

The Great Equalizer: My Life as a Kidney Kid and Beyond EasyLink Access #: 230

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There comes a time in people's lives when they face a tragedy, a life-changing moment or string of events. It is how individuals handle adversity that will truly define them. It shows the world what they are made of and what their mark on their loved ones, their community, and even the universe, will be.

It is the great equalizer. But the time and weight of the tragedy separates us. Some of us will journey with this moment for our entire lives. Hopefully, it will give us perspective, empathy, and maturity rather than bitterness and cynicism. Others will be dealt the low points in their lives much later. One can hope that, in their shielded years, they have gathered coping skills and a sense of self to help them navigate the minefields.

Like most pre-teens, I was pretty sure my friends had life a lot easier than me, but I was brought up to know how lucky I was to be living a nice suburban life surrounded by people who loved me. Also fairly typical of 12-year-olds, I thought I knew quite a bit about the world and took plenty of opportunities to share my infinite wisdom with my parents and the other adults in my life. In hindsight, this self-confidence and desire to comprehend the challenges in my daily life served me well. It gave me the ability to understand, belief that I could overcome, and downright chutzpah to face my greatest challenge.

"My World Was Swirling"

For over a month, I had been dragging. I had aches and pains and would come home from school exhausted. We hoped that the end of the school year and summer break would bring some relief and answers to what these mounting non-descript symptoms meant. What I probably needed was a vacation--which I went on, to Hawaii--where my condition promptly worsened, and I was hospitalized. Without a diagnosis in sight and my health daily deteriorating, my two-week Hawaiian vacation ended with an emergency flight home to San Diego, CA, where we were directed to go straight from the airport to Children's Hospital.

My world was swirling, and I felt horrible. Although incredibly scared, I mostly just wanted to know what was wrong with me. So did my family. So did the doctors.

It was the first instance of many in my life when I was lucky enough to be in the hands of doctors who shielded me from their own doubts and exuded a confidence that they would figure out what was going on and take care of me. My Mom settled

into a similar presence, and I think her actions had a lot to do with the attitude I formed. She showed me her concern but never her fear. She might shed a tear with me over what I was going through, but I never saw her crying for me.

I think for me, one of the hardest things about being sick is the not knowing. I have had many ailments in search of a diagnosis. Once I know what I am up against, I feel like I know how to deal with it--treat it and/or live with it.

"What I Did Over My Summer Vacation"

After a month in the hospital, I was given a diagnosis. I had gone into acute renal failure as a result of a rare auto-immune disease called Wegener's Granulomatosis. Doctors began treatment immediately, and, within a matter of hours, I felt better. My parents broke the news to me, and I was... elated! I was so glad to know what was wrong with me! After hearing my reaction, my Dad remembers thinking: "It's not really a great thing to have." But, somehow, I knew I wasn't as bad off as I could have been, and I could finally put my finger on the diagnosis, something I continue to try to do nearly 20 years later.

That first hospital stay in 1989, or what came to be called "what I did over my summer vacation," taught me a lot about dealing with chronic illness. Just as my kidney function improved, my disease lent itself to horrible nosebleeds that prompted emergency midnight surgery--an early example of the peaks and valleys I continue to face.

My roommate was also 12 and had suffered a major stroke, leaving her unable to walk or talk. I learned to appreciate my attentive family who visited daily, particularly since my roommate's family visited once over the course of several weeks and stayed only for a matter of minutes. I also have my roommate and her daytime attendant to thank for introducing to me a multiple-decade addiction to the TV soap opera, "The Young and the Restless." My roommate and so many other kids I met throughout the years struggled with challenges that made mine seem small.

While my doctors and family must have been worried about my looming kidney failure, my main concern was getting out of the hospital in time to attend my father's wedding and start the eighth grade with my over-achieving friends. I was so worried the teachers of the accelerated classes would turn me away if I didn't start on time. Thus began the balance I tried to maintain for many years--keeping up on both a social and educational basis while living with chronic disease.

HD or PD?

