Texas Center for Pediatric and Congenital Heart Disease

Patient and Family Handbook

dell children's
Ascension

The University of Texas at Austin
UT Health Austin

An introduction to our handbook

Facing a diagnosis of congenital heart disease can feel overwhelming. You likely have many questions, concerns, and even some fears. We created this handbook to provide you with information and resources to support you through your congenital heart journey. The handbook also includes a special section where you can keep important medical information and details about your care.

You are an important part of the care team, and we look forward to working alongside you to achieve the best possible outcomes.

We hope you find this handbook to be a helpful source of information and support throughout this journey.

With gratitude,
Your Dell Children's Congenital Heart Team

> “Learning your child has a diagnosis can be scary and destabilizing to you and your family. The good news is that you will get through this. Your family has the opportunity to grow closer in love for one another. You and your child may also develop a richer attitude of thankfulness when you see how many people have dedicated their life’s work to caring for children like your child and mine.”

-Deanne, Dell Children’s Heart Mom

To our patients and families,

It is our privilege to welcome you to Dell Children's Medical Center and the Texas Center for Pediatric and Congenital Heart Disease. We know that having a diagnosis of heart disease in your child, friend, family member, or yourself is one of the greatest challenges one can face. We have put together this handbook to help on this journey. Our mission is to surround you and your loved ones with the highest level of care, compassion, and respect. Please know that we honor the trust you place in us, and we offer our solemn commitment to your care.

Yours sincerely,

Charles D.

Charles D. Fraser, Jr., MD, FACS, FACC
Chief, Pediatric and Congenital Heart Surgery
Director, Texas Center for Pediatric and Congenital Heart Surgery
Professor of Surgery and Perioperative Care – The University of Texas at Austin, Dell Medical School

Dear Fellow Heart Family,

I am so glad that you have found Dell Children's and are now part of the Dell Children's Heart family. While we know that this is such a delicate time in your life and you face many challenges ahead, as a fellow heart family who received all of our care here at Dell Children's, I wanted to ease your mind that you are in the best possible place to receive the most wonderful care. The care here at Dell Children's is world class. From the line cooks in the cafeteria, the cleaning service who comes into the room with a smile, and all the way up to the world-renowned surgery team, they are here for you every step of the way. The team here at Dell Children's is a part of your journey throughout life, and they are rooting for you every step of the way!

My daughter spent 155 days here in the Cardiac ICU, where we met so many wonderful people. From the nurses, cardiologists, anesthesiologists, and everyone in between, this team has been the biggest cheerleader for my daughter. Their goal is to surround the patient and family with compassion and respect, and they are here through all the ups and downs.

Whether you are just now beginning on your family's heart journey or you are a seasoned heart family, the level of respect and care from the team remains unparalleled. This handbook has many great resources, and there are people at every corner waiting to help. From one heart family to another, we are cheering you on.

Yours truly,
Eva-Ann's mom

To my fellow heart families,

We were once in your position; feeling the weight of an impossible decision on our shoulders. The choices from our past; the ones that we made for ourselves that at the time were so "important" now seem so distant and silly. This time you are choosing for your child; your entire world and who you live for. We were there just a couple years ago. At the start, we had traveled for our daughter's care because that's what we needed to do. When Addie's surgeon moved to Austin, our hometown, we combed through all the factors and possibilities. Would moving care be the right decision? Though, what is really on your mind is, will it be the wrong one? I can't offer you the answer as to what is best for your family, and your heart warrior. What I can offer is our experience and advice from the decision we made just over two-and-a-half years ago.

We discussed the options with our family and confided in our favorite local cardiologist. What we heard from everyone, and what you are hearing now, is that the decision is ultimately yours to make. For us, we decided to completely transfer care to Dell Children's. I can honestly say we have never looked back. Our regrets amount to zero.

It was more than being close to home, it was the love and personal care that Addie received that brought us relief. The relief of feeling we had made the right decision and knowing our daughter was in good hands. It was the kind of specialized care we had always wanted for Addie. Not just experts in cardiac care, but a truly compassionate team with a focus on her as an individual, and her needs. Remember that wherever you go, a cardiac team is not complete unless it includes you! I really learned this during our time at Dell Children's. We really felt like part of the team and that our input was not only heard, but solicited.

I've heard the saying in the heart community that, "The worst heart defect to have is the one your baby has." To parents, these words ring so true. It doesn't matter what people have said to you or what you have read, know this, it's irrelevant how "simple" or "complex" people say your baby's heart defect is. We have felt the same pain you are feeling now. We are all in the same boat; just trying to make the best decision for our kids. We want you to know that choosing Dell Children's was the best decision we could have made for our daughter. It has been a blessing that we can never repay. We will always have a deep appreciation for everyone that cared for Addie during her time there, and we carry a special love for the surgeon that quite literally touched our daughter's heart.

Sincerely,
Addie's mom

Dear Prospective Adult Heart Patient,

Welcome! As a recent adult congenital heart patient at the Texas Center for Pediatric and Congenital Heart Disease at Dell Children's, I would like to welcome you. The program you are about to become a part of has many top-notch professionals who will help you and your family from beginning to end.

For me, the process of getting my heart repaired was a long and difficult journey. I was born with several pediatric heart conditions that have affected my life in different ways. Before surgery, I started working with the team psychologist weekly to work through several issues. Having that unique support was something that helped me in numerous ways.

One reason why I chose Dell Children's is that they treat the whole person and their family. This is true for both pediatric and adult patients. My wife was able to be with me in the hospital the entire time, which was comforting to me. Each person we met was first-rate and fully dedicated to their jobs. No matter how busy things were, each time I needed something the staff would not leave the room until all my needs were addressed. As a person who is blind and hard of hearing, I was grateful that Dell Children's accommodated me and my disabilities. They even allowed and encouraged me to wear my hearing aids when entering the operating room so I could hear everything I needed to before anesthesia.

After my surgery, when I returned home, the real part of my recovery began. At this writing, it has been seven weeks since my surgery. I am making slow but steady progress, going through post-surgery physical therapy, and still meeting with the psychologist. I can see a difference in how I feel, and in my stamina, now versus before the surgery.

As an adult patient, please know that you will get the best treatment here. You will have the commitment of each staff member and medical professional. What I've been through has not been easy, but the Dell Children's staff helped me through each step of the process.

You will meet many people along your heart journey. You can take comfort that each person here is dedicated and passionate about their jobs and how they help patients and families. No matter how tough things have been, there were people to help and walk alongside me in my journey. I wish the same, along with a speedy recovery, for you.

Sincerely,
Wayne

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About the Texas Center for Pediatric and Congenital Heart Disease Program

The Texas Center for Pediatric and Congenital Heart Disease — a partnership between Dell Medical School and Dell Children's — diagnoses, treats, and manages the care of children and adults with pediatric and congenital heart disease. Led by Chief of Pediatric and Congenital Heart Surgery, Charles Fraser, Jr., MD, who has been part of some of the finest institutions in medicine, our team provides world-class, family-centered care.

Our treatment approach

The Texas Center for Pediatric and Congenital Heart Disease care team is capable of treating rare and complex cardiac cases to ensure the best possible outcomes. Patients are cared for by a dedicated interdisciplinary care team, meaning you will benefit from the expertise of multiple specialists across a variety of disciplines. Our fellowship-trained and board-certified physicians have extensive experience treating heart disease in patients of all ages and work alongside a team of pediatric and congenital cardiac experts, including cardiologists, cardiothoracic surgeons, interventional cardiologists, critical care specialists, hospitalists, anesthesiologists, perfusionists, nurses, advanced practice providers, social workers, psychologists, child life specialists, dietitians, physical and occupational therapists, pharmacists, respiratory therapists, cardiac sonographers, and more, providing unparalleled care for patients and their families every step of the way.

Conditions we treat

The Texas Center for Pediatric and Congenital Heart Disease is comprised of highly specialized pediatric and congenital cardiac care providers experienced in treating a variety of conditions. See our website for a full listing of conditions we treat: https://partnersincare.health/texas-center-for-pediatric-and-congenital-heart-disease/conditions

Services we provide

Our program provides a number of comprehensive cardiac care services for patients throughout their lives.
Specialties within our program include:

- Cardiac Fetal Program
- Cardiac Neurodevelopmental Outcomes Program
- Coronary Anomalies Program
- Heart Failure, VAD, and Transplant Program
- Single Ventricle/IMPACT Program
- Adult CHD Program
- Interventional Cardiology
- Electrophysiology

See our website for a full listing of services we provide:
https://partnersincare.health/texas-center-for-pediatric-and-congenital-heart-disease/services

Dell Children's information

Location and parking information

Main Hospital Address: Dell Children's, 4900 Mueller Blvd., Austin, Texas 78723
The Cardiac Care Unit (CCU) is located on the 2nd floor of the hospital (2 North). Of note, when you enter the hospital, you are on the 3rd floor, so you go down one floor to the CCU.

Main Hospital Phone: (512) 324-0000

Outpatient Clinic Address: 4910 Mueller Blvd., 1st floor, Austin, Texas 78723 (Dell Children's Specialty Pavilion).
Clinic hours are Monday through Friday from 8:00 a.m. – 4:30 p.m.

Clinic Phone: (512) 324-0091

Parking at Dell Children's Staff & Visitor Garage is always free! There are currently two parking areas for visitors, as illustrated on the parking map below.

- The Blue parking garage is for hospital patients and families (please, do not park in Strictly Pediatrics Parking Garage as this garage is for their clinic and charges money to park).
- The Green Parking Garage is for Specialty Pavilion clinic patients and families.

