A Caregiver's Journey with Cutaneous Lymphoma

As shared by Emily P.

In March, 2014, I received a phone call that no one ever wants to get. It was my fiance, Brett, calling to tell me he had just been diagnosed with a cancer called mycosis fungoides (MF). He had just returned home from a follow-up appointment with his dermatologist that he had originally thought nothing of. I was at work, and everything became a blur. I ran out the door immediately, jumped in a taxi and rushed home with tears streaming down my face. At that moment, I knew nothing. I didn't know what kind of cancer mycosis fungoides was, how serious it was, or what was in store for our future. When I got home, all I wanted to do was hug Brett and not let go.

As most people do nowadays, we jumped on our computers and Googled ourselves into a frenzy. We prayed to come across positive findings, but the internet is filled with worst case scenarios. We both knew we needed to stop and learn more about it from professionals and reputable sources. After a few hours passed, and we had spoken to some doctors and talked things through with each other and with family, we were able to compose ourselves and think more rationally. The first few days were definitely hard, but as we learned more about MF and Brett's stage 1A diagnosis, we were reassured that this was something that could be treated and managed. It would require some small life alterations, but for the most part Brett would be able to live a long and normal life.

As it happens, our wedding date was less than 5 months after Brett's diagnosis, and we used that as major motivation to combat his patches and come to terms with this change in our lives. We were planning a 3 week Hawaiian honeymoon, and I knew that the last thing that Brett wanted was to have to apply a cream or visit a phototherapy center while we were in paradise. He diligently used the cream and went to phototherapy appointments, and by our wedding day, the patches were virtually gone.

As Brett's wife, I am continually amazed at his strength and positivity on a daily basis. Since being diagnosed, the patches on his skin have disappeared and reappeared on a couple of occasions. He is fortunate that the topical steroids generally eliminate the patches fairly quickly. With each recurrence, we feel more confident in handling this disease, and I am always there to assure him that he can tackle it.

I wouldn't exactly call myself his caregiver, but as his wife and as someone who loves him and wants the very best for him, I work with him to maintain a healthy lifestyle by way of eating healthily, working out and staying busy. We do make time every couple of weeks to do a skin check to make sure that old patches haven't come back and that no new ones have appeared. Brett is a true inspiration. He is almost always in a good mood and makes it his daily mission to make other people laugh and smile. I rarely see him worrying about his MF, which puts my worry about it at ease. I admit there are times when I probably think about it more than he does, but I usually try to avoid bringing it to his attention because I don't want him to dwell on it. However, I am always available if he ever wants to talk about it or share new research that he has found.

Brett and I are in this 100% together. My best advice to any spouses or caregivers going through the same thing is to live life to the fullest, practice gratitude and enjoy being together. Oh, and to avoid Googling. If you have any questions, your doctors or the Cutaneous Lymphoma Foundation website are your best resources.