Six months after my initial hospital stay and diagnosis, I was summoned to chronic dialysis. I was home alone when my nephrologist called to tell me I had to begin renal replacement therapy treatments. In theory, I had been prepared. I had been told it was just a matter of time before I would require dialysis. My Mom and I had been briefed on both hemodialysis (HD) and peritoneal dialysis (PD), and I had been convinced to choose continuous ambulatory PD. I had met other PD patients my age. I had even been on PD while in acute kidney failure in the hospital. But nothing had prepared me for the dose of reality I was just fed. I took the news stoically and burst into tears when I hung up the phone. I must have known the finality of the words my doctor uttered. I would forever have the end-stage renal

disease (ESRD) stamp. The "failure" in kidney failure is a strong and definitive word.

I began PD and felt wonderful. Pounds of fluid came off, and my blood was finally being cleaned. I was trained, along with my Mom, to do three exchanges a day. I even kind of liked the process. It was like I was a doctor or nurse scrubbing in and performing a procedure.

How About a Transplant?

Around this time, the doctors started to talk to me and my family about a transplant. Being young and having a young, healthy family was a good sign that I could find a living-related donor match. Everyone thought this was a great idea, but, when they approached me about it, I was resistant. I was in the euphoric stage that some new dialysis patients experience. I really thought that I would be happy living on PD forever.

I had heard stories of some of the other young dialysis patients who had rejected multiple transplants and, in my twisted logic, I thought they deserved a transplant more than me. I also despised the prednisone I had been put on and was weaning off. It made me gain weight and have a bloated face and stomach at a time when young girls are especially sensitive to their appearance. In 1990, transplant patients had to be on steroids, and I really didn't want to take that medication for the rest of my life. I expressed this feeling to my doctors, and sirens went off. The most common reason for organ rejection in teens is non-compliance or not taking medications. They decided to lay off the subject for a while and let me come to a place of really wanting a transplant.

In hindsight, this decision haunts me. I think of how much my life would have been different if I were able to live my high school years healthy with a transplant. I wish I had been better informed, and my parents and doctors would have kept encouraging transplantation. But I know I had a lot to learn that only the experience could teach, and I do believe everything happens for a reason.

Just about the time I got sick of dialysis, my underlying disease started to creep back, taking transplant discussions off the table. The PD exchanges increased to four a day and, eventually, I switched to continuous cycling PD, which consisted of a machine I hooked myself up to nightly. Dialysis became a chore and started to get in the way of my daily life.

The Image Problem and Different Feelings

As a high school freshman, I had to participate in the requisite general physical education (PE) activities, but I dreaded it more than most. With a tube coming out of my stomach, I was always careful about how I dressed to cover it up and sensitive to making sure people didn't see the tube slide outside my clothing. Now, imagine changing clothes in a locker room with a hundred other girls! Once I was dressed and on the field, the teacher limited what I could participate in. I was thankful he didn't make me run the mile, but just sitting on the bench during softball seemed to me like a waste of my time. I got a doctor's note and was excused from PE for the remainder of high school.

My freshman year, I was assigned as a teacher's assistant in the health office for

my suddenly free period. It ended up being a blessing as I became close with the school nurse and eventually used the time to do an exchange at school. I am sure sick students were confused as to why I would stay in the bathroom for 30 minutes!

Although I did exchanges at slumber parties and class trips and could technically keep my social and educational routine, I started to feel increasingly different than my peers. I was going through something they couldn't relate to, and their stresses about grades or boys seemed insignificant to me.

I always surrounded myself with good friends and, while they showed obvious care and concern for me, I did feel they sometimes put me at arm's length. I also put up barriers as well to shield them and my school identity from what I was going through.

A Support Network

As I got older, I opened up more about my condition. I was also having more and more health problems and was increasingly absent from school. An infection forced me off PD and onto HD. The closest pediatric unit was 50 minutes away from my home, and my parents and I made the drive three days a week.

It became harder to be involved in the extra-curricular activities that I loved when I had to take six hours out of my Monday, Wednesday, and Friday evenings to go to dialysis. I was very active in theater, but had to miss sports practices. No more Friday night football games, and I was in the hospital or just getting out of the hospital for my junior and senior proms.