More detailed information can be found online at: https://www.dellchildrens.net/about-us/parking/

Getting around the hospital

Hospital Maps

The inpatient Cardiac Care Unit (CCU) is located on the 2nd floor (2 North)

The main entrance to the hospital is located on the 3rd floor

The Neonatal Intensive Care Unit (NICU) is located on the 4th floor

> **"Be an active part of your medical team. Learn about your condition, ask questions, and know about your care. Your input matters."**
>
> -Chris,
>
> Dell Children's Adult Heart Patient

Helpful hospital phone numbers

Phone Line	Phone Number
Main Hospital Number/Operator *Hours: 24/7*	(512) 324-0000
Emergency Department *Hours: 24/7*	(512) 324-0150
Texas Center for Pediatric and Congenital Heart Disease *Clinic Hours: M-F, 8 a.m. - 4:30 p.m.*	(512) 324-0091 (512) 380-7532 (fax)
Information Desk *Hours: M-F, 8 a.m. - 4 p.m.*	(512) 324-9999 ext. 86592
Hospital Admissions/Registration *Hours: M-F, 8 a.m. - 4:30 p.m.*	(512) 324-0159
Inpatient Cardiac Care Unit (CCU) *Hours: 24/7*	(512) 324-0200
Gift Shop *Hours: M-F 8:00 a.m. - 8:00 p.m.; Sat. 10:00 a.m. - 4:00 p.m.; Sun. 11:00 a.m. - 3:00 p.m.*	(512) 324-0147
Patient Liaison/Feedback Line *Hours: M-F, 9 a.m. - 6 p.m.*	(512) 324-0109
Medical Records/Health Information Management *Hours: M-F, 8 a.m. - 4:30 p.m.*	(512) 324-0180
Hospital Security *Hours: 24/7*	(512) 324-0160
For Questions About Hospital Billing *Hours: M-F, 8 a.m. - 4:30 p.m.*	(512) 324-1125 or (800) 749-7624
For Questions About Dell Children's/Seton Physician Billing *Hours: M-F, 7 a.m. - 5:30 p.m.*	(512) 324-8960

Local resources

Location accommodations

When families travel from out of town to seek treatment at Dell Children's, there are several lodging options. We have compiled a short list for your convenience. This is not an endorsement of these entities, nor is it a guarantee of any listed rates. Speak to a social worker with the program if you have specific questions or needs.

Ronald McDonald House: (512) 472-9844 or https://rmhc-ctx.org/
Ronald McDonald House can be used by families who live more than 25 miles away from the hospital. The patient must be age 21 or under to qualify. Ronald McDonald House asks for a donation of $20 per night, but no family is ever turned away if they can't pay. The house is located across the parking lot from Dell Children's and parking is free. A social worker must request a reservation on your behalf.

Residence Inn by Marriott – University Area: (512) 469-7842
The Residence Inn is located within walking distance and offers a medical rate (currently $109/night). Each room has a kitchenette, and pets are allowed. Complimentary breakfast is also provided. Parking is free. Call the hotel directly and ask for the medical rate to book.

Holiday Inn – Austin Midtown: (512) 451-5757
The Holiday Inn is located about 2.5 miles from Dell Children's and offers a medical rate (currently $79/night). Suites with kitchenettes are available. There is an on-site restaurant where kids eat free. Parking is free. Call the hotel directly and ask for the medical rate to book.

Extended Stay America – 8 Austin locations: https://www.extendedstayamerica.com/?CorpAccount=992878647564
Extended stay offers eight locations with medical rates (currently ranging from $35/night to $79/night). Book on their website above to choose your location and to get the promotional rate or call one of the Austin locations and ask for the "Seton Austin Rate."

Medicaid Transportation Program: Call the number on the back of your Medicaid card
If your child (under age 20) has Medicaid, you may be able to get help with mileage, meals, and lodging while your child is hospitalized.

Austin-East KOA campground: (800) 562-8743 or https://koa.com/campgrounds/austin-east/
For families with RVs, there is a KOA RV park about 8 miles from Dell Children's. Call for availability and reservation information.

Airbnb: https://www.airbnb.com/
Some families choose to book private accommodations for their stay in Austin. You can find a number of properties located in the Mueller neighborhood through Airbnb.

Local transportation options

Capital Metro Bus Service: https://www.capmetro.org/

zTrip (formerly known as Yellow Cab Austin): https://www.ztrip.com/austin/ or 512-452-9999

Rideshare: uber.com and lyft.com

Local shops and restaurants

Dell Children's is located in the Mueller area of Austin. This mixed-use urban village includes 400,000 square feet of retail shops. You can read more here about the variety of retail stores, restaurants, banks, parks, and trails within walking distance of Dell Children's: http://www.muelleraustin.com/retail/regional/

Your Congenital Heart Care Team

You will meet a number of different healthcare providers along your heart journey. Here are some of the most common providers you may meet, with a description of what they do.

Cardiac Intensivists

Cardiac intensivists are the primary doctors in charge of care while the patient is receiving ICU-level medical care in the Cardiac Care Unit. These specialized doctors are in charge of directing all medical care for the patient.

Cardiologists

Cardiologists are the doctors who specialize in pediatric and congenital heart disease. Many specialize in one aspect of heart care, such as heart rhythm, catheterization, or imaging. You will have a primary cardiologist, but other cardiologists may also be involved in your treatment plan.

Cardiac Hospitalists

Cardiac hospitalists are the hospital pediatricians in charge of care while the patient is receiving step-down-level medical care in the Cardiac Care Unit. This level of care is typically a “step down” from ICU-level medical care. These doctors are in charge of directing all medical care for the patient.

Neonatologists

Neonatologists are the primary doctors in charge of care while the patient is receiving care in the NICU. These specialized doctors are in charge of directing all medical care for patients in the NICU. They also help the cardiac intensivists and cardiac hospitalists to manage issues specific to newborn patients in the CCU.

Advanced Practice Providers

Nurse practitioners and physician assistants work under the direct supervision of the physicians and surgeons, and participate in many different aspects of the diagnosis and treatment for patients with CHD.

Case Managers

During your hospital stay, case managers are available to help coordinate any outpatient therapies, medical supplies, or specialized medications you may need prior to discharge home.

Operating Room Team

There are several important providers who help care for the patient in the operating room. In addition to the primary surgeon, there is an assistant surgeon, several nurses, scrub techs, perfusionists, anesthesiologists, and other medical support staff.

Radiology

The patient may need different types of imaging performed during their hospital stay, which may include X-ray, ultrasound, CT scan, or MRI. These images are performed by trained radiology techs and are read/interpreted by radiologists (specially trained doctors).

Cardiac Anesthesia Team

Cardiac anesthesiologists and nurse anesthetists are specially trained in the use of anesthesia for cardiac patients. This team uses a wide range of anesthesia techniques during surgery (or other procedures requiring sedation) to meet the needs of each patient.

Lactation Consultants

Lactation consultants are registered nurses who provide expert education and assistance around breastfeeding and lactation.

Cardiac Perfusionists

Perfusionists are members of the cardiac operating room team. They manage the heart-lung bypass machine, which puts oxygen into the blood, takes carbon dioxide out, and moves blood throughout the body. When a patient is on the machine, the perfusionist controls the patient’s blood pressure, temperature, and other vital signs under the direction of the team physicians.

Rehab Therapists

Rehab therapists will work with patients to help maximize physical and cognitive potential in order to prepare for safe discharge home. Physical therapists focus on gross motor skills like getting out of bed and walking. Occupational therapists work on fine motor and self-care tasks like bathing, dressing, and feeding. Speech-language pathologists specialize in communication, cognition, and feeding difficulties.

Patient Care Technician (PCT)

PCTs do a variety of things to support patients. They assist with personal care and activities of daily living, report findings or changes in the patient's condition to nursing staff, assist in patient transport to and from the unit, help keep patient rooms neat and clean, and maintain medical equipment.

Nurse Navigators

These are specialized cardiac nurses who help guide patients and their families from surgery consultation, through the hospital stay, to discharge home. They provide coordination and support to families and provide medical teaching so families are confident in caring for the patient once they return home.

Pharmacists

Hospital pharmacists ensure medications prescribed to patients are the correct medications, using the correct dosages, and following appropriate administration schedules. They may also recommend certain medications to the treating physicians based on their expertise.

Respiratory Therapists

Respiratory therapists are specialized professionals who provide care for the lungs. They work closely with the physicians and nurses to recommend treatment options to ensure comfortable breathing and adequate airway clearance for patients.

Clinical Dietician

Clinical dieticians are registered nutrition professionals who address specific dietary concerns important to heart health and recovery from surgery. Our dietitians will work with you to identify and manage any specific nutritional concerns.

Nurses

Registered nurses assess each patient's condition and provide direct bedside care, as well as emotional support, information, and education. There are a variety of specialized nurses who will be directly responsible for care along your journey, from pre-operative appointments, through surgery, to post-operative care.

Psychosocial Team

This team includes certified child life specialists, licensed social workers, licensed psychologists, and chaplains. The psychosocial team provides supportive care to help patients and their families adjust to the emotional impact of life with CHD. This team has a variety of tools and techniques to help optimize each family's social, emotional, mental, and spiritual growth.

Expressive Therapies

The expressive therapy team consists of board-certified music and art therapists. Using music and art, these professionals facilitate opportunities for patients and families to express feelings, problem solve, process procedures/diagnoses, and generally increase coping skills throughout hospitalization.

Cardiac Sonographers

Cardiac sonographers are specially trained professionals who perform ultrasounds on the hearts of adults and children with suspected or confirmed congenital heart disease.

