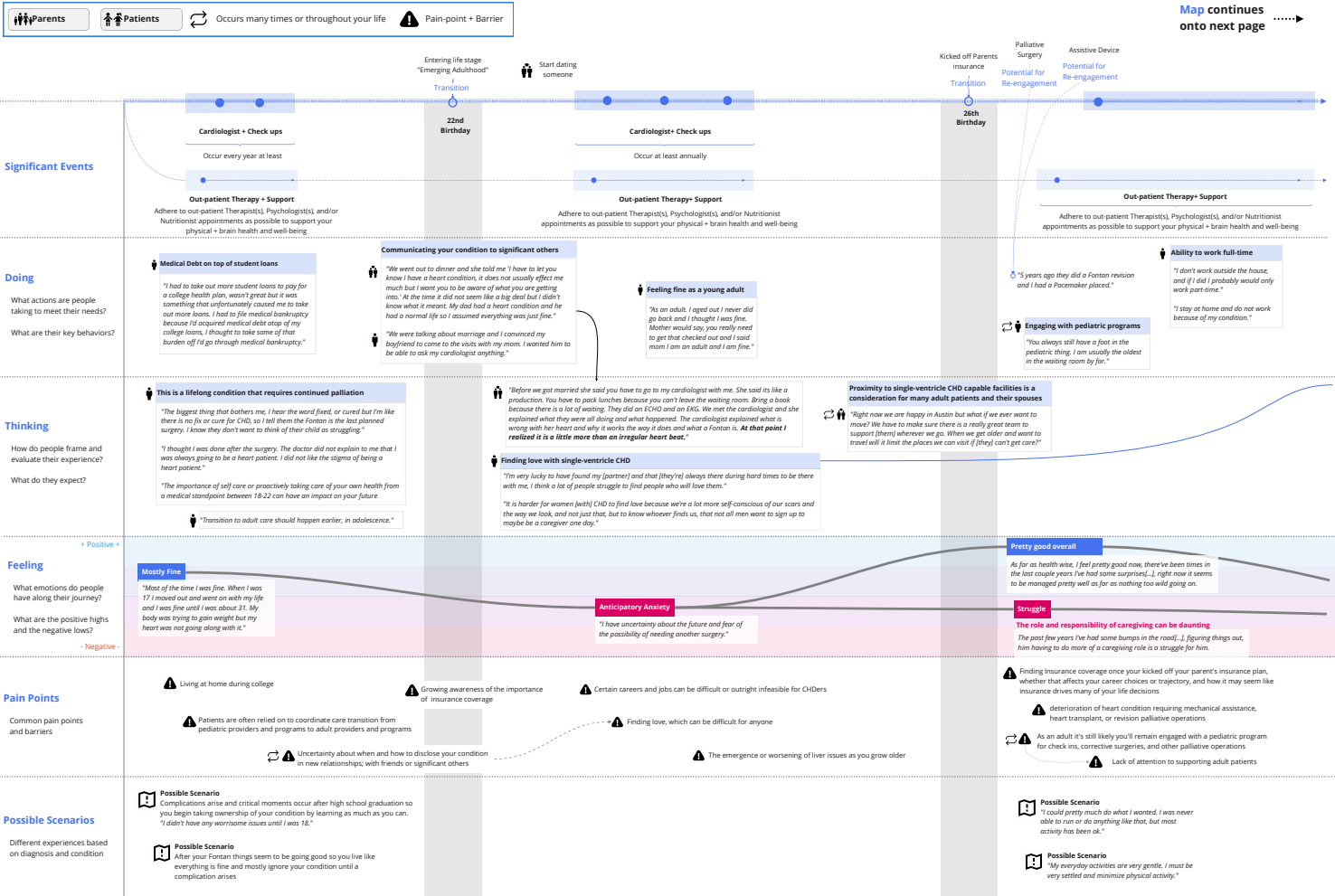


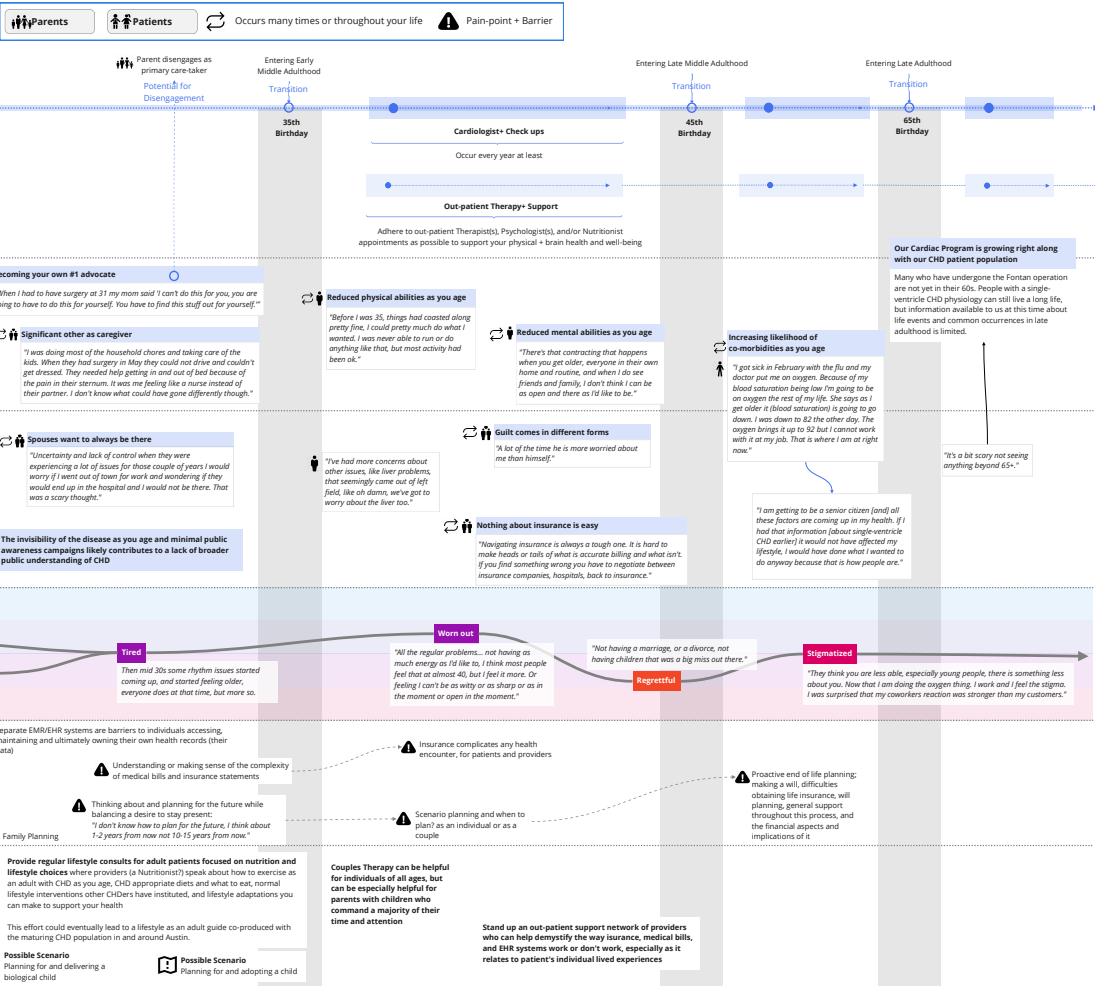
Adulthood: Owning the care of your condition and potentially sharing ownership of your condition with a partner



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Map continued from prior page



- ### Things to Consider
- The earlier sections of this Adulthood Map are more relevant for adult and potentially adolescent patients
 - The later steps of this Adolescence Map are more relevant for adult patients and their significant others as they age
 - 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

Co-morbidities and medical complications developing as you grow older

Non-cardiac comorbidities in adulthood are increasingly common in single-ventricle CHD, and that is due mainly to the extended lifespans afforded patients by new medical treatments. They come as a surprise to many patients who have to adjust their work, hobbies and lifestyles due to a decreased physical capacity. It is important to develop screening programs for comorbidities and for treatment of common single-ventricle CHD disorders, with emphasis on disease prevention, quality of life improvements and socio-psychological care.

Dating, long-term relationships, and significant others taking on the role of care taker

Most patients report being very up-front about their condition with potential partners. Partners, on the other hand, frequently report not understanding what they were "signing up for". Communicating the gravity of one's condition to a significant other, not ignoring the fact that that person may eventually have to play the role of a caretaker, paves the way for a great relationship. When and how to do it is up to the individual. Is coaching on this sensitive topic possible?

Family planning, having biological children, and adoption

Because of the increased risks to both the mother and the fetus, doctors tend to not recommend that women with single-ventricle CHD become pregnant. Also, the chance of having a baby with single-ventricle CHD is higher in one of the parents has it, and a little higher if that parent is the mother. But many young couples feel it is worth taking a chance, and many have healthy babies. A support service that advised and guided through the best path for them —whether pregnancy or adoption — could be helpful.

Likelihood of engaging with a pediatric program as an adult in lieu of local specialists

The number of adults with congenital heart disease is increasing. It does not follow that the number of specialists in adults with single-ventricle CHD is also increasing. Adult single-ventricle CHD specialists are rare in the country, and non-existent in Austin. Adult patients are forced to continue to see their pediatricians, but adults are not large children. In addition to not receiving the specialized care they need, adult patients have to deal with a system that is not prepared for them in details from toys and small furniture in waiting rooms to lack of guests in adult sizes.

Adulthood
Childhood
Emergence
Prenatal