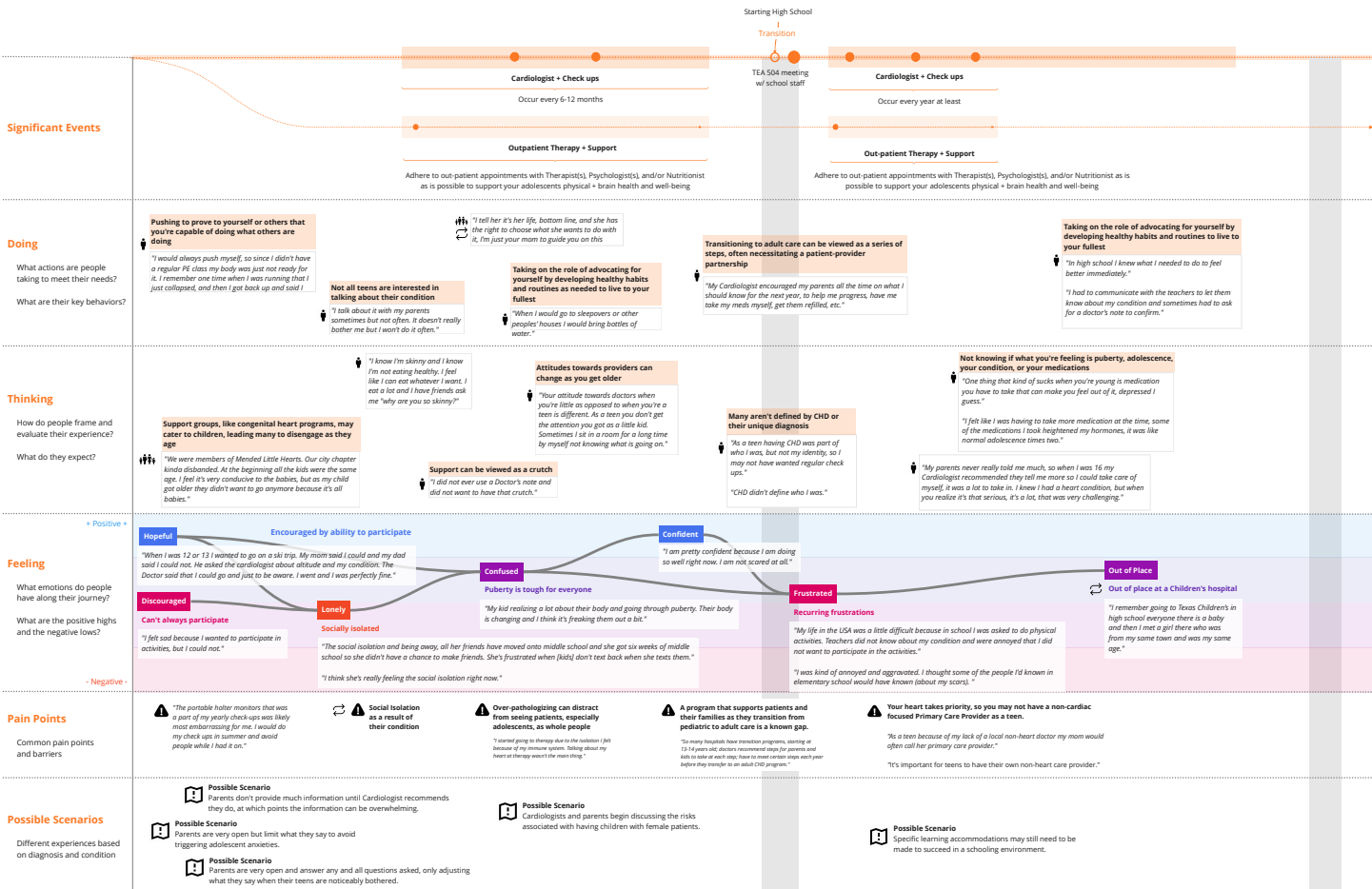


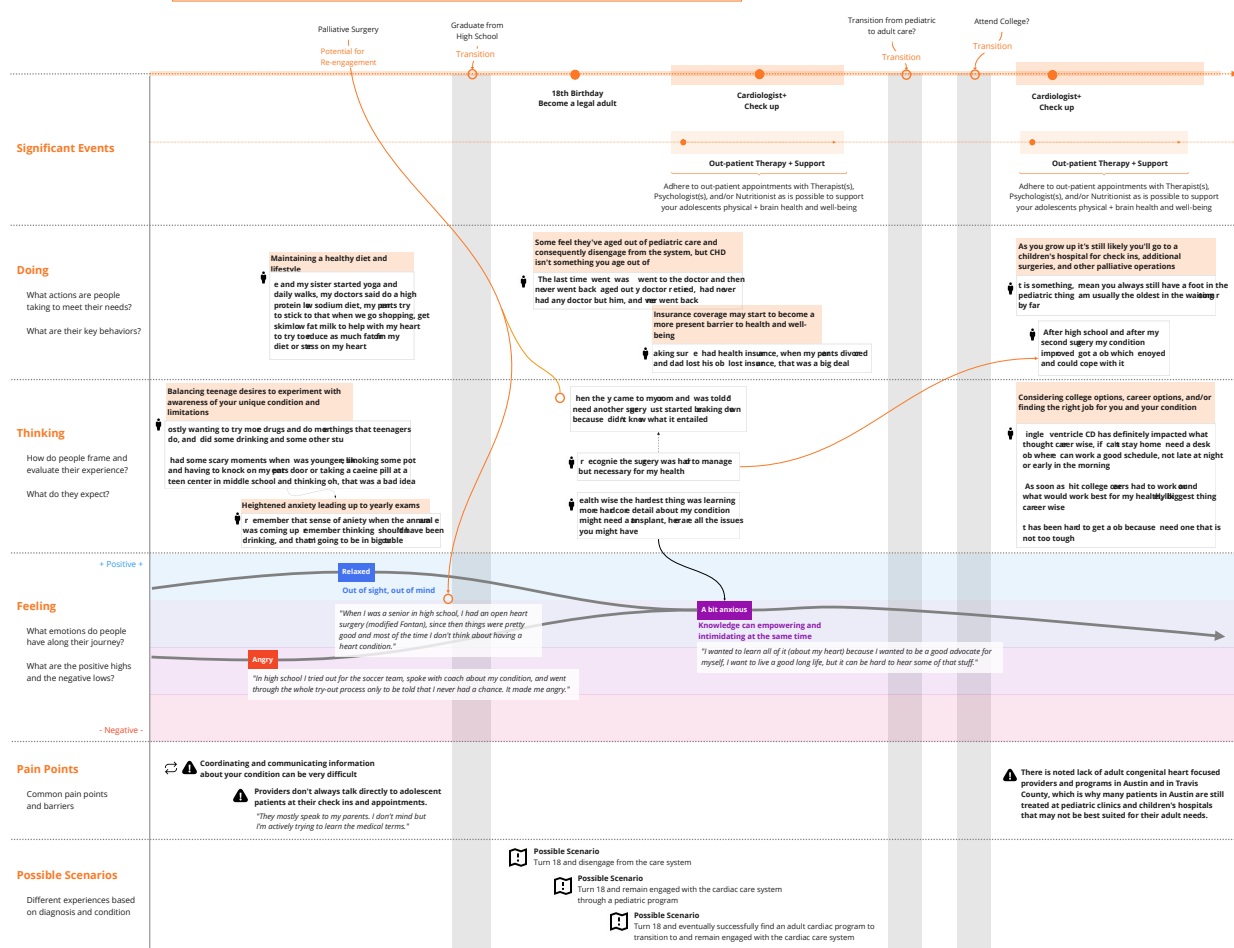
Parents
Patients
Occurs many times or throughout your life
Pain-point + Barrier



Adolescence: Taking steps towards owning the monitoring & management of your condition while working to avoid artificially limiting your teen or yourself.

Map continued from prior page

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



Things to consider

- The earlier steps of this Adolescence map are more relevant for parents
- The later steps of this Adolescence map are more relevant for patients as they mature and develop
- 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

As you mature, expect to take on more ownership of your condition so you can care for and advocate for yourself along with support from your family

Learning more about your health and your condition can be an emotional journey, but ultimately it is what will empower you to be responsible for yourself as an adult and stay healthy as you grow older.

Finding a balance between career aspirations, family planning, and the realities of your condition is going to be an individual process

All teenagers have to make choices to set themselves up for the kind of adult life they want to have. For teens with single-ventricle CHD there are some extra factors to consider when thinking about education, jobs, and having your own family some day. It is a good time to start these conversations with your family and health care providers so you can practice learn more and start working toward the life you want.

Transition to Adult Care is a known gap in Austin, filled by Dell Children's, which means adolescents and adults often engage with programs designed for children

Because of the prolonged need of surveillance for complications, patients with congenital heart disease tend to develop a deep attachment to their pediatric doctors. The transition to adulthood can be critical in that sense. When they become adults, and need to switch doctors, there is a risk of lapses in care that exposes them to adverse health outcomes. Many patients choose to stick to their pediatricians, and report being the oldest person in the waiting room.

Puberty and Adolescence are difficult for most, your diagnosis and condition may make this challenging time even more challenging

Adolescence is rife with physical, social and emotional challenges. Developmental steps that are already difficult are even more difficult for single-ventricle CHD patients. These include accepting physiological changes, body image, selecting a partner, finding a social group, completing school, self identity and adopting a healthy lifestyle. A formal transition program may help prepare young adults for transfer of care and responsibilities.