Cardiac Genetics

Because many children and adults with congenital heart disease also have associated gene differences, there is a team of people dedicated to studying and treating patients with identified gene differences.

> **"The CHD journey is not a straight path. It will have turns and sometimes you will go backwards, but you will make progress."**
>
> -Dave, Dell Children's Heart Dad

Dell Children's is a teaching hospital, so you may see various student learners during your time here. All trainees are supervised by experienced practitioners from their discipline (medicine, nursing, physical therapy, etc.).

All about heart surgery

Many patients with congenital heart disease require surgery at some point in their life. The information here is meant to prepare patients and families for the surgery journey.

Surgical consultation

If your cardiologist refers you for possible heart surgery, you will get a phone call from our surgery office to set up a consultation appointment. If you are currently in the hospital, the consultation may take place at the bedside.

What to expect:

Your consultation will include a visit with our whole team. You will be asked to complete some paperwork upon your arrival to our clinic.

- The nurse or advanced practice provider (physician's assistant or nurse practitioner) will meet with you first to discuss important medical history and to learn more about your family.
- You will also meet with a member of our psychosocial team (clinical social worker, psychologist, and/or child life specialist). Part of the meeting includes assessment tools that tell us how your whole family is doing — these tools allow us to provide comprehensive, supportive care that is meaningful to your family.
- You will then meet with the surgeon to review the diagnosis, discuss surgical options, and hear the surgeon's recommendations. The surgeon might also recommend additional tests that need to be completed before the surgery date.
- Finally, you will meet with the cardiac surgery nurse navigator who will help you to obtain any medical clearances needed before surgery, and will serve as your main point of contact leading up to surgery.

What to bring:

- Parent or adult patient's ID and patient's insurance information.
- A list of procedures or surgeries the patient has had in the past; any other important health history (allergies, dietary restrictions, etc.).
- Current medication bottles or a clear photo of the bottles with all prescription information visible.
- Any questions you might have for the surgeon.
- Any emotional or practical concerns you might have for the psychosocial team (coping or mental health concerns, family concerns, financial concerns, developmental considerations for the patient, school or employment questions, etc.).

Getting ready for surgery

If you were seen in our clinic for consultation, our surgery scheduler will reach out to you (generally within 1 – 2 weeks of the consultation appointment) about possible surgery dates. If you are currently in the hospital, someone will come meet with you about a surgery date.

Please understand that even once you have a surgery date, it may be changed due to the patient becoming sick or surgical emergencies that occur with other patients. We do our best to try to avoid this, but some circumstances are beyond our control. If this happens, our scheduler will reach out to you to let you know about the change and to talk about other possible surgery dates.

What you need to do:

- Work on getting the medical clearances and tests needed before surgery. Call our office if you are unsure about what you need to do.
- Stay healthy! The patient must be healthy for the 6 weeks leading up to surgery; otherwise surgery may need to be delayed. Symptoms that may lead to a delay in surgery, and reasons to call us, include cough, congestion, runny nose, fever, vomiting, or diarrhea. If you are unsure about a symptom, please call us.

- If the patient is a child, talk with your child and their siblings, as appropriate, about the upcoming surgery. We recommend talking to children in an honest, developmentally appropriate way about their condition and their surgery. See the handbook section starting on page 20 on coping for helpful tips and information. Reach out to our psychosocial team if you have questions or need guidance.
- Think about logistical plans for the surgery (who will care for children at home, what you need to do to take time off from work, how you will get to the hospital, etc.). Reach out to the psychosocial team if you have questions about, or need help with, things like insurance, lodging, FMLA paperwork, school absence notes, etc.

Pre-operative testing appointment (PAT or "pre-op appointment")

You will need to come to the hospital for a pre-operative appointment a few days before surgery. Some patients are admitted to the hospital a few days before surgery for this pre-operative testing and appointment(s).

What to expect:

- PAT appointments can last up to 4 – 5 hours, so please plan accordingly for a long day.
- During the appointment, you will meet with a pre-op nurse, a cardiac surgery advanced practice provider, the cardiac anesthesia team, and other providers.
- A child life specialist will also be available to meet with children (pediatric patients, siblings, and children of adult patients) to talk about what to expect on surgery day.
- You will have tests and labs, usually including a blood draw, nasal swab, EKG, and a chest X-ray. Other tests in addition to those listed may be needed.
- You will be told what time to arrive on surgery day, when the patient needs to stop eating and drinking, and any other special instructions as needed (such as bathing with special antiseptic skin cleanser wipes the night before surgery to help prevent infection).
- Ask for a written copy of this information or take notes in the notes section of this handbook.

What to bring:

- Parent or adult patient's ID and patient's insurance information.
- A list of procedures or surgeries the patient has had in the past; any other important health history such as previous reactions to anesthesia (allergies, dietary restrictions, etc.).
- Current medication bottles or a clear photo of the bottles with all prescription information visible.
- Any questions you might have for the surgery team or anesthesiologist.
- Patients ages 18+ should bring a copy of their advance directive forms (ask a social worker if you need these forms).

Other things to think about:

- Make yourself available to talk with children and their siblings about the upcoming surgery. Use tips from the child life specialist to have honest, developmentally appropriate conversations.
- Confirm your plans are in place for practical concerns (you have someone to care for children at home, you have a way to get to the hospital, you have a post-op plan to stay locally if you live out of town, etc.). Reach out to the psychosocial team if you have questions or concerns about these things.

Surgery day

When you arrive at the hospital on surgery day, you will check in at the same area where you were seen for your pre-operative appointment.

What to expect:

- The patient will be brought back to a pre-op room. The team will check all vital signs. The patient will complete another set of antiseptic skin cleanser wipes and change into hospital pajamas.
- You will meet with multiple medical team members, including the cardiac surgery advanced practice provider and the cardiac anesthesiologist.
- When it is time for the patient to go back to surgery, caregivers will have a chance to walk with them as they move toward the operating room hallway. At that point, caregivers can give the patient a hug and say, "see you later."
- A team member will take the caregivers to the cardiac surgery consultation room while the patient is in surgery. The cardiac nurse navigator will provide updates every 1 – 2 hours throughout surgery so caregivers know how things are going.
- When surgery is complete, the surgeon will come out to speak with caregivers about how the surgery went.
- The patient will be brought back to the Cardiac Care Unit (CCU) after surgery. The surgery team will provide a hand-off to the CCU medical staff. Expect this to take anywhere from 60 – 90 minutes. After this period, caregivers will then be allowed to come into the CCU to be with the patient.
- The patient may have several lines and IVs when they come out of surgery. They also may or may not have a breathing tube. This is all typical. As the patient becomes more awake, alert, and active, the lines and equipment will be taken out over the next few days.
- Two parents/caregivers are welcome to stay at the patient's bedside 24 hours per day. All other visitors must follow the visitation hours. All visitors must be well and without any contagious illness.

Please note that hospital visitation policies are always subject to change based on current infection rates in the hospital or community, or other public health/safety concerns.

What to bring:

- Parent or adult patient's ID and patient's insurance information.
- Any last-minute questions you might have for the medical team.
- A bag for the patient that includes comfortable pajamas/clothes that button up, a familiar stuffed animal or other comfort item from home, favorite activities or games, special snacks or food that might not be available in the hospital.
- A parent/caregiver bag that includes any comfortable bedding from home (hospital pillows and blankets can also be provided), a change of clothes for one week, toiletries, cell phone and charger, meals or snacks from home (you will have access to a refrigerator and a microwave in the family waiting room).
- Current medication bottles or a clear photo of the bottles with all prescription information visible.
- The blood typing wristband that was provided to you at the pre-operative testing (PAT) appointment.

Getting ready to go home after hospitalization

Before the patient can leave the hospital, there are few important things that will need to happen. You can read more about what to expect in the hospital on page 14.

What to expect:

- The patient must be able to eat, drink, and be up and moving around as they normally would before going home.
- The patient must also be able to urinate, pass gas, and have a bowel movement before going home.
- Pain must be under good control with oral medication.
- Parents/caregivers must receive discharge teaching from the cardiac surgery nurse navigator. This education includes wound care instructions, sternal precautions, etc.
- You will receive the post-operative clinic appointment and follow-up cardiology appointment as part of the discharge paperwork.

Please remember that if you are from out of town, your surgeon may require you to stay locally in Austin until the post-operative clinic appointment. Talk with the social worker if you have questions or concerns about this.

What you need to do:

- Make sure you understand the care required for the patient at home. Ask questions if there is something you do not understand.
- Make sure you are able to get all prescription medications filled. Make sure you understand the types of medications to give the patient at home, as well as how much and how often to give them.
- Think about who you can ask for help in caring for the patient or household once you return home. Take advantage of people who offer to help or support you.
- Call the patient's primary care provider to make a follow-up appointment within one week of discharge.
- Make sure you have transportation to your follow-up appointments. Reach out to the social worker if you have questions or concerns about this.

Post-operative appointment

About one week after release from the hospital, you will come to our surgery clinic for a follow-up appointment.

What to expect:

- Post-op appointments can last up to 2 – 3 hours, so please plan accordingly.
- The patient will see the cardiac surgery advance practice provider. The incision will be examined, and stitches will be removed if they weren't removed in the hospital.
- The child life specialist can be available, with advance notice, if the patient would benefit from support during this visit.
- The patient will also have a chest X-ray. The patient may need other tests in addition to this — we will let you know if this is the case.

What to bring:

- Parent or adult patient's ID and patient's insurance information.
- Current medication bottles or a clear photo of the bottles with all prescription information visible.
- Questions and/or concerns about the patient's care.

