

Prepare to Fight: Living through bone marrow transplant with a child

Written by: Jess Johnson

Kyle and I sat in the living room, I felt numb. Henley and I were leaving in just a couple days, Kyle and the twins would join us a few days later. Transplant was just over a month away. Were we prepared? Was I ready to leave? Had we thought of everything?

Many people told us, transplant wasn't something we could really prepare for. I disagreed. We had to try, we were preparing to fight for Henley's life. We would kill her existing bone marrow, expect her to live through that and pray new cells, donated by a young man in Germany, would grow in her body and give her a new life.

We asked the doctors, which days should we expect to be the worst? Kyle and I talked about what we thought our days would look like. Then the thought that had been in the back of our minds since she was diagnosed with Shwachman-Diamond Syndrome; "What if she dies?" asked Kyle, "What will we do?" We talked through every step of that possibility, right down to her funeral.

One of the best things we did pre-diagnosis when Henley was hospitalized at seven weeks old, was talk through some of the "What if" scenarios. When Henley needed to be flown to a better hospital ten hours from our home, it wasn't as scary, we just implemented the plan we had already discussed.

As a Police Officer, I was trained to think ahead. Train through multiple scenarios, until it becomes muscle memory. When faced with the conflict, training will kick in, you will fight and it will require little thought, because you prepared for this. You trained for this. You were ready. That is how I wanted to approach transplant. Now on the "other side" I realize although we did "train" for the challenges, I personally did little to prepare myself emotionally. Yet another trait from my previous profession. I separated some of my emotions, so I could react and think through things. Nearly a year later, I find myself struggling with the emotional effect transplant has had on me.

If you know the possibility of transplant exists in your child's future, prepare for the fight now. When the time comes, implement the plan. It won't be perfect, but it will feel a little less scary. You will feel more confident, and you will be your child's best gift. Here six things to consider:

1. Identify the type of caregiver you are and communicate that to your child's team.

Everyday there was a surprise, something I didn't expect, didn't know was coming. I needed to understand the why behind each medication, each procedure, each protocol. Some providers in our team learned this about me faster than others. I remember dreading when certain providers were on service, because I knew it would be a greater challenge for me to communicate with

them. The longer Henley was hospitalized, the more opportunities there were to explain to her team what I needed to understand as her caregiver. There was one conversation that was a turning point, a light bulb moment for me, with a hospitalist on Henley's team. He told me it is challenging for him, as a medical provider, because he has an entire unit of patients, all with caregivers who expect something different in terms of information. We talked through my expectations and my entire relationship with this doctor changed from that point forward. He helped me realize I needed to do a better job communicating how my brain worked and why, not just become frustrated with him or others on the team.

2. Understanding Protocol

Learn the word "protocol" and challenge your team to look past that word and look at your child as an individual, not just a diagnosis. This word will define the doctor's each step, understanding what it means will help you advocate and articulate the things the medical providers aren't considering or seeing. *Remember, you know your child better than anyone else in the world.* It is your job to help the doctors see your child through your eyes.

3. What brings you JOY?

Take time to think of things that will bring you happiness during this journey. I had a very difficult time stepping away, especially when things reached their worst. On those days, the best I could do was walk downstairs and buy a coffee or take a short lap around the unit. On better days, I found time to shower at our apartment, instead of the hospital or meet our twins on the playground for an hour. I filled Henley's room with Bible verses written on post-it notes. I had a calendar and a book I would make notes in. I bought myself fancy sharpie markers and color coded things I would write. Music was another thing that brought me a great amount of joy and comfort. I had a playlist on my phone named "Henley" that I listened to over and over again. It would calm me. It would remind me to trust God, and I would often pray through many of those songs.

4. Saying NO!

I can't stress how important it is to get comfortable with this word, give yourself permission to say it. Practice saying it, outloud. Really, say it right now. Think about how it feels the first time it rolls off your tongue, then say it ten more times.

I breastfed Henley exclusively through the transplant. She refused bottles, and I refused the idea of a continuous feed pump. Even when I was told by doctors and pharmacists that I should not be breastfeeding during chemotherapy, I refused to follow their recommendation. Yes, there was risk to me, but Kyle and I weighed those risks and chose what was best for Henley, and that was me feeding her.

