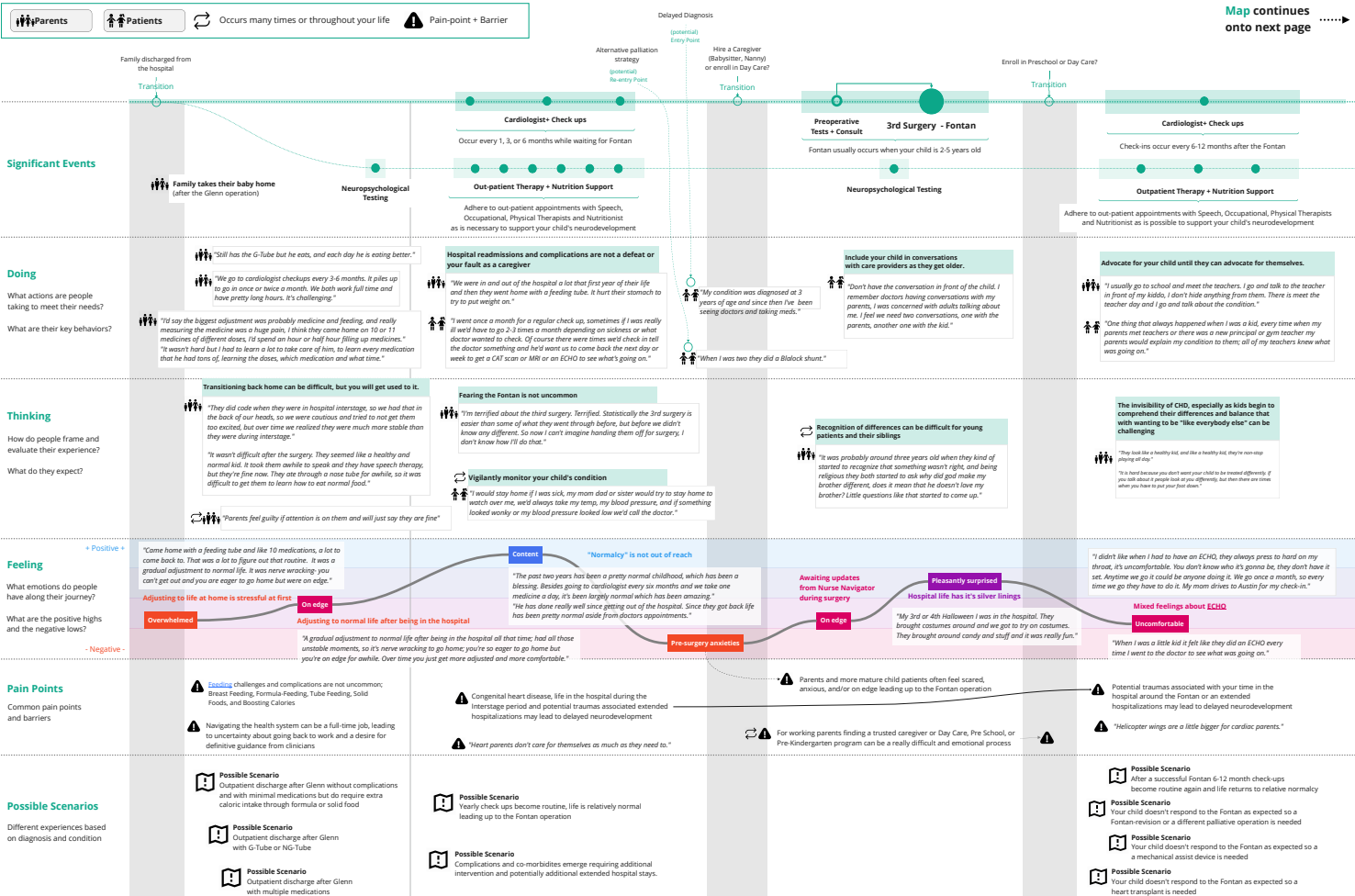


Childhood: Coming to terms with your condition as you grow up and start school.