What you need to do:

- Make sure you keep your other follow-up appointments as recommended (cardiologist, primary care provider, etc.).

Ongoing medical care after surgery

After the patient has been seen at the post-operative appointment, their primary care doctor and primary cardiologist will resume their regular medical care. These doctors will be the primary point of contact for anything related to the patient's heart or overall health.

The cardiologist's office will tell you how often they want to see the patient, which may depend on the diagnosis and any other medical conditions the patient has.

If you have a surgical concern, like a problem with the wound, feel free to call the surgery clinic to speak to a medical provider.

About cardiac anesthesia

Many cardiac tests and procedures, including surgery, require anesthesia. Families often have questions about going under anesthesia. Here is some information from our chief of cardiac anesthesiology, Dr. Erin Gottlieb.

What to expect:

- A cardiac anesthesiologist manages the care and treatment in providing pain relief during and immediately after surgery.
- The anesthesiologist and all members of the anesthesia team are specially trained to provide care to patients with congenital heart disease.
- Before surgery, the anesthesiologist will meet with you to discuss what type of anesthesia will be used and how it will be given. They will also address any questions that you have concerning potential side effects and the patient's experience during and after surgery.
- During surgery, the anesthesiologist will provide medications to ensure the patient's comfort and safety. The anesthesia care team monitors the patient's vital signs, watching for changes in heart rate, breathing, and blood pressure, making adjustments in the anesthesia to keep the patient comfortable.
- After surgery, the team will closely monitor the patient as they emerge from anesthesia. Some patients are fully alert while others are groggy and sleepy for several hours. In addition, nausea and vomiting can occur as a side effect of the anesthesia. The anesthesiologist and the CCU team work together to reduce any side effects and implement a pain control plan to make the patient's recovery as comfortable as possible.

Risks of anesthesia

- Even though anesthesia is much safer today than ever before, every anesthesia exposure and surgery has an element of risk. In fact, it may be difficult to separate the risks of anesthesia from the risks of the surgery itself. Anesthesia is used to take away pain and discomfort from the patient and make it easier for a procedure to be accomplished in the best way possible. These benefits must be weighed against the risks of anesthesia itself.
- The specific risks of anesthesia are like that of any medication. Each type of anesthetic has a specific set of risks and side effects associated with it. The anesthesiologist will talk to you about the various types of anesthesia that may be used for the patient and the advantages and disadvantages of each kind.

Safety announcement from the U.S. Food and Drug Administration:

- The U.S. Food and Drug Administration (FDA) issued a safety announcement on Dec. 14, 2016, regarding the potential effect of anesthetics on children younger than 3 years of age. This includes:
  - A single, short exposure to anesthesia appears to be safe.
  - There is some evidence that longer (>3 hours) or repeated exposures could have negative effects on behavior or learning.
  - Much more research is needed.

Other factors to consider:

- Because anesthesia or sedation is necessary during most surgeries/procedures to keep the patient safe and comfortable, discuss the following items with your doctor before your procedure:
  - Should the procedure be done now or when the patient is older?
  - How long is the procedure expected to take?
  - Will repeated or additional procedures be needed?

About the Cardiac Care Unit (CCU - 2 North)

During your hospital stay, the patient will likely stay in the Cardiac Care Unit (CCU). This unit was created specifically for children and adults with congenital heart conditions and is run by a multidisciplinary team of specialized healthcare providers who work together to care for the patient. Our unit has both intensive care, for patients whose conditions are more complicated and require more monitoring, and step-down care, for patients who need less monitoring and are typically closer to being able to go home. When patients are in intensive care, they will be checked on more frequently, and the nurse taking care of them will have only one to two patients, whereas when patients are more stable and in step-down, they will be checked on slightly less frequently and their nurse can have up to three patients. For the duration of your stay, you will be taken care of by professionals with experience caring for patients with congenital heart conditions.

In-room accommodations for families:

Each room on the unit is private and has a fold-out daybed for two parents/caregivers. We can supply you with pillows and blankets. Each room also has a private bathroom with a shower, a work desk, a closet, a flat screen TV with DVD player, and free wireless Internet. If you need more space or expect a lengthy stay, talk to your social worker about other lodging options that might be available for you.

Breastfeeding/pumping mothers receive complimentary meal trays throughout the stay. Ask your nurse for more information. Breast pumps and lactation consultants are also available.

Visitation guidelines (Covid 19 information):

At this time, limitations within all Ascension care settings are necessary for the safety of our patients, visitors, care teams, and community to control the spread of the virus.

Hospital visitation policies are subject to change at any time. **Be sure to call ahead a few days before your appointment or planned hospital admission to ask about the current guidelines.**

- Because this is an intensive care unit, the number of visitors allowed in the patient's room is limited to two at a time.
- No visitors under the age of 15 are currently allowed.
- All visitors will be asked health screening questions when they enter the hospital. Visitors determined to have symptoms of possible illness or infection will not be allowed to enter our unit in order to protect the health and safety of our patients.

Expectations for families

Please wash your hands: We want our patients to recover as quickly as possible, and a big part of this is making sure that we are keeping them healthy by not bringing in germs from outside the hospital or spreading germs between patients. To help with this, we request that families wash their hands at the scrub sink *each time* they enter the unit, and that they use hand sanitizer upon entering and exiting the patient's room.

Keep the room free from clutter: We want you to feel at home during your stay, and you are welcome to bring necessary belongings. However, please make sure to keep your room clean and tidy. This is an important part of keeping the patient safe and being able to provide them with the care they need. We also request that you try to keep the counters in your room clear so that nurses can use them as a workspace. Patients are welcome to eat their meals in the room, but we ask that parents/caregivers eat their meals outside of the patient room. There is a family room located right outside of the CCU with a refrigerator, microwave, sink, etc.

Participate in the patient's care: Though your ability to be directly involved in hands-on care may be somewhat limited right after surgery, your supportive presence is important. As the patient begins to feel better, we want to make sure that you are participating in care in whatever way makes sense (bathing, feeding, helping with medication, etc.). Talk with your nurse to see what you can do (this will vary throughout the recovery process). For example, once the patient moves from ICU-level care to step-down-level care, you will be expected to learn and demonstrate the care that will be needed at home. Also, parents/caregivers are always welcome to participate in rounds to hear the plan of care and to offer input or ask questions.

Entering other patient rooms: Entering other patient rooms is not allowed. This is to maintain effective infection control and patient privacy. Families who want to visit with one another are encouraged to find a place outside of the CCU, such as the family lounge, coffee shop, or Healing Garden.

Emergent procedures: On occasion, we will have emergent situations taking place in patient rooms. If this occurs, we will put up screens to protect the privacy of patients and ask that you do not go past those rooms. In some situations, we may request that families either leave the unit or remain in their rooms for the duration of a procedure. We thank you for your understanding.

Audio and video recording: Please note that it is a violation of Ascension Texas' policy for a patient or visitor to use personal recording devices to record or photograph operations, procedures, associates, or other patients or visitors without the permission of all parties present.

A typical day in the CCU

While each day in the hospital varies, here is an idea of what you can expect:

4:00 a.m. - 5:30 a.m. Morning labs and x-rays will take place.

6:45 a.m. Day shift nurses come in. Night shift nurses give report to the incoming day shift nurses, discussing each patient's history, current condition, and overnight events.

7:00 a.m. – 8:00 a.m. During weekdays, surgical rounds begin at either 7:00 a.m. or 8:00 a.m. This is where the large team discusses each patient and their plan of care for the day.

Activities during the day vary. ICU-level patients will have more in-depth medical rounds later in the morning and again in the evening. You may expect visits from therapists (occupational, physical, respiratory, and speech), the psychosocial team (social work, psychology, child life), or other specialists (pulmonology, neurology, nephrology, etc.). Patients may also need to leave the unit for a procedure (CT, MRI, catheterization, etc.).

6:45 p.m. Night shift nurses come in. Day shift nurses give report to incoming night shift nurses about the day and plan of care.

9:00 p.m. Unit quiet time hours begin so patients can rest. **It is important for patients to maintain a day/night schedule as much as possible in order to decrease sleep-wake disturbances.**

Routine care and medications are continued overnight, as necessary. ICU-level patients will have rounds again in the evening.

Psychosocial assessment and family well-being

Your family's mental, emotional, and spiritual well-being is an important part of the congenital heart journey. We have a comprehensive psychosocial team of licensed social workers, licensed psychologists, certified child life specialists, and chaplains. Our psychosocial team performs routine assessments related to patient and family functioning and well-being. By identifying psychosocial needs as early as possible, and implementing appropriate interventions, we can help each patient and family to maximize their potential.

When you are first seen by our program, you will meet with a team social worker and/or psychologist as part of your clinic visit or hospital admission. You will also be asked to fill out a few brief questionnaires. These questionnaires help our team understand how best to support your entire family throughout this journey.

Cardiac Neurodevelopmental Outcomes Program

The Cardiac Neurodevelopmental Outcomes Program tracks, monitors, and manages the development of children with congenital heart disease who undergo surgical intervention as infants. Children with complex congenital heart disease are at higher risk for neurodevelopmental disabilities than other children. This program detects and treats developmental delays with the goal of optimizing each child's development. Developmental delays might include mild cognitive impairment, oral-motor discoordination, expressive speech and language differences, impaired visual-spatial and visual-motor skills, attention-deficit/hyperactivity disorder (ADHD), learning disabilities, and more.

