing. You can request a visit from spiritual care from your nurse.

For more information, call the Spiritual Care Department at 734-936-4041, or visit: <https://www.uofmhealth.org/patient-visitor-guide/counseling-spiritual-services>

# Patient & Family Support

## CHC Support and Resources

### Stepping Stones Program - Palliative Care

When a child is seriously ill, each person in the family is affected differently. That is why it is important that you, your loved one, and your family get the support and care you need during this difficult time. A special type of care called palliative care can help.

#### What is the difference between palliative care and hospice?

The goal of **palliative care** is to improve the quality of life for an individual who is at *any* stage in a serious illness, whether the disease is curable, chronic, or life-limiting. This care also helps support the patient and family communication with the care team. Palliative care can be provided *at the same time* as providing curative and life-prolonging treatment.

**Hospice care** focuses on providing physical, emotional, and spiritual comfort at the end stages of life. Hospice care provides no curative treatment and may not be provided at the same time as curative or life-prolonging treatments.

#### How Can Palliative Care Help Me?

Our Stepping Stones team provides an additional layer of support to improve the well-being of the entire family. Some of the ways we can help:

- Management of uncomfortable symptoms such as pain, nausea and constipation.
- Guidance with difficult treatment choices.
- Communication between your child, family and care teams.
- Emotional, social and spiritual support.

*"The first time my doctor mentioned palliative care to me, I thought they wanted to give up hope on my child. I was so upset that I didn't consider meeting the team for several more months. Looking back on it now, I wish I had met with them right off the bat. They gave all of us so much support, help, AND hope that really made our lives better. They really understood exactly what we needed. And they did it while the doctors continued to heal my child so that eventually we could all go home." - Heart Parent*

If you feel that your child, your family, or you could benefit from palliative care, please ask your child's health care providers about getting a referral for palliative care services.

You can also find more information at: [www.mottchildren.org/palliative-care](http://www.mottchildren.org/palliative-care)

# Patient & Family Support

## Sites and Resources

### Education, Support, and Advocacy Websites

The following resources provide additional information. Our center's web site is also a source of information on these topics [www.mottchildrens.org/congenital](http://www.mottchildrens.org/congenital).

#### CONGENITAL HEART DISEASE AND GENERAL INFORMATION

##### American Heart Association

<https://www.heart.org/en/search#q=congenital&sort=relevancy>

<https://www.heart.org/en/search#q=pediatric&first=10&sort=relevancy>

Camp Odayin <https://campodayin.org/>

**Cardiac Networks United** - an integrated pediatric and congenital cardiovascular research and improvement network

[www.cardiacnetworksunited.org](http://www.cardiacnetworksunited.org)

##### Centers for Disease Control and Prevention

<https://www.cdc.gov/ncbddd/heartdefects/>

##### Congenital Heart Disease, Cove Point Foundation

<http://www.pted.org/>

**Congenital Heart Public Health Consortium** - formed by collaboration of American Academy of Pediatrics, the Centers for Disease Control, and other organizations.

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/chphc/Pages/default.aspx>

##### Conquering CHD

(Formerly: Pediatric Congenital Heart Association)

[www.conqueringchd.org](http://www.conqueringchd.org)

##### Heart Safe Schools – Project ADAM

[www.mottchildren.org/projectadam](http://www.mottchildren.org/projectadam)

[www.projectadam.com](http://www.projectadam.com)

**National Institutes of Health, National Heart Lung and Blood Institute**

<https://www.nih.gov/about-nih/what-we-do/nih-almanac/national-heart-lung-blood-institute-nhlbi>

##### National Pediatric Cardiology Quality Improvement Collaborative - QI for single ventricle patients

[www.npcqic.org](http://www.npcqic.org)

##### Mended Little Hearts

[www.mendedhearts.org](http://www.mendedhearts.org)

**Sisters by Heart** - parents of children with hypoplastic left heart syndrome. This site includes regional information for the USA, Brothers by Heart, and Hope After Loss

[www.sistersbyheart.org](http://www.sistersbyheart.org)

##### The Children's Heart Foundation

check for state chapters and Facebook pages

[www.childrensheartfoundation.org](http://www.childrensheartfoundation.org)

#### ADULT CONGENITAL HEART DISEASE AND TRANSITION

##### Adult Congenital Heart Association

[www.achaheart.org](http://www.achaheart.org)

**I Heart Change** - designed for young people with CHD transitioning from pediatric to adult heart care

[www.IHeartChange.org](http://www.IHeartChange.org)



# Patient & Family Support

## Sites and Resources

### CARDIOMYOPATHY, ADVANCED HEART DISEASE, VENTRICULAR ASSIST DEVICES, AND TRANSPLANT

**Children's Organ Transplant Association** - providing fundraising assistance for transplant families

<https://cota.org/>

**ACTION Learning Network**, quality improvement for heart failure and ventricular assist device patients

[www.actionlearningnetwork.org](http://www.actionlearningnetwork.org)

**Children's Cardiomyopathy Foundation**

<https://www.childrenscardiomyopathy.org>

**Enduring Hearts** - research on pediatric heart transplant

<https://enduringhearts.org/>

**Hypertrophic Cardiomyopathy Support**

[www.4hcm.org](http://www.4hcm.org)

