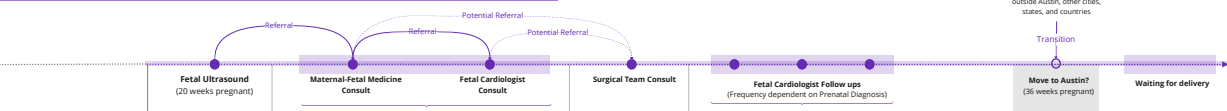


# Prenatal: Expectation Shattering Diagnosis

Parents
Patients
Occurs many times or throughout your life
Pain-point + Barrier



## Significant Events

**Doing**

- Learning about the diagnosis:** Lots of self-guided research and google searching. Going to different forums and clinical websites to understand the basics of the diagnosis.
- Meeting with multiple specialists:** We meet with lots of specialists. The immunologist told us that he wouldn't have normal immune system and we weren't sure if that would happen. We know now that it didn't, but it was a lot of stress at that time.
- Shopping around for and selecting a program + hospital:** You shop around for the surgeon, you don't shop around for the internist or the nurses, even though you spend more time with them. We developed a relationship with our surgeon, but we talked with the internist and nurses way more than him.

**Thinking**

- Accepting that your baby's anatomy is evolving and uncertain:** Every appointment we had a different view of the anatomy and the diagnosis changed too, this was part of the roller coaster at the beginning.
- Grappling with the tension of considering termination and hope:** We were looking at the termination cut off in other states if we needed more time. We didn't know there was hope.

**Feeling**

- Stressed:** Coping with a life altering decision
- Overwhelmed:** Panicled online research
- Confused:** Complex planning with limited support
- Stressed:** Preparing for birth can be a logistical challenge
- Guilty and/or Confused:** Making sense of the diagnosis by seeking information as a way to take back some control
- Optimistic:** Confidence in care as things go as planned
- Confident:** We had our 20 week anatomical scan in Austin. They could see that something was wrong with the heart. They were talking about MRI and that is not the correct diagnosis. They were not cardiologists or heart experts. It was very upsetting and stressful.
- Expectation shattering diagnosis:** We took it very bad when we learned about the defect. She was alone when she heard the news for the first time.
- Shocked and/or Devastated:** That was an incredibly stressful period especially knowing that it was a life altering decision.
- Insured and income are sources of concern:** We went from two incomes to one overnight.
- Uncertainty about life in the hospital and what you may need:** We had questions that no one had ever answered. I had no one to ask.
- Insurance and income are sources of concern:** We had a lot of social workers reach out in [city]. They wanted to help with parking, child care, lactation, in [city] they had to come and do classes when I was pregnant and do a tour with the NICU.
- For four weeks there was a bit of a vacation period when we were in the city and we were just waiting. We knew we were keeping the baby, we knew the surgery plan. We knew there was nothing we were going to do until he was born.**

**Pain Points**

- Guilt is a common reaction when the diagnosis is initially established**
- Difficult to listen to many voices and make sense of different specialist's perspectives and opinions**
- While working to understand your baby's possibly changing diagnosis, online research can be tricky since each family's experience is unique and not all sources of information are credible**
- Coping with your baby's changing anatomy and diagnosis and the associated uncertainty and anxieties**
- Parents often have lots of questions about next steps and are not always able to find adequate answers to mediate their stressors and anxieties**
- Every family and their CHD experience will be unique, so some families and caregivers need more help and support than others**
- Job and/or financial insecurity for one or both caregivers**

**Possible Scenarios**

- Possible Scenario 1:** Prenatal Diagnosis at 20-week ultrasound
- Possible Scenario 2:** Prenatal Diagnosis changes as anticipated due date nears
- Possible Scenario 3:** No Prenatal Diagnosis at 20-week ultrasound
- Possible Scenario 4:** Prenatal Diagnosis does not change as anticipated due date nears
- Possible Scenario 5:** Already live in Austin
- Possible Scenario 6:** Move to Austin and stay with family, relatives, friends
- Possible Scenario 7:** Move to Austin and rent apartment or home
- Possible Scenario 8:** Move to Austin and stay at the Ronald McDonald House

## Things to consider

- This part of the journey is **more relevant for parents**
- Experience varies according to location, city, available specialists, and anatomy
- Not all families are diagnosed prenatally** (see the Lifelong Journey Overview map for more details)
- Every family and every patient is different, your journey will be too. This is meant to serve as a point of reference based on patient and family interviews conducted in the Summer of 2020.

## Common Challenges

**Conflicting emotions**

Excitement, fear, grief, and joy collide. Parents go from expecting a normal kid to learning that their baby will need lifelong medical care and constant monitoring during their first years of life. Diagnosis is a life-altering event for families, where life-and-death decisions have to be made very quickly. However many families also experience the anticipation and joy that other expectant parents have, while preparing to face the challenges ahead.

**Shopping for surgeons**

Parents need to decide where they want to go for this highly specialized treatment and, for many, this is the first time they have to deal with the complexities of the healthcare system. The ones that dig deepest, and have the means to do so, find out how to shop for a surgeon and what to look for before entrusting a care team with their newborn.

**Learning without knowing**

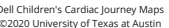
There are abundant opportunities to learn more about congenital heart disease during this time. Parents receive information directly from providers, they may learn more from online resources, and some may even reach out to their networks and online communities to find other parents who have been through the same process. However, because some things about the baby's anatomy can only be confirmed or known after birth, there are few resources which inform parents of what will happen precisely during their baby's treatment.

**Logistics**

Having a baby will change a family's life, and having a baby with single-ventricle CHD will change it even more. It disrupts family life. Before delivery, families may need to move within a few minutes of the hospital they choose. Some people move in with friends or family, rent an apartment, or live at the Ronald McDonald House. Families also need to consider transportation to and from the hospital to be with their child. If you have older children you may have to change your child care plans to accommodate uncertain and unexpected demands of your time during and after the interstage period.

**Job insecurity**

Parents face substantial pressure to be present in the hospital as much as possible during the interstage period. Most people have to figure out how to balance their desire to be with their child and their need to maintain employment and insurance. It will be difficult for both parents to hold on to their jobs. Some care takers may be able to take an extended leave of absence or divide responsibilities with their partner. Other families have to make harder decisions between the income and financial security they need and being attentive to their child and the expectations of the hospital.



Adult/hood

Adolescence

Childhood

Interstage

Prenatal

Adult/hood

Adolescence

Childhood

Interstage

Prenatal