The Cardiac Neurodevelopmental Outcomes care team treats patients both in the inpatient and outpatient setting. During inpatient care, the entire Cardiac Neurodevelopmental Outcomes team rounds together and meets routinely to discuss how each patient is doing, what is going well, what needs additional attention, and overall goals for the upcoming week. Upon discharge, the care team will provide your family with appropriate referrals as needed. Depending on your child's needs, outpatient referrals may include:

- Physical, occupational, speech, or feeding therapies through Dell Children's or a provider close to your home
- Early Childhood Intervention (ECI) for therapies in the home for children ages 0 – 3
- Cardiac Neurodevelopment Follow-Up Clinic

> **"Try to learn as much as you can about your child's condition, diagnosis, medical expectations, etc. Don't be afraid to ask any questions or for further explanations."**
>
> -Dana,
> Dell Children's Heart Mom

Cardiac Neurodevelopment Follow-Up Clinic

The Cardiac Neurodevelopmental Program provides routine monitoring with a comprehensive team that follows patients from birth through the teenage years. If you are referred to the program, you will be contacted by our clinic to schedule your appointment at each time point:

Infant and Toddler Clinic (Ages 0 – 2):

Your child will have neurodevelopmental testing to evaluate their cognitive, language, and motor development. This testing will also evaluate your child's social, emotional, and behavioral development. Your child will also have a screening visit with a neurologist or a nurse practitioner. They will conduct an exam, including assessment of mental status, speech, cranial nerves, muscle tone, motor skills, sensation, and reflexes. You will discuss your goals and concerns for your child with the team and will receive the results of testing and treatment recommendations at the end of the appointment. If needed, referrals will be made for physical, occupational, speech, and/or behavioral therapy.

School Readiness Clinic (Ages 3 – 5):

Around the time your child is starting preschool and kindergarten, our practitioners will administer neuropsychological evaluations. The evaluations will assess your child's thinking skills, early academic knowledge, language, motor skills, and early attention development. The evaluations will also assess your child's social, emotional, and behavioral functioning. Recommendations to promote development and learning will be provided in a feedback appointment and in a written report that will be shared with your child's cardiologist.

School Age Clinic (Ages 6 – 18):

Your child will be evaluated at several time points while they are in school. These time points have been identified as transition periods with increased expectations, where children with congenital heart disease are more likely to experience new difficulties. The key points of evaluation typically include 3rd grade, prior to starting middle school, prior to starting high school, and prior to transitioning to adulthood. Neuropsychological evaluations will be tailored to your child, but generally include an evaluation of your child's intellectual skills, language, visual-spatial skills, learning and memory, attention, executive functioning (skills such as self-regulation, planning, and organization), academic skills, and motor skills. The evaluation will also assess your child's social, emotional, and behavioral functioning. Recommendations to promote development and learning will be provided in a feedback appointment and in a written report that will be shared with your child's cardiologist.

Congenital heart outcomes, research, and quality

The Health Transformation and Design Program

The Health Transformation and Design (HTD) program is the arm of our program devoted to improving the lifetime care of individuals with congenital heart disease and their families by measuring outcomes, ensuring quality care, and advancing the field through meaningful research.

Our program is part of the academic and clinical collaboration between Dell Medical School at the University of Texas at Austin and Dell Children's. The program is rooted in a comprehensive approach to understanding and improving congenital heart disease. Our multidisciplinary team's research initiatives are broad and constantly growing. Our team of researchers uses various methods to study different parts of your journey with congenital heart disease:

- **Clinical outcomes data**
  We support annual reporting to a variety of national clinical outcomes patient registries. These registries help our clinical staff measure how well we are doing on a national platform. Our outcomes are always available to you.
- **Quality assurance and quality improvement**
  Through clear quality assurance and quality improvement processes, we are constantly thinking about what we can do better and making meaningful changes to improve the care we provide.
- **Clinical research**
  Our program is involved in ethics board-approved clinical research efforts in order to help our patients and families thrive. This research includes things like testing the effectiveness of certain medications or medical interventions or interviewing patients about their care experiences.

Your involvement in our work is important, and it will help us transform healthcare for the future. At some point along your journey, you or your family may be approached about contributing to our research or quality improvement initiatives. We suggest you discuss research participation with your family to have an idea about what research and quality improvement projects you will or will not be open to.

We look forward to partnering with you to solve critical problems and guide program enhancements for patients and families affected by congenital heart disease. If you or your family have any research-related questions you can reach a member of our research team via email at: CardiacResearch@austin.utexas.edu.

Caring for yourself and your family

The health and well-being of everyone in the family is extremely important, and we are here to support you throughout this journey. Below are some helpful pieces of advice to deal with various emotions that are commonly experienced by parents, patients, siblings, and children of adult patients. Please reach out to the psychosocial team when you need support, information, resources, or just a listening ear.

How can I help my child cope through treatment/hospitalization?

Being in the hospital can be a stressor for children and patients of any age, and it can be hard to know how to best help your child. Here is a short guide to some behaviors you might see in your child, and ideas of what you can do to help your child have the best possible treatment experience.

Infants

Developmental tasks: Establish trust with caregivers, learn about world through senses, meet basic physical needs

Fears: Separation from parents, strangers, loud noises

Typical reactions to hospitalization: Irritability, crying, acting less playful, confusion of day/night routine, lethargy

What can you do? Hold baby when possible, swaddle, rock, speak softly, play soft music, sing, read aloud, use a pacifier, speak gently before touching baby, provide bright toys and visual stimulation (if medically appropriate), help create a more typical routine, use various toys to distract your child during procedures (ask your child life specialist for ideas), avoid hunger (when possible), and keep room at comfortable temperature

Toddlers

Developmental tasks: Increasing independence, growing vocabulary, exploring their world

Fears: Loud noises, darkness, environmental changes, masks, strangers

Typical reactions to hospitalization: Irritability, crying, acting less playful, confusion of day/night routine, lethargy, temper tantrums, poor appetite, not wanting to take medicine

What can you do? Involve toddler in care as able (e.g., feeding, bathing), name objects and give basic explanations, use night light/soft music, provide toys, sing favorite songs, read books, help promote a more typical sleep schedule (activities during day, lights off at night), bring familiar objects from home, have favorite foods for them to eat, ask your nurse for creative ways to give medications, give them words to help them express themselves: “I am feeling happy/sad/tired/bored/itchy/scared/calm/excited”

Preschoolers

Developmental tasks: Continuing to explore/learn about surroundings, increasing independence, acquisition of new skills like walking and potty training, increasing verbal abilities

Fears: Being separated from parents, darkness, medical equipment, unfamiliar places, harm/changes to body, pain, strangers, fear that their illness is their fault, loss of control, misconceptions about care, magical/fantasy thinking

Typical reactions to hospitalization: Regression (bed wetting, acting out), aggression, nightmares, increased clinginess

What can you do? Provide toys that capture their attention, have designated playtime they can look forward to, maintain schedule (activities during day, lights off at night), use night lights, explore opportunities for imaginative play, go for walks (when possible), bring familiar objects from home, explain that illness is not their fault, explain all treatments in basic terms, allow children to make choices (e.g., beverage they want when taking medicine, outfit to wear), engage in music and/or art activities

School age children

Developmental tasks: Building self-worth through involvement in activities, awareness of privacy

Fears: Injury/changes to body, pain, death, separation from parents, darkness, being alone, lack of privacy, loss of control

Typical reactions to hospitalization: Regression (bed wetting, acting out), aggression, withdrawal, resistance to authority, fear, sleep disturbances, misunderstanding of care, guilt, depression, anxiety

What can you do? Respect privacy, explain all treatments clearly and simply, offer choices whenever possible, ask medical staff to talk directly to your child when possible, ask medical staff if child can see/touch/explore medical equipment that will be used, give child tasks to help with care, engage in activities that build sense of accomplishment, play games, read books, listen to music, tell stories, allow child to express feelings/anger through art and physical activities, provide familiar toys/objects, seek out special accommodations at school as needed

Adolescents

Developmental tasks: Building relationships, development of self-identity, increasing independence and transitioning to managing their own care

Fears: Social issues, inability to be independent, rejection, bodily changes or injury, pain, death, isolation, lack of privacy

Typical reactions to hospitalization: Concerns about body image, sleep disturbances, depression, anxiety, withdrawal, testing limits of authority

What can you do? Respect privacy, allow for choices whenever possible, encourage participation in medical care as appropriate, explain procedures, encourage interactions with peers, play games, listen to music, utilize relaxation techniques, encourage journaling, allow to talk about feelings and frustrations, seek out special accommodations at school as needed

Special considerations for special needs: If the patient has special needs, please let us know how we can help. We have experience working with children and adults with various special needs, and our goal is to make this experience as positive as possible. Please be sure to share with us strategies that you use at home to help minimize stress.

Coping with pain

We know that as a parent/caregiver you want to relieve your child from any stressful or painful experiences while in the hospital. When it comes to surgery and medical procedures, we cannot remove all sore and somewhat painful sensations. However, our team will take multiple steps to address pain for any and all procedures.

One way you can help us is validating your child's concerns while providing realistic expectations. If your child asks, "Is it going to hurt?" it's helpful to respond with a statement like, "It will feel a little bit sore and a little uncomfortable. It's important that you tell me and your nurses so we can all help as much as possible." This allows them to know that those feelings are normal and then helps them focus on ways to address the concern.

Helping siblings or other young family members cope

A serious, life-threatening illness like CHD affects everyone in the family. Children with an ill family member (such as a sibling, parent, or grandparent) can experience many different feelings as they try to understand and navigate the illness.

