

**Interstage: An intense but temporary rollercoaster.**

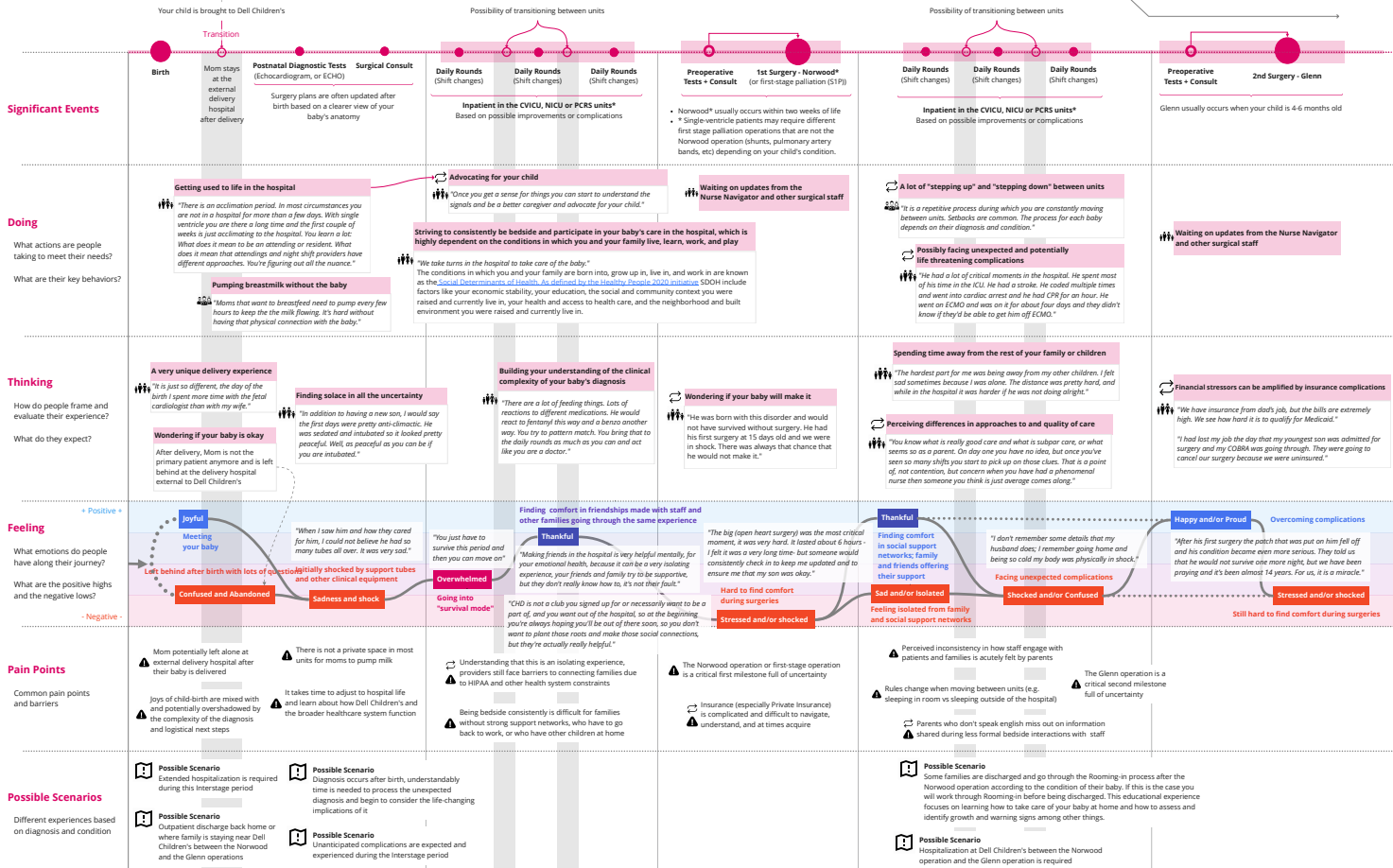
Parents

Patients

Occurs many times or throughout your life

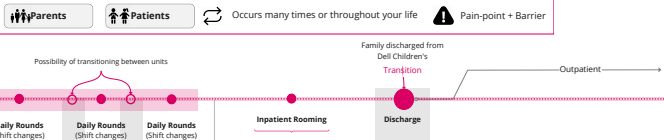
Pain-point + Barrier

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Map continued from prior page

Interstage: An intense but temporary rollercoaster.



Significant Events

**Inpatient in the CVICU, NICU or PCRS units\***  
Based on possible improvements or complications

**Doing**

**Getting used to rotating providers and hospital life**  
"Day one in the hospital and I didn't know the rhythm of the hospital and how it works. After time you learn what a shift change looks like and what procedures are... in those first few days everything is new and interesting and you don't know what frustration or exhaustion is. A lot of it is absorbing these things."

**Potentially exhausting yourself physically**  
"You are basically living in the hospital. Sometimes you're only sleeping an hour a day. At the same time you want to be sure you are there for the rounds."

**Getting ready to take care of your baby at home**  
"They teach you things like how to manage the tube in the hospital until you have to do it at home. At the beginning I was nervous but you get used to it."