I look back and see a lot that I missed out on during the high school years. But, as I age, I find a lot of perfectly healthy people didn't have the ideal high school experience. I also realize I did a lot for what I was going through. Having been actively involved in school as a pre-dialysis patient, I knew I wanted to keep myself connected even with my health difficulties. Having a supportive family and active network of friends encouraged me to be involved as well. They expected that I could do it.

I took challenging classes and maintained good grades, especially when I was present for class, and my teachers were understanding enough to adjust the assignments when I was hospitalized. But I remember writing a psychology case study while in the hospital for a pulmonary hemorrhage and my parents reading Harper Lee's Pulitzer Prize-winning novel, *To Kill a Mockingbird*, to me while I lay in the hospital with a tube coming out of my side.

The Emotional Toll

The first hour or two of dialysis seemed like a great use of time to get some studying in. After that, however, I became drained and would put the books down to sleep or watch TV. My concentration was shot after the second hour of dialysis. I was lucky that school always came easily to me because my brainpower was limited under those conditions.

The increasing health problems began to take an emotional toll on me. I had anxiety about my future, and even if I would have one. I felt battered by life, and it seemed that everything that could go wrong with my body did. Although I have always been

a happy person, I am sure I was experiencing some depression. A therapist helped me find coping tools, but she could never tell me the words I was looking for: "Everything will be fine. You will be healthy."

Graduating With Honors

I graduated from high school with honors and even received an award from the principal acknowledging what I had achieved despite my health. Ironically, I had to receive the award and the scholarships I won with my nasal passages packed from my many nosebleeds.

By the end of high school, I had no vanity left in me! I went on to community college, and it was great! My schedule enabled me to attend college for less than half of the time I attended high school, and the rest of the time was my own. Dialysis was still a chore, but it didn't get in the way as much as it did before.

"A New Surge of Energy"

The summer after my first year of college, I was finally emotionally and physically ready for a transplant. My Mom donated her kidney to me on June 21, 1995. My world changed, and, in some ways, it was almost too dramatic for me. I went from feeling pretty good to feeling like I just had major surgery. I was on lots of medication and suffered from insomnia. I was so used to things going wrong with me that I drove myself crazy looking for signs of rejection. It took a while for me to settle in with my new kidney. I would occasionally experience a sense of panic like I was forgetting something. I was--it was dialysis!

Once the kinks were worked out, I began to slowly feel healthier. About three months post-transplant, I realized my body had a new surge of energy, and I really felt good.

Health, Happiness, and Hope

Twelve years have gone by, and I am lucky enough to still have my kidney. I completed my BA at the University of San Diego and was able to move into the dorms and experience college the way I had hoped. As I aged and as my health improved, I found I was better able to relate to my peers and them to me.

After my undergraduate education was completed, I moved to Los Angeles and received my MFA in TV production at Loyola Marymount University. My thesis was a film on teenagers with kidney disease. The experience making the film reminded me how far I had come, and I gained an invaluable perspective. It also got me connected to the Renal Support Network (RSN) and the current teenage patient population through RSN's Annual Renal Teen Prom.

Conclusion

A few years ago, I attended my high school reunion. My friends were nervous about seeing old faces, but I knew people would just be happy to see me healthy. And they were! I even won the award for most interesting career. Pretty good for a girl who didn't know if she would live to see high school graduation! I currently work in television in Los Angeles, and I truly believe the years I spent on dialysis and in the hospital with TV keeping me entertained somehow contributed to my chosen career.

Most importantly, however, those formative years being a teenager on dialysis shaped my outlook on life and who I am as a person. In an odd twist of fate, I would never trade in the perspective my adversity gave me, and I am grateful I learned early on what is of fundamental importance in my life.

About the Author

Malia Langen has lived with kidney disease for 18 years. After spending her teenage years on dialysis, she received a successful kidney transplant in 1995, courtesy of her mother. She is a native Southern Californian and currently resides in Los Angeles and works in the television industry as well as serving on Renal Support Network's Board of Directors.

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