Typical reactions: Children with an ill family member can experience things like fear, worry, sadness, anger, jealousy, guilt, and resentment. You might notice changes in the child's mood or behavior, changes in sleep, or problems at school. These are normal. What's most important is that you let the child know they are not alone. Children who have an ill family member can thrive with extra support and understanding.

What can you do?

- Keep children informed with honest, age-appropriate information about their family member's health. Kids know when adults are hiding something, and sometimes they can imagine even scarier things if they don't know the truth.
- Assure children they are not to blame for their family member's illness.
- Involve children in their family member's care in small, simple ways. They will feel more in control if they can help in some way like gathering supplies (diapers, wipes, snacks) or preparing and serving food. However, be mindful of limiting major caretaking responsibilities, which are more appropriate for adults.
- Invite children to visit the hospital whenever possible and appropriate. If they are not able to visit, have them call, video chat, or send emails. They may even want to make artwork or send a card. For help in preparing them for a hospital visit, contact your child life specialist.
- Provide children with a safe space to talk about their worries, feelings, and questions without judgment. Sometimes children just want to be heard and have their feelings validated.
- Help children to identify other trusted adults who they can also speak to if they feel they cannot speak directly with you. It can be normal for them to not want to overburden a parent or caregiver.
- Be honest about your own feelings and don't be afraid to express your emotions. You are the model — set the tone for healthy expression of feelings and emotions.
- Form connections with other families so that children can meet other kids with family members with CHD. Your social worker can help you to locate these resources.
- Be consistent with rules and limits. It's easy to be more lenient when the family is under stress, but too many changes at once can feel confusing and scary. Maintaining rules and limits also helps with the transition after a hospitalization. It provides a sense of stability for the children and the family.
- Try to maintain as normal a routine as possible. Enlist help from family and friends so children can attend school regularly, participate in extracurricular activities, and spend time in their typical environment.
- Engage children (as appropriate) in planning for the unplanned. Ask them how they would like to be informed if another family member is going to pick them up from school, for example.
- Reach out to the school to let them know about major changes in the family. Stay in communication with the school about any behavioral concerns it might have, and ask about a designated person children can speak to at school if they are worried or in need of extra support (e.g., school counselor).
- When you can, spend some one-on-one time together. Something as simple as playing a board game or going out for ice cream can maintain normalcy and let them know they are loved and valued.
- If you see signs of serious depression or anxiety, excessive anger, or other concerning behaviors, seek help immediately. Your psychosocial team is here to provide support and guidance.
- Continue to reassess the needs of children. Be willing to learn new skills and seek out additional support as your family's life and needs change over the years.

Remember that each child is unique and will respond to situations in their own way. Allowing open dialogue, being honest with the child, and answering questions without judgment are great ways to support them. Remember that adults often set the tone, so the more you can work to create a safe, stable, and supportive environment, the better it will be for the child.

Taking care of yourself: advice for parents

Being the parent of a child with a heart condition can be challenging and it can be easy to put yourself last. However, research shows that parental distress is closely connected to how a child adjusts to their illness. It is important to prioritize your physical, mental, and emotional well-being throughout your child's journey so that you have the strength and energy that you need for both yourself and your child. You are an important part of the medical team!

Common reactions parents and caregivers may experience:

- **Fear:** What kind of limitations will my child have? Will he/she be able to do what other children can do?
- **Guilt:** Did I do something to cause this?
- **Sadness:** I just want my child to be healthy. I wish things were different.
- **Anger or frustration:** Why is this happening to my child?
- **Confusion:** What does this mean for my child's future? How do I parent a medically fragile child?
- **Envy:** I wish my child was like other children.

Helpful tips for managing these emotions:

- Acknowledge your emotions rather than denying them. It is okay to feel sad, frustrated, angry, and confused. You can only process these emotions if you recognize that you are feeling them.
- Consider keeping a journal. Journaling can help you decompress and process your experience.
- Talk to someone you trust. Consider talking to a counselor or joining a support group of parents whose children have had similar experiences and know what you are going through. Ask your social worker for referrals and resources.
- Take time for yourself. Go for a walk in a park, have a date night, take a bath, eat a delicious meal, have coffee with a friend, take a nap, or do something else that brings you joy. Taking time for yourself will help you have more energy to devote to caring for your child.
- When you feel confused, ask questions. The world of medicine can be filled with an overwhelming amount of unfamiliar words and information, so if something is unclear it is always okay to ask for further explanation. We can also help point you to reputable sources to learn more about your child's diagnosis, surgery, and/or procedures.
- Choose a friend or family member who can be a point person for medical updates so you don't have to call everyone yourself. Phone/text trees or websites such as CaringBridge can be helpful in keeping multiple people updated with less stress for you.

Ways to take care of yourself:

- Your health also needs to be a priority. Make sure that you eat well, stay hydrated, and get enough sleep. Try to go for walks outside or take a few moments to explore the hospital's Healing Garden.
- Please accept or ask for help from family and friends. Some ways they can help include watching other kids, doing laundry at home, making meals or providing gift cards to local restaurants, coordinating transportation, caring for pets, etc.
- Ask your team "What is the plan for today?" Or "What are the goals for today?" Understand that these goals will change over the course of treatment.
- Take things one day at a time. Celebrate the little victories and milestones.
- When meeting with the medical team, take notes or ask a family member to be the notetaker. Clarify any confusion you have regarding your child's medical condition or care.
- Please communicate with your psychosocial team and/or nurse about your needs so we can help you take care of yourself. We can provide support and can also help you to seek help from outside supports such as your doctor or a therapist in your community. Asking for help is one of the best things you can do to help yourself and your family.

Coping with chronic illness: advice for adult patients

Living with a chronic illness can be disruptive to you and your family's life in a number of ways. Physical symptoms and related changes can be difficult to cope with, such as experiencing chronic pain or struggling with physical limitations, the inability to work or enjoy your usual activities, or role reversals at home.

The emotional aspects of illness can also be quite challenging. Common feelings can include stress, isolation, sadness, hopelessness, fear, worry, anger, guilt, and resentment. You might notice things like changes in your mood (anxiety and depression are quite common), changes in your sleeping or eating patterns, or problems in your relationships at work and at home.

How can I start to feel better?

The most important step you can take is to talk to someone about how you're feeling. A trusted professional can help you to understand and deal with what you're feeling. They can help you to identify coping strategies and create a treatment plan that meets your specific needs. Support groups may also be helpful. Being able to connect with others in similar circumstances can make you feel less alone. Learning to effectively cope with the complexities of having a chronic illness can help to improve your quality of life — something you deserve!

Reach out to the psychosocial team if you would like to talk to one of our psychologists or clinical social workers, or if you would like a referral to another professional in your community.

Family resource list

We are committed to providing high-quality, family-centered care. We believe every patient and their family deserves the best information, care, and support, which is why we've compiled a list of resources that may be beneficial to you and your family.

Educational resources

American Academy of Pediatrics, Congenital Heart Public Health Consortium:
https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/chphc/Pages/default.aspx

American Heart Association: https://www.heart.org/en/health-topics/congenital-heart-defects

Centers for Disease Control and Prevention: https://www.cdc.gov/ncbddd/heartdefects/index.html

Johns Hopkins Cove Point Foundation: http://pted.org/

National Institutes of Health: https://www.nhlbi.nih.gov/health-topics/congenital-heart-defects

United Network for Organ Sharing: https://unos.org/

Congenital heart disease data and outcomes

American Society of Transplantation: https://www.myast.org/

National Pediatric Cardiology Quality Improvement Collaborative: https://npcqic.org/

Pediatric Acute Care Cardiology Collaborative: https://pac3quality.org/

Pediatric Cardiac Critical Care Consortium: https://pc4quality.org/

Scientific Registry of Transplant Recipients: https://www.srtr.org/

The Society of Thoracic Surgeons: https://www.sts.org/

Hospital resources

Thyme Out Café (Cafeteria)

The cafeteria is located on the 1st floor. Hours are 6:30 a.m. to 7:30 p.m. Monday – Friday, and 7:30 a.m. to 6:30 p.m. on weekends. There is nighttime service offered from 8:00 p.m. to 1:00 a.m. Tuesday – Saturday.

Holy Roast coffee shop

The coffee shop is located by the main elevators on the 3rd floor. Hours are 6:30 a.m. to 5:00 p.m. Monday – Friday only.

Chapel and reflection garden — 3rd floor

The chapel is open 24 hours a day and is welcoming of all faiths and spiritual backgrounds. A schedule of services is posted at the entrance.

Family Resource Center and Simply Safety store — 3rd floor (near the main entrance)

The Family Resource Center provides information and support for patients and families related to hospitalization, child health and safety, parenting, and other topics. The Simply Safety store offers affordable car seats, bicycle helmets, and other child safety items. Hours are 10:00 a.m. to 4:00 p.m. Monday – Thursday and 12:00 p.m. to 4:00 p.m. Friday – Sunday.

Gift shop — 3rd floor (near the information desk)

Lori's Gifts offers a variety of gifts and snacks, as well as personal care items and over-the-counter medications. Hours are Monday – Friday 8:00 a.m. to 8:00 p.m.; Saturdays 10:00 a.m. to 4:00 p.m.; Sundays 11:00 a.m. to 3:00 p.m.

Healing garden

Outdoor spaces available for families include a Healing Garden, accessible on the 2nd floor through the south entrance near PICU, along with a number of beautifully designed walkways and courtyards. The central courtyard is accessible from the 2nd floor, while patios overlooking the central courtyard are accessible from the 3rd and 4th floors.