**Transitioning back home after the interstage period**  
"It's a gradual adjustment to normal life after being in the hospital all that time. We had all those unstable moments, so it's nerve wracking to go home. You're so eager to go home but you're on edge at the same time."

Thinking

**Dealing with an overwhelming amount of provider voices**  
"In one point I calculated how many doctors and nurses cared for our son over six months and it is insane! High. It feels like so many different people to communicate with. This goes back to the issue of not feeling like there was someone who you look back."

**Trying to control the feeding process**  
"With feeding there is this maternal and biological drive and that makes sense. Every heart mom gets obsessive about the feeding. It is something you feel like you should understand and be able to control."

Feeling

**Positive**

**Eager and/or Optimistic**  
Being with your baby and getting to hold them

**Joyful and/or peaceful**  
Celebrating successes, small and large

**Optimistic**  
Seeing progress or stepping down to less intensive units

**Relieved**  
The hardest part is over

**Loved**  
"Supporting each other and making us grow stronger and closer as a family."

**Stranger family bonds are built through adversity**

**Appreciative**  
"When you are going through the process it is so traumatic. I was a lot younger then and I have grown a lot since. I don't know if I could have discussed what I was going through at the time, I was so disconnected."

**Relieved**  
"I didn't know that there was hope. Now I know I just needed to survive it. I wish someone had told me that at the beginning."

**"The hospital experience was terrible. It was an awful time. He was in the hospital for 42 days."**

**"It's going to be hard. Six months of high stress and a bit of different permutations of outcomes. It is a hard spot to be in. The segment of this and that there are mitigations you can put in place to make it easier."**

**Negative**

**Exhausted**  
Physical toll of "living in the hospital"

**Anxious**  
Learning how to take on full ownership of your baby's care

**Intense, emotionally heavy journey**

Pain Points

**Parents interact with many Providers during their time in the hospital, sometimes Providers have conflicting opinions or a different approaches to engaging with patients and their families**

**Feeding, which will seem like a natural process, becomes a milestone on the path to being discharged home due to the impact of caloric consumption on baby development**

**Physical and mental fatigue and/or exhaustion take a toll on parents**

Possible Scenarios

**Possible Scenario**  
Most families are discharged and go through the "Rooming" process after the Glenn operation according to the condition of their baby. This is the case you will work through "Rooming" before being discharged. This educational experience focuses on learning how to take care of your baby at home and how to assess and identify growth and risk factors among other things.

Things to consider

- This part of the journey is more relevant for parents
- Experience varies according to location, unit, available specialists, and anatomy
- Some families stayed in the hospital during all the interstage period or might be discharged before the first surgery and/or in between surgeries (See: A life long journey and map 2.2 for more details)
- Every family and every patient's experience and needs may be too. This is meant to serve as a point of reference based on patient and family interviews conducted in the Summer of 2020.

Interstage and the IMPACT program

**What is the interstage period?** Interstage refers to the "high risk" period between your child's first major operation, the Norwood (or first stage palliation surgery) and their second major operation, the Glenn operation. The Norwood (or other first stage palliation surgery) is performed as soon as your baby is physically ready after birth, and the Glenn operation is performed between 4 and 6 months of age. The heart works very hard after the Norwood operation, and your child will likely require feeding support and careful monitoring for potentially life-threatening medical complications during the first six months of their life.

**What is the IMPACT program?** The Center for Pediatric and Congenital Heart Disease at Dell Children's has an **Interdisciplinary Monitoring Program for Ambulatory Cardiac** care known as the IMPACT program. This program was started to support Single Ventricle patients and now offers support to other high-acuity patients.

**Daily Rounds:** These are daily visits from the care team including different disciplines, there are two main daily rounds one by the surgery team and one by the psych-social team. They will walk through the latest updates, goals for the day and next steps.

**\*Where you'll be during the Interstage:**

There are three primary inpatient care units and one outpatient cardiac clinic that your baby might stay in, transfer between, or be seen in depending on the complexity of care their diagnosis requires. According to your baby's specific journey you might transition back and forth between these units.

**CCU: Care Cardiac Unit**

Located on the second floor the CCU offers specialized cardiac care. All babies being monitored for cardiac conditions come to the CCU. The Cardiac Care Unit is home to the most intensive care-oriented CVICU and the intermediate care-oriented PCRS.

**CVICU: Cardiovascular Intensive Care Unit**

All post-op hearts will be cared for in the CVICU. The CVICU centralizes the most intense cardiac care in the hospital by cardiac intensivists as well as nurses and other support staff that work most extensively with our patients. The experience for families will differ based on how sick their child is. The most critically ill will have multiple members of the nursing and support team assigned specifically to care for them and they will likely interact with the cardiac intensivist team frequently until the child stabilizes.

**PCRS: Pediatric Consultative Referral Service**

The Pediatric Consultation and Referral Service (PCRS) has a dedicated arm of physicians that have special interest in training and caring for cardiac patients. When patients are admitted to the hospital under the care of PCRS, they will receive medical care from a PCRS attending physician with the rest of the cardiac team.