**Pediatric Heart Transplant Society**

<https://pediatrichearttransplantsociety.org/>

**Transplant Families** - a site managed by families

[www.transplantfamilies.org](http://www.transplantfamilies.org)

### SOCIAL MEDIA

C.S. Mott Children's Hospital –

- Facebook, Twitter, Instagram, YouTube, Pinterest, Mott Blog
- Gwen Fosse RN - Facebook

Sites of national organizations which also include state chapters:

- Action Learning Network
- The Children's Heart Foundation
- Mended Little Hearts

Sites established and managed by families

- Heart Families from Mott
- Heart Families of Western Michigan
- Hearts of Hope of Southeast Michigan
- Heart Families of Western Michigan
- Michigan Heart Families

There are many well-intentioned and informative Facebook pages and websites, but it is always recommended that you research any site to know who manages it and if it has a medical review board.

*Always* consult your own cardiologist regarding you/your child's care.

Disclaimer: This document contains information and/or instructional materials developed by Michigan Medicine for the typical patient with your condition. It may include links to online content that was not created by Michigan Medicine and for which Michigan Medicine does not assume responsibility. It does not replace medical advice from your health care provider because your experience may differ from that of the typical patient. Talk to your health care provider if you have any questions about this document, your condition or your treatment plan.

# Special Programs

The Congenital Heart Center has an extensive range of programs and clinics to serve patients and families with various conditions and specific needs. To learn about these go to: <https://www.mottchildren.org/conditions-treatments/ped-heart/programs-and-clinics>. A few examples of special programs are included here.

## Research and Innovation

Being treated at a teaching hospital means that many of your child's care providers are also leaders in clinical research. Clinical research studies have the ultimate goal of curing disease and improving quality of life. These studies allow members of your health care team to find the most effective care methods. There are hundreds of U-M researchers who work hard to improve treatment, detect and prevent disease, and educate families about serious health conditions. In fact, current treatment options are often based on prior research. Medical research often helps us advance care for our patients.

It is possible that your child may be eligible to participate in a research study. Participation offers hope and a partnership with researchers to find better treatments and advance medical knowledge around the world. If someone approaches you regarding a specific study, know that participation is always optional. We encourage you to speak with your health care team about research opportunities or any concerns.

<https://www.mottchildren.org/conditions-treatments/ped-heart/research-and-innovation>

## Patient Reported Outcomes – Longitudinal Follow-up Program

At the University of Michigan Congenital Heart Center, our overall goal is to optimize treatments that will allow children with congenital heart disease to thrive and enjoy an excellent quality of life into adulthood. To accomplish this goal, we believe it is important to understand your child's outcome over their entire lifespan, beyond just the in-hospital or immediate post-operative period.

Through our Longitudinal Follow-up Program, we have incorporated long-term assessment of outcomes into our standard clinical practice. Your care team at the University of Michigan Congenital Heart Center will communicate with you and your referring doctors throughout your child's course of treatment and subsequent follow-up in order to understand these important aspects of your child's care and treatment over the long-term.

If you have any questions about this program, please contact:

**Suzanne Viers**, Program Coordinator

Email: [spolliey@med.umich.edu](mailto:spolliey@med.umich.edu)

Phone: (734) 232-7115

# Special Programs

## Neurodevelopmental Follow-up

Our Congenital Heart Center Neurodevelopmental Follow-up Clinic can help families to identify emerging follow-up delays. Although many children with heart disease are thriving, research shows that children who need cardiac surgery during the first year of life are at higher risk for developmental, learning and behavioral concerns later in life.

The types of challenges faced by children with heart disease may vary by age. For example, infants may be more likely to have delays in motor skills, such as head control or movement. School-age children or adolescents may have problems with school performance, particularly the self-regulation skills that enable them to plan, focus attention, remember instruction and successfully juggle multiple tasks. Even though some children may not have any obvious developmental or learning problems, they may benefit from periodic assessments at the Congenital Heart Center Neurodevelopmental Follow-up Clinic. <https://www.mottchildren.org/conditions-treatments/ped-heart/programs-and-clinics/neurodevelopmental-clinic>

## Heart-Safe Schools: Project ADAM

Our community outreach service includes helping schools to become heart safe schools through our affiliation with Project ADAM. When schools are prepared for responding to a cardiac emergency, it makes a whole community safer. <https://www.mottchildren.org/conditions-treatments/ped-heart/project-adam>

## Education Specialist

Our Congenital Heart Center education specialist and hospital teachers work alongside our medical teams to serve as the bridge between the medical setting and the school community. They can assist patients and families in navigating school challenges, educational services, such as IEP (Individualized Education Program) and 504 Plans, and a return to school following illness or hospitalization. To meet with our education specialist, please ask your cardiologist or social worker.

## .....And More

Remember to go to <https://www.mottchildren.org/conditions-treatments/ped-heart/programs-and-clinics> for more information about programs in the Congenital Heart Center.

# Notes and Questions:

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Author: Congenital Heart Center Guidebook Committee

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