Ronald McDonald family room — 4th floor (near NICU)

The Family Room is a resource for families who live less than 25 miles away. This space has a full bath with toiletries available, laundry room, small kitchenette with food/snacks, TV lounge, and small play area for kids. Families can access this space from 9:00 a.m. to 9:00 p.m. daily.

Community support resources

American Heart Association: https://www.heart.org
A non-profit dedicated to improving heart health and reducing deaths from cardiovascular diseases and stroke through education, research, and community programming.

Adult Congenital Heart Association: https://www.achaheart.org/
The mission of the Adult Congenital Heart Association is to improve and extend the lives of the millions born with heart defects through education, advocacy, and research. They do this through a wide and growing range of programs, services, and activities.

Any Baby Can: http://anybabycan.org/
Any Baby Can provides in-home therapy, parenting education, mental health counseling, medical case management, resource navigation, and other support like Early Childhood Intervention. Ask your hospital social worker to see if you might qualify for services.

Aunt Bertha: https://www.findhelp.org/
A useful search engine where you can search for a variety of programs in your area, such as food, housing, transportation, legal services, and employment.

Camp del Corazon: https://www.campdelcorazon.org/
A non-profit organization out of California, providing year-round opportunities for children and teens with heart disease.

CaringBridge: https://www.caringbridge.org/
A free website where you can document your child's journey to keep family and friends updated.

Casey's Circle: https://caseyscircle.org/
An Austin-based non-profit that provides tools, education, resources, and social events to help improve the quality of life for medically complex children and families.

Children's Cardiomyopathy Foundation: https://www.childrenscardiomyopathy.org/
Information and family resources for children living with cardiomyopathy.

The Children's Heart Foundation: https://www.childrensheartfoundation.org/texas/
The Children's Heart Foundation was founded in 1996 and is the country's leading organization solely dedicated to funding congenital heart defect (CHD) research. Their mission is to fund the most promising research to advance the diagnosis, treatment, and prevention of CHDs.

Complex Child: https://complexchild.org/
A free online magazine for parents of children with complex healthcare needs and disabilities. The magazine offers information for parents on a wide variety of topics.

Congenital Heart Information Network: https://www.facebook.com/TCHIN.org/
The Congenital Heart Information Network provides reliable information and resources to people affected by CHD.

Dell Heart Families Facebook Page: https://www.facebook.com/groups/dellheartfamilies/
A parent-run, supportive Facebook group for the immediate family of children who have been or will be treated at Dell Children's. **Note: This group is not run or endorsed by Dell Children's.**

Down Syndrome Association of Central Texas: http://www.dsact.org/
The association's mission is to provide education, support, and resources to individuals with Down syndrome, their families and professionals, and the community, while building public awareness and acceptance of the abilities of individuals with Down syndrome.

Hand to Hold: https://handtohold.org/
Hand to Hold helps families before, during, and after a NICU stay by providing powerful resources for the whole family and one-on-one support from someone who has been there.

Heart Families Blog: https://heartfamilies.com/
A local parent-run blog with advice, stories, and support for the heart family community.

Heart Heroes: https://heartheroes.org/
A non-profit organization out of Nebraska that provides hand-sewn, custom-designed Hero Capes to CHD children nationwide.

Kids with Heart: https://kidswithheart.org/
Kids with Heart National Association for Children's Heart Disorders provides support for families affected by CHD through surgical care packages, support groups, parenting matching, and an online listserv.

Little Hearts: https://www.littlehearts.org/
Little Hearts, Inc. is a national organization dedicated to providing support, education, resources, networking, and hope to families affected by congenital heart defects. Membership consists of families nationwide who have or are expecting a child with a congenital heart defect.

Lotsa Helping Hands: https://lotsahelpinghands.com/
A free website where you can create a calendar to organize help for your child and family. People can sign up to help you with things like meals, rides, housework, etc.

Make-A-Wish Foundation: https://wish.org/
Children ages 2 ½ to 17 diagnosed with critical illnesses, including certain cardiac conditions, qualify for a wish experience. Ask your social worker for more information.

March of Dimes: www.marchofdimes.org
MoD educates medical professionals and the public about best practices, supports lifesaving research, and provides comfort, support, and advocacy to families in the NICU. Dell Children's has a NICU Family Support Program Coordinator. Ask your social worker for more information.

The Marfan Foundation: https://www.marfan.org/
The Marfan Foundation works tirelessly to advance research, serve as a resource for families and healthcare providers, and raise public awareness.

Medical Transportation Program (MTP): Call the number on the back of your Medicaid card or visit https://hhs.texas.gov/services/health/medicaid-chip/programs/medical-transportation-program
MTP provides non-emergency medical transportation services for people with Medicaid who don't have a way to get to medical appointments. The program also provides meals and lodging for parents of children 20 and younger staying overnight in the hospital.

Mended Hearts/Mended Little Hearts: https://mendedhearts.org/
An organization providing support, education, hospital outreach, and advocacy to pediatric and adult congenital heart patients and their families. Check out the local Austin chapter at https://www.facebook.com/MendedLittleHeartsAustin/

Navigate Life Texas: https://www.navigatelifetexas.org/
This website is especially for families and parents of children with disabilities or special healthcare needs and is designed to offer support, inspiration, resources, and links to services available.

Parent Companion: http://www.parentcompanion.org/
A website for Texas parents/caregivers of children ages 0 – 5 with suspected or diagnosed disabilities. The website provides information, support, and connections to other parents.

Pediatric Congenital Heart Association/Conquering CHD Texas: https://www.conqueringchd.org/texas/
A program aimed at improving the lives of those with congenital heart disease and their families through CHD education, support, research, and awareness.

Pediatric Heart Network (part of the National Institutes of Health): http://www.pediatricheartnetwork.org/
A network of hospitals throughout the U.S. and Canada that conduct CHD research. This website has information about CHD research studies and support resources for families.

Ronald McDonald House: (512) 472-9844 or https://rmhc-ctx.org/
The Ronald McDonald House can be used by families who live more than 25 miles away from the hospital. They ask for a small donation of $20 per night, but no family is ever turned away if they can't pay. Ask your social worker if you are interested in a reservation.

Sisters by Heart: http://www.sistersbyheart.org/
A national volunteer organization that strives to help HLHS moms with newly diagnosed babies. They provide information and resources to help you better understand HLHS. All volunteers are moms with children who have HLHS and understand what you are going through. Check out their website for the local area Facebook group.

The Society of Thoracic Surgeons, Patient Guide to Surgery: https://ctsurgerypatients.org/
This patient guide provides information on congenital heart defects and their treatment.

Texas 2-1-1: https://www.211texas.org/
2-1-1 Texas is committed to helping Texas citizens connect with the services they need. The website provides accurate, well-organized and easy-to-find information from state and local health and human services programs. 2-1-1 Texas is free and available 24 hours a day.

Texas Parent to Parent: https://www.txp2p.org/
Texas Parent to Parent (TxP2P) is committed to improving the lives of Texas children who have disabilities, chronic illness, and/or special healthcare needs. TxP2P empowers families to be strong advocates through parent-to-parent support, resource referrals, and education.

UNOS Transplant Living: https://transplantliving.org/
United Network for Organ Sharing (UNOS) is the private, non-profit organization that manages the nation's organ transplant system under contract with the federal government. They also provide information, support, and resources for patients and families going through the transplant process.

Vela: https://velafamilies.org/
An Austin-based non-profit that offers workshops, case management, support groups, and social events for English- and Spanish-speaking families of children with special needs.

Wonders & Worries: https://www.wondersandworries.org/
Wonders & Worries is a Texas-based non-profit that provides free, professional coping support to children and teenagers during a parent's serious illness. Services are available in English and Spanish.

Financial assistance resources

Children's Organ Transplant Association: https://cota.org/
COTA helps families raise funds for transplant-related expenses. COTA is the owner and administrator of all funds so families are not taxed on the funds, nor do the funds jeopardize a family's ability to participate in other assistance programs.

Cerner Charitable Foundation: https://www.cernercharitablefoundation.org/
Provides financial assistance for children 18 and under for medical treatment, equipment, displacement costs like lodging and gas, and vehicle modifications. Must meet financial guidelines.

United Healthcare Children's Foundation: https://www.uhccf.org/
Provides medical grants for children ages 16 and under with any commercial health plan coverage. Must meet financial guidelines. Grants can be used for medical services, treatments, or therapies that are prescribed by a physician.

Variety of Texas: https://www.varietytexas.org/
Variety of Texas supports Texas children (21 and under) with special needs and their families by providing resources and empowering experiences. They can provide financial assistance for things like medical procedures, mobility equipment, vehicle modifications, prosthetic limbs, and life experiences for children. Families must be able to demonstrate financial need.

Insurance/medical benefit resources

Children with Special Health Care Needs (CSHCN): (800) 222-3986 or https://hhs.texas.gov/services/disability/children-special-health-care-needs-program
Low-income families with children age 20 and younger who have a major medical condition (expected to last at least one year and which limits major life activities) may qualify for free medical coverage. There is typically a waiting list for this program.

Health Insurance Premium Payment (HIPP) Program:
https://hhs.texas.gov/services/financial/health-insurance-premium-payment-hipp-program
If anyone in your family is enrolled in any Medicaid plan (except for CHIP and the STAR Health managed care program), you can get help with paying for employer-sponsored health insurance.

Marketplace/Healthcare Exchange: https://www.healthcare.gov/
If you need insurance and you do not qualify for state assistance (Medicaid or CHIP) or employer-sponsored coverage, you may be able to purchase an insurance plan here.