**NICU: Neonatal Intensive Care Unit**

Located in 4th Floor. Babies come to the NICU for many reasons, but primarily because they need more care than is offered in the regular nursery. The goal of the NICU is to provide excellent care to your baby and provide you with the tools needed to share positive experiences with your baby. The Level IV NICU has 30 beds and offers 24-hour coverage by neonatologists, nurses, surgical specialists, and ancillary staff who work closely with physicians in a variety of specialties to care for the diverse medical needs babies there. The NICU has all private rooms that control light and sound to aid in the healing of the newborns. There are also Infant/Parent Bonding Rooms to provide monitored support to help parents prepare for home care.

**Cardiac Clinic**

4th floor. The Cardiac Clinic is sometimes referred to as the "IMPACT" clinic. This is where providers follow IV Intensive patients who are discharged and living at the Ronald McDonald House or live close enough to Dell Children's to stay at home.

**Outpatient Unit**

Parents frequently go home with a G or NG Tube and require Speech Therapy after the interstage period

Common Challenges

Supporting Approaches (brain development)

Open heart surgeries at this early stage of life can impact your baby's neurodevelopment, which is why different therapies and psych-social support are essential to support the development of your baby's brain during the interstage period and onward through infancy and toddlerhood.

Neurodevelopmental Behavioral Domains



- Providers who can support your baby's neurodevelopment:**
- Nutritionist:** Measure growth and ensure adequate caloric intake (accounting for possible food allergies).
  - Speech Therapist:** Work with you and your baby on feeding skills if your baby has difficulty with traditional oral feeding.
  - Physical Therapist:** Evaluate your baby's physical development and muscle use.
  - Psychologist or Licensed Social Worker:** Support the bonding between babies and parents by providing appropriate emotional development, management of family stress, and education around appropriate coping mechanisms.
  - Child Life Specialist:** Help families and children cope with the challenges of hospitalization, illness, and disability.
  - Music Therapist:** Music can be used to address some of the physical, emotional, cognitive, and social needs of your baby.

Feeding and Nutrition

Due to multiple surgical operations and potential complications or prolonged hospitalization your baby will likely need some extra nutritional help to support their physical and brain development. Depending on their diagnosis and condition they will likely progress or revert through the following cycle of feeding:



This feeding method is used to feed your baby until their digestive system is ready to eat. Breast, or bottle feeding. This feeding provides all the nutrients your baby needs through the vein. Providers utilize this method of feeding when your baby's digestive system is not mature enough to absorb adequate nutrients through oral traditional feeding methods. If your baby is intubated and/or has traditional oral feeding methods are not possible.

Once your baby is stable enough to receive nutrients through their stomach, usually through G-tube or bottle feeding. This feeding provides all the nutrients your baby needs through the vein. Providers utilize this method of feeding when your baby's digestive system is not mature enough to absorb adequate nutrients through oral traditional feeding methods. If your baby is intubated and/or has traditional oral feeding methods are not possible.

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**Fear and parent-child bonding:** Initially it may be very shocking to see your baby connected to multiple machines. Your baby may also appear to be very fragile, which may lead you to be sure to touch them. Touch and emotional engagement can provide early childhood development. Be safe to touch them. The most appropriate way to connect with your baby based on their diagnosis and condition.

**Logistical burdens of being consistently at bedside:** For all families and especially those lacking social support, the logistics that enable parents to be at bedside on a consistent basis can become burdensome. Families are tasked with potentially negotiating bedside shifts between parents, catching up or engaging during provider rounds, balancing their duties at work, their family expenses, and caring for their other children at home. These logistical burdens in addition to the emotional gravity of the interstage period can be very intense.

**Partnering with Providers to advocate for your baby:** As you spend more time with your baby and observe their behavior, you'll grow to better understand their cues and body language, putting you in a position to advocate from more effectively. You'll spend more time with your baby, your role and relationship with providers may also evolve into more of a partnership. You may be relied upon by Providers to be your baby's advocate. Learning when and in what ways to engage with Providers to best support your baby can be challenging.

**Interstage can be isolating, even with a strong support network:** Even though family and friends might try to be supportive they may just not "get it." The interstage period is a complex, highly emotional journey that is best understood by those who have been through it themselves. While it is uncomfortable, establishing social connections with other families going through their own interstage journey or with families and patients who have been through Interstage themselves can be a very helpful, especially for families and parents who had to move to central Austin, leaving family and support networks at home.

**Multiple Providers means multiple voices, opinions, and at times approaches:** Over the course of the interstage period you will interact with a lot of different Providers. There are a lot of different providers working in the CCU, CVICU, NICU, and the Cardiac Clinic at Dell Children's. Providers frequently rotate in and out of these units. Sometimes you may hear seemingly conflicting opinions and will notice inconsistencies in approaches to care, which may feel like a lack of support.

**Parents neglecting self-care is all too common:** It is common for parents to dedicate themselves to the full-time care of their baby during the interstage period. It is also common that in doing so parents neglect self-care. It can be hard to leave your baby's bedside but you need to make time to take care of yourself so you can be there as your best self for your baby to take care of them during this stage of their Child Journey.