



Colorado Heart Families

Support for the CHD Journey



www.ColoradoHeartFamilies.com

Welcome to the Heart Institute

This pamphlet was put together by local Heart Moms. We all have a child who is treated at Children's Hospital. We have sat in the same chairs and walked these same hallways. The intention of this booklet is highlight some information we wish we had known when we first started this journey.

The two most important things to remember throughout this journey are that you know your child better than anyone, and that you are your child's advocate. Don't be afraid to speak up or ask questions. Everyone is here to help your child get better.

Our website and email address are on the cover; PLEASE feel free to reach out. We know how difficult this journey can be and hope you find this information helpful and comforting.

Organization of Your Child's Care Team

Attending: the physician responsible for your child's care.

Fellow: physicians who have completed residency training and are completing additional training in a specialty.

Resident: has advanced training in care of hospital patients. The resident reports to the attending physician about your child's progress every day.

Advanced Care Providers: registered nurses or physician's assistants with additional education and clinical training in specific area of healthcare. They work in all areas of the hospital to perform physical exams and procedures, order lab tests, and teach parents about issues related to their child's care.

Charge Nurse: responsible for the daily operations of the unit. In addition to your child's bedside nurse, the Charge Nurse helps facilitate the care of your child and is available each shift if you have any questions.

Nurse: is available at your child bedside and is responsible for planning and coordinating your child's care throughout their stay.

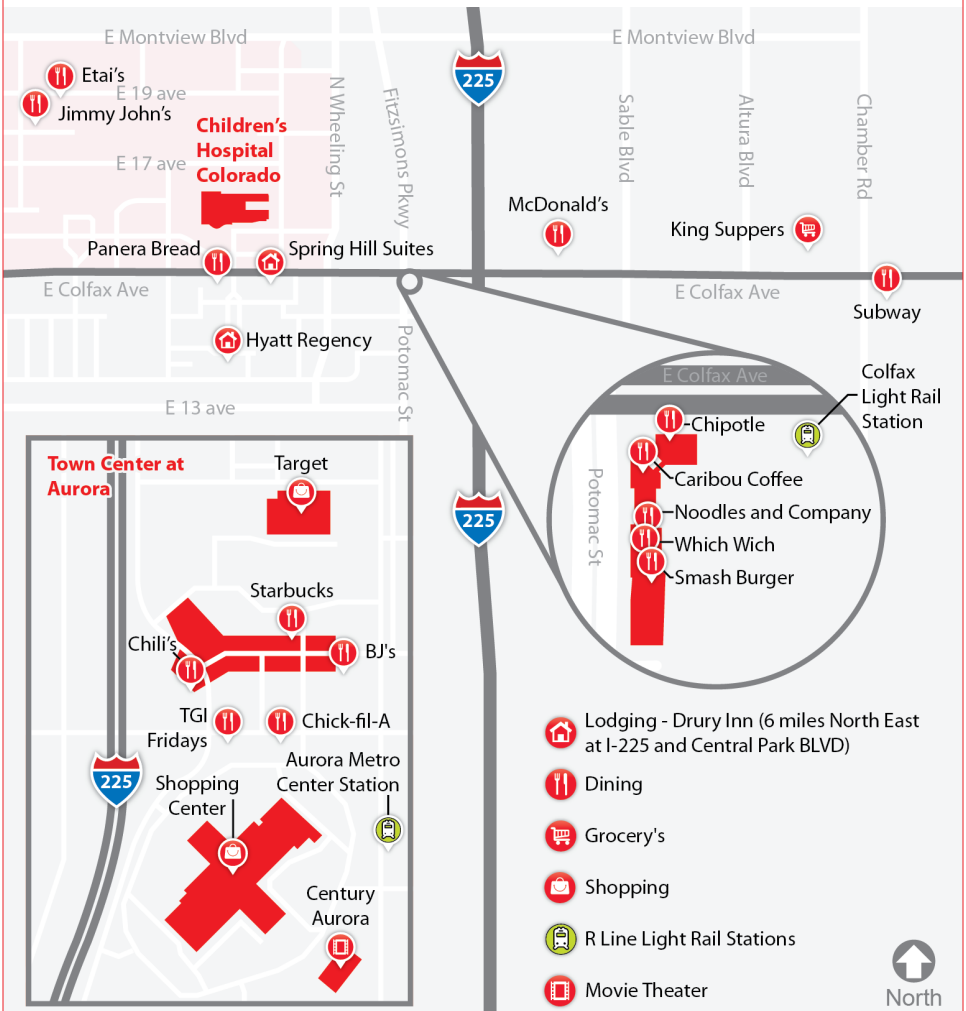
In addition to these providers, Children's also has a number of specialists including Child Life, Social Workers, Psychologists, and Spiritual Care available to you. Ask your child's nurse if you are interested in meeting with any of these specialties.