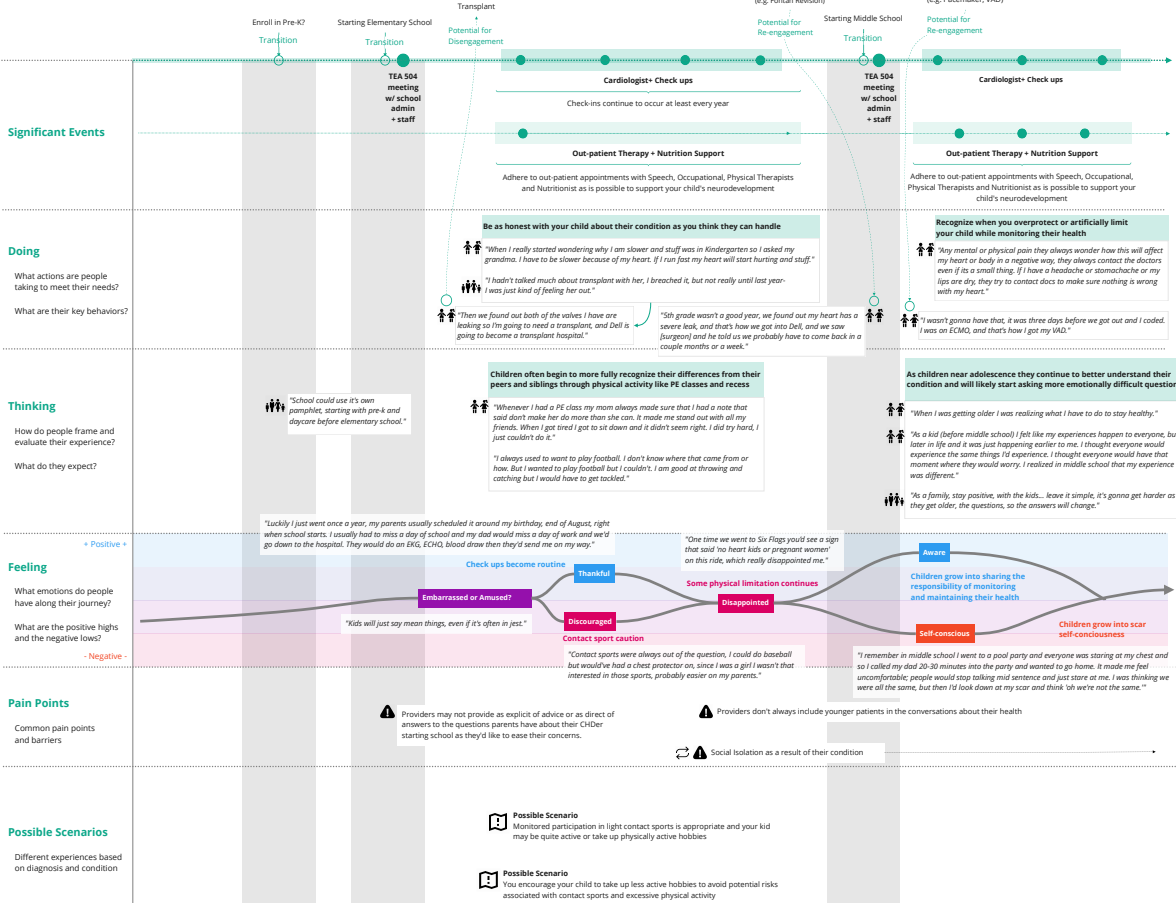
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Adulthood, Adolescence, Childhood, Intergate, Prenatal

Childhood: Coming to terms with your condition as you grow up and start school.

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



Things to Consider

- The earlier stages of Childhood (Infancy and Toddlerhood) steps are more relevant for parents
- The later steps as you near Adolescence become more relevant to child patients
- Palliative support required varies according to your geographic location, cardiovascular specialist availability, and your unique diagnosis and anatomy
- Every family and every patient is different, your journeys 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

Feeding and Feeding Support

There is a high likelihood that your child will have needed an assistive eating device during the Intersage period and that they may need feeding support once they come home. Approximately 70% of patients end up needing a G-Tube during the Intersage period and a considerable portion end up going home with some form of feeding support. Eating is a challenge during Intersage that continues once you bring your child home. Feeding via eating and sucking is highly associated with speaking so it is important to remain patient and persistent when it comes to feeding.

Medication Management

Some people have described caring for their child at home as feeling like a pharmacist due to getting used to managing your child's daily medication needs. For others medication management is less of a challenge and is something their children quickly grow into managing themselves.

Navigating normalcy while striking an appropriate balance between monitoring and helicoptering as a parent

Many kids don't want to feel or be perceived as different and will do their best to act "normal" like their siblings and peers, at times overcompensating to do so. While it is important to vigilantly monitor your child's condition, do your best not to artificially limit them or stop them from reaching their full potential. You might be surprised by what your child is capable of if you give them space and autonomy to test and understand their own boundaries.

Do remain aware of your children's activity in extreme heat or cold, and ensure they are consistent about staying hydrated.

*Additional palliative operations may be needed

The need for a single or multiple palliative operations after the Fontan is not uncommon. In many instances patients get to choose whether or not they want to undergo an operation. As your child matures, educating them about their condition is crucial as it will help them make a more informed decisions about elective or necessary palliative operations.

[A Parents Guide to Cardiac Surgery](#)

Additional Units and Clinics

PCU: Pediatric Intensive Care Unit

Located in the 2nd floor the Pediatric Intensive Care Unit (PCU) at Dell Children's is the only critical care facility expressly for children in Central Texas. This 24-bed unit delivers highly-specialized care to children with a host of illnesses and injuries, many of them life-threatening. Our pediatric intensivists, working with a team of subspecialists and nurse practitioners, participate in the care of all patients admitted to the PCU. Emphasis is placed on a multidisciplinary, collaborative approach to care for a diverse and challenging patient population.



CCC: Comprehensive Care Clinic

Established in 2012, Children's Comprehensive Care (CCC) clinic is a primary care clinic dedicated to the care of children with complex medical issues. Our program is part of the Dell Children's Medical Group of pediatric subspecialties. This innovative model creates a cohesive family-centered care delivery system to provide wraparound care for children with challenging medical needs.