Medicaid Buy-In for Children Program:
https://hhs.texas.gov/services/health/medicaid-chip/programs-services/children-adults-disabilities/medicaid-buy-children
The Medicaid Buy-In for Children program offers low-cost Medicaid services to children with disabilities in families that make too much money to get Medicaid. They also have an adult program for adults with disabilities who are working. There are income limits you must meet.

Medicaid Waiver Programs: (877) 438-5658 or https://hhs.texas.gov/laws-regulations/policies-rules/waivers
Medicaid waiver programs are services provided by the State of Texas to eligible individuals with disabilities. They are called waivers because the programs “waive” the usual Medicaid eligibility criteria. The most commonly used waiver program for children with CHD is the Medically Dependent Children’s Program. Please be aware that most waiver programs have long waitlists. Helpful information for parents can be found on the https;//navigatelifetexas.org website.

Supplemental Security Income (SSI):
https://www.ssa.gov/ssi/text-child-ussi.htm
Children with disabilities who medically qualify as disabled through the Social Security Administration can receive a monthly SSI disability payment. SSI is a need-based program available to families with low income. Medicaid is included if you qualify. The SSI Child Disability Starter Kit can be found here: https://www.ssa.gov/disability/disability_starter_kits_child_eng.htm

Texas Benefits for Low-Income Families (Medicaid, SNAP, WIC, and TANF): https://yourtexasbenefits.com/
Low-income families with children who are 18 and younger and U.S. citizens may qualify for free or low-cost medical coverage, as well as money to buy healthy food.

> **“Be part of the team in the care for your child. If you notice a change, speak up. Providers can change but the parents are always the same, and you may notice something that others cannot.”**
>
> -Katie, Dell Children’s Heart Mom

Important medical information

This section of the handbook is for you to keep important medical information and records. Use it however you would like to help stay organized and keep key information handy.

Emergency Medical Information Form

American College of Emergency Physicians®

American Academy of Pediatrics

Name: ______________________________

Home Address: ______________________________

Parent/Guardian: ______________________________

Signature/Consent*: ______________________________

Primary Language: ______________________________

Birth Date: ______________________ Nickname: ______________________

Home Phone: ______________________ Work Phone: ______________________

Emergency Contact Names & Relationship: ______________________________

Phone Numbers: ______________________________

Physicians

Primary Care Physician: ______________________________

Emergency Phone: ______________________ Fax: ______________________

Current Specialty Physician: ______________________________

Emergency Phone: ______________________ Fax: ______________________

Specialty: ______________________________

Anticipated Primary ED: ______________________________

Pharmacy: ______________________________

Anticipated Tertiary Care Center: ______________________________

*Consent for release of this form to healthcare providers

> **"It took a whole team to care for my daughter and our family during our medical journey of open-heart surgery. I learned that I had to ask for help and that it is ok to ask for help. It takes a village."**
>
> -Allison, Dell Children's Heart Mom

Diagnoses/Past Procedures/Physical Exam:

1. __________

2. __________

3. __________

4. __________

Synopsis: __________

Baseline physical findings: __________

Baseline vital signs: __________

Baseline neurological status: __________

Medications: __________

____

Significant baseline ancillary findings (lab, X-ray, ECG): __________

Prostheses/Appliances/Advanced Technology Devices: __________

Management Data:

Allergies, Medications, Foods to Avoid: __________

And why? __________

Procedures to Be Avoided: __________

And why? __________

Immunizations:

Dates					
DPT					
OPV					
MMR					
HIB					

Dates					
Hep B					
Varicella					
TB status					
Other					

Antibiotic prophylaxis: __________ Indication: __________ Medication and dose: __________

Common Presenting Problems/Findings with Specific Suggested Managements

Problem: __________

Suggested Diagnostic Studies: __________

Treatment Considerations: __________

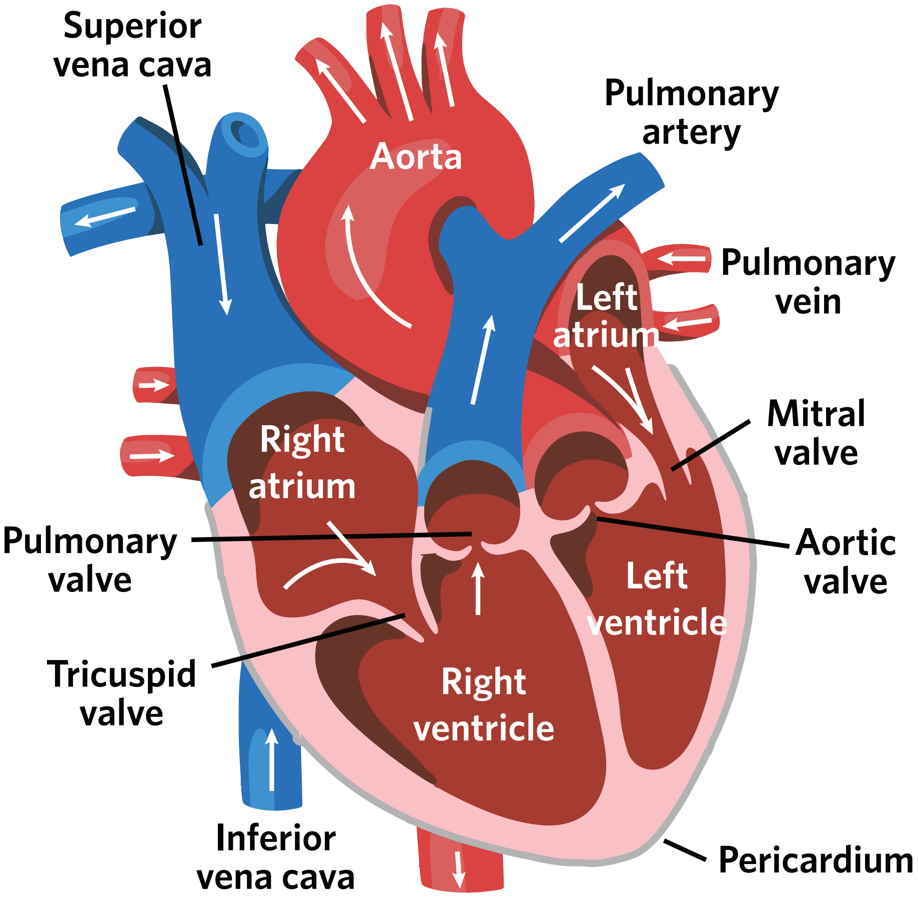
Comments on child, family, or other specific medical issues

____

Physician/Provider Signature: __________ Print name: __________

How a typical heart works

1. Deoxygenated ("blue," oxygen-poor) blood from the body comes into the right atrium from the superior and inferior vena cava.
2. Blood goes from the right atrium to the right ventricle through the tricuspid valve.
3. The right ventricle pumps blood through the pulmonary valve and out the pulmonary arteries to go to the lungs.
4. In the lungs, blood gets more oxygen and then goes back to the left atrium through the pulmonary veins (now "red," oxygen-rich blood).
5. Blood goes from the left atrium through the mitral valve to the left ventricle.
6. The left ventricle pumps oxygenated (oxygen-rich) blood through the aortic valve out to the aorta.
7. Blood goes from aorta to all over the body, carrying oxygen and nutrients to cells.



My unique heart

Ask your provider to provide a drawing of your heart and place here.

Appointment and procedure log

Date	Medical Provider/Location	Reason for Appointment or Procedure	Details

About Ascension Texas

In Texas, Ascension operates Ascension Providence and Ascension Seton, which includes Dell Children's Medical Center, the region's only comprehensive children's hospital and pediatric Level I trauma center, and Dell Seton Medical Center at The University of Texas, the region's only Level I trauma center for adults. Ascension Seton partners with Dell Medical School at The University of Texas at Austin and shares a common vision of transforming healthcare through a focus on quality and value. Serving Texas for 115 years, Ascension is a faith-based healthcare organization committed to delivering compassionate, personalized care to all, with special attention to persons living in poverty and those most vulnerable. Ascension is one of the leading non-profit and Catholic health systems in the U.S., operating 2,600 sites of care—including 150 hospitals and more than 50 senior living facilities—in 20 states and the District of Columbia. Visit www.ascension.org and www.dellchildrens.net

About UT Health Austin

UT Health Austin is the clinical practice of the Dell Medical School at The University of Texas at Austin. UT Health Austin clinicians collaborate with colleagues at the Dell Medical School, The University of Texas at Austin, and in the community to utilize the latest research, diagnostic, and treatment techniques in every clinical encounter. Our experienced healthcare professionals deliver personalized, whole-person care of uncompromising quality and treat each patient as an individual with unique circumstances, priorities, and beliefs. Working directly with patients and their families, we create individualized care plans to designed to help our patients reach the goals that matter most to them — in the care room and beyond. Visit www.uthealthaustin.org

About the Partnership between Dell Children's Medical Center and UT Health Austin

UT Health Austin is the clinical practice of the Dell Medical School at The University of Texas at Austin. The partnership between UT Health Austin and Dell Children's brings together a team of highly specialized providers who are at the forefront of the latest research and technological developments in the field of pediatric and congenital heart disease to build an integrated system of care that is a collaborative resource for clinicians and their patients.

Contact us

Texas Center for Pediatric and Congenital Heart Disease
Dell Children's Medical Center
4900 Mueller Blvd., Austin, TX 78723

Dell Children's Specialty Pavillion: outpatient clinic
4910 Mueller Blvd., Austin, TX 78723

512-324-0091
partnersincare.health/pediatric-cardiology

For more information about our program, to refer a patient, or request a second opinion, please follow the QR code to our website.

dell children's
Ascension

The University of Texas at Austin
UT Health Austin