For additional information about other members of your child's care team, including Respiratory Care and Physical Therapists, visit the Children's Hospital Colorado website and select *Your Visit*, then *Planning Your Visit*, and finally *Care Team*.

What to Have for Your Stay

- Personal bedding- pillow and blankets, especially for your child
- Laptop/iPad, music, movies, books, or other entertainment
- Comfort items from home, especially for your child
- Snacks and beverages
- Journal to keep track of things, your thoughts, and questions for your child’s team
- Chargers for your phone and other electronics

Resources Close to Children’s



CICU-CPCU Transition

Useful things to know when transitioning from the Cardiac ICU to the Cardiac Progressive Care (Step Down) Unit

- The CPCU is a lot more hands-on for families. You are encouraged and expected to tackle more of your child's daily cares including feeding, bathing, and soothing. If you need to grab a bite to eat (or shower) let your nurse know and they will keep a close eye on your kiddo.
- The nurse-to-patient ratio in the CICU is 1:1 post surgery, and 1:2 when your child is stable. The ratio in the CPCU is often 1 nurse to 3 or 4 children. Be a little patient. If your nurse is busy, a nurse at the station may be willing to help!
- You are still welcome and encouraged to participate in rounds. You can also request a meeting to discuss your child's care with their team.
- If there are things you are not comfortable doing for your child, ask your nurse to help or show you. Perhaps even schedule a time so they can get coverage for their other patients and devote more one-on-one time to teaching you.
- If you have specific requests, write them on the white board in your child's room. For example: No TV past 9pm.
- You are not required to stay the night with your child. However, as discharge approaches, you must prove to the team that you can take care of your child independently. If staying the night is a challenge, make arrangements now.
- You can get your child up and moving by walking to the playroom or out to the lobby. If your child is under precautions, you may be restricted in where you are allowed to go. Ask your nurse if you are unsure.
- Water, milk, juice, and ice are located in the kitchen across from the nurses' station. Linens are located in the closets between the rooms and the hall.

Helpful Things to Know

- Financial Counselors are available if you have any questions regarding possible bills that you may incur while inpatient. You also may be eligible for Medicaid coverage even if you have private insurance. Ask your child's social worker and call the Financial Counseling office for more information.
- Resource Nurses are available to assist your child's nurse. They have additional training and are generally quite successful in placing IVs, so if your child requires multiple IVs or is a "hard stick", feel free to ask for one.
- Sleep rooms are located throughout the hospital and can be booked the morning of your stay on a first-come, first-serve basis. For more information, visit the Volunteer Office on the first floor or call them at (720) 777-6887.
- Showers are located in the CPCU and on various floors throughout the hospital. Just ask for directions and/or a code to use these.
- Laundry Facilities are located on the 2nd floor and the Volunteer Office has detergent packs. Please be aware that if your child is on precautions, you will not be allowed to use these.
- There is a late night menu (after 9pm) in the cafeteria, which is open 24 hours.
- The Creative Play Center is available for siblings up to age eight on a first-come, first-serve basis and is located off the west end of the Fresh Market Place (cafeteria). Siblings will not be allowed if the patient is under precautions. For more information, call (720) 777-6999 and ask for the Creative Play Center.
- The Walgreens Pharmacy on the first floor is a compounding pharmacy. Contact them at (720)262-4524.
- If you wish to get out and see something fun, many places allow free or discounted admission for families while inpatient. Contact the Concierge Service at (720) 777-8029, Monday-Friday from 7:30am-7:30pm.
- For free days at local institutions like the Denver Art Museum and the Denver Zoo, check out the Scientific and Cultural Facilities website at scfd.org

Congratulations, You're Going Home!

It is a REALLY big day! You are finally taking your child home and you are excited but probably scared at the same time. Take a deep breath and know that you will do a wonderful job. If you have any questions or concerns, you have a wonderful team who is not only able, but WILLING to help you whenever you need. So, keep the cardiology and nurse's numbers handy and tap into the support system and resources you have been given.

Some things to expect in the coming days and weeks ahead:

- You will probably visit the Cardiology Clinic 2-4 times in the first month after discharge, depending on your child's diagnosis and medical needs.
- You will need to keep track of your baby's eating, weight, medications, and oxygen trends (try to not make yourself crazy by taking these too often!)
- Expect to hit bumps in the road- they are normal in any recovery. However, if something in your gut tells you it's not right) or you need some peace of mind), call Cardiology Clinic and talk to one of the nurses.

Most of all, believe in yourself because YOU CAN DO THIS! Enjoy being home!

Heart Hugs!



Additional Support

Pediatric Congenital Heart Association <http://conqueringchd.org/colorado>

Heart Mommas Colorado - Find us on Facebook!

Heart Dads Colorado - Find us on Facebook!

Colorado Single Ventricle Families - Find us on Facebook!