The Transition Tango

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Ever since Kayla was born we have been struggling to learn the steps to this perpetual transition tango. At birth she was whisked off to the newborn intensive care unit with a transition home shortly thereafter. At three months she was transitioned into a pair of eye glasses after an optometrist realized she was in need of visual correction. When six months rolled around yet another transition with the diagnosis of severe visual impairment with an underdeveloped brain; this newest transition offered us the medical diagnosis of septo-optic dysplasia. We were introduced to many more dance steps over the next ten years. At age six the transition to a diagnosis of autism, at age ten we transitioned into the diagnosis of panhypopituitarism which offered us the experience of having “life threatening conditions”, and then liver disease.

Each one of these new steps brought with it a new physician with the knowledge and experience of each newly acquired diagnosis. We didn’t resist each of the transitions, but we didn’t welcome them either. Kayla was around fourteen when I realized the doctor who held all this information, the doctor who navigated the maze of specialized medicine with all of its mystery titles and foreign information, was Kayla’s pediatrician, Dr. Hester. The pediatrician had the lead in this dance with a step called pediatric medical care. Sheer terror rolled over me as I realized there could be an expiration date for each of the professionals who helped me unscramble medical terms and understand how they affected Kayla and her life.

It was then that I started asking each of Kayla’s specialists what their expiration date would be in Kayla’s world. The first was her pediatrician who reported, “most likely when Kayla is 21.” I thought, “Okay, that gives me a few more years!” Then I moved on to the endocrinologist, the gastroenterologist, neurologist, pediatric dentist and the developmental and behavioral pediatrician. All reported an expiration date of 18 years of age, except the developmental – behavioral pediatrician, she reported that in her practice she would support Kayla forever. My heart did the happy dance!

So I added up all the information I had received, endocrinologist, neurologist, dentist and gastroenterologist all would have an early transition, but the pediatrician would be right beside us because we wouldn’t have to transition from her for a few more years. But the best news of it all was that Kayla would be able to receive the needed support for the rest of her life from her developmental pediatrician… or so we thought.

A few months before Kayla turned 18 the medical group which provided all of Kayla’s medical care amended their policy on admission of a person over the age of 18 into their children’s hospital through the emergency department. Since that is how Kayla was typically admitted due to acute adrenal crisis, we found ourselves in a panic. The pediatrician did not have hospital privileges in the other hospital on campus. Terror consumed my thoughts. Then we learned Kayla’s developmental pediatrician had passed away unexpectedly after a short battle with cancer.

Again the dance steps had changed but this time it felt as though the music had stopped as well. No one could imagine how this unexpected situation engulfed our thoughts and emotions. We were forced into this transition process with no support and guidance. We felt alone. We later learned Dr. Hester, the pediatrician, was working behind the scenes to connect with an old friend, inquiring if she would accept Kayla into her family medicine practice. When that connection was secured, I was forwarded the whole conversation between physicians and asked if I would be interested in meeting a doctor who wanted to take Kayla's care as her own. It touched me to see how Kayla's needs were described in this referral process.

In the hustle to find a physician we were tripped up once again. The connection to the new potential physician came just shortly after Kayla turned 18 years old. When we called the insurance company to have her PCP changed from the pediatrician to the family medicine doctor, the insurance company informed us they would need to speak with Kayla since she was an adult. I explained to them that Kayla does not talk or communicate in any typical way. I was told we would need to have her sign an agreement to allow us to make this change for her. I tried to explain that she doesn't write either. They encouraged me to obtain an attorney to get a Power of Attorney. After many challenges with the legal system we were required to request guardianship through the court system in order for Kayla to complete the transition from pediatric care to adult medical care.

It was the day we walked into the new PCP's office that I learned, the music is nice, the moves are sweet but it's the partner that makes it a dance. Kayla's anxiety was pretty high but ours was even higher. Kayla resisted any interaction from the new doctor. She dealt with her anxiety by rocking and quietly humming different tunes. While the new PCP, Dr. Franklin, continued to learn as much as she could from me and my husband, she continued to attempt interacting with Kayla. When I went to show a mark on Kayla's arm to the doctor, Kayla quickly let us know "I want no part of this new doctor thing!" the singing stopped and the swaying ended. After much conversation, Dr. Franklin told Kayla that she recognized one of the tunes she was humming. Dr. Franklin told Kayla "I have twins and they love the High School Musical" and with that, Dr. Franklin began singing the song she identified. Kayla began to slowly rock again as she listened. After Dr. Franklin finished the chorus Kayla acknowledged the doctor's singing and showed her appreciation by allowing the doctor's touch to take her pulse and check her breathing with a stethoscope. The transition tango came to an end, with grace, honor and respect between our new doctor and Kayla.