They often presented things as, you **MUST** do this or you **CANNOT** do this. When I challenged them on things that I was concerned about or didn't agree with, like breastfeeding, I found they would adjust their language to more of a recommendation versus an order.

There was one particular day I refused all of her morning medications, until further discussion could be had with her team. Another day I activated the Rapid Response Team when I felt Henley wasn't getting the care she needed. It brought a huge team of providers into the room, a fresh set of eyes who evaluated Henley, spoke to her team of doctors and to me and ensured we were doing everything possible to give Henley the best care.

I also challenged the hospital policy on Henley's sleeping arrangements. At her very worst, it was impossible to set her down. The only way she would rest was in our arms or sleeping next to me. Sharing a bed with your child at our hospital is against policy, but I explained my reasons over and over again to providers and a charge nurse. It was not an option for me. I slept, holding Henley in my arms every night, at the hospital for well over a month. When I had reached the point of complete and utter exhaustion and had not slept more than an hour or two for four days, we were given a night nurse who held Henley for a few hours and allowed me to try and sleep.

5. Preparing Financially

Good food, coffee, additional caregivers and comfortable housing. You will need all of these and they will cost money. It's OK to accept help from others. Accept the blessings God gives you. It's OK to ask friends and family if they will host a benefit to raise money for the process of transplant. Most importantly though, take advantage of the time you have now to prepare.

We had begun following Dave Ramsey's Financial Peace University shortly after we discovered we were pregnant with Henley. We had no idea she would be born with a disease that would turn our lives upside down. Taking control of our finances and changing the way we looked at money before we were in true crisis prepared us for the challenge of a medically fragile child. When Henley was diagnosed we moved quickly and prioritized what was most important to us, materialistic things and our horse ranch lifestyle were two things that didn't make the cut. Although we were able to maintain ownership of our home, we sold many things and nearly all the horses. Surprisingly this wasn't a terribly difficult decision for us, instead it gave us peace and made us feel in control. There were additional things on the list that also would have gone, if needed.

Utilize Bite Squad or Grubhub, a food delivery service. Make a list of friends or family members you can call on when needed. Hire a nanny if you have additional children.

Our twins were 2 years old when we began the transplant journey. It was very important to us to have consistent, structured care for them and maintain as much "normal" as possible. When you are finally discharged, keeping all the medications on schedule, caring for a central line, going almost daily to the clinic for labs and being available to respond urgently to the hospital if your child develops a fever will leave you little time to focus on your other children. Having supports in place will allow you to maintain focus on your medically fragile child who will take months and months to heal.

Fully evaluate your housing options and what is best for your family. Ronald McDonald House was not a comfortable option for us for a variety of reasons. Instead, we rented a two bedroom apartment one mile from the hospital. Yes it was much more costly financially, but it provided a significantly better environment for our family and for Henley to heal in.

6. Hospital Living

Most of the meal options at our hospital didn't accommodate the dairy free, egg free diet I had to comply with while breastfeeding Henley due to her allergies. The food service hours were also fairly limited. I was allowed to use the toilet in Henley's room, but not the shower. Instead I had to go to a public shower down the hall. The hospital room had a couch that folded into a twin size bed. Bring your own bedding and pillows if the hospital will allow it, but prepare to wash them daily. Kyle's job became being my full time support. He would do my laundry daily, bring me fresh bedding, prepare me meals, bring me mail, pick up things at Target I thought might make a long miserable hospital stay, more comfortable. His arrival at the hospital each day, meant I could walk down the hall and take a shower. I would not have survived without his daily presence.

Final Thoughts

Although it may seem painful to imagine your child going through transplant; knowledge is power, prepare and train for this fight. Take control. Explore options when you can, without some of the emotion and stress that will undoubtedly be present if or when the time comes.



Jess Johnson lives in North Dakota with her husband, Kyle, twin daughters, Everly and Coven and youngest daughter, Henley. Henley was diagnosed with Shwachman-Diamond Syndrome at three months of age and received a bone marrow transplant at the University of Minnesota Masonic Children's Hospital. She will celebrate her one year transplant anniversary in May along with her second birthday. She is now a bright, happy, thriving child thanks to the gift of transplant.

Left: Jess and Henley, March 2019