Letter to ER:
Reflections and Beyond

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ABSTRACT

In this narrative, the author shares his perspective from both sides of the spectrum. First, he comments as a concerned husband and father and then also as a physician. They share their exhaustion and frustration at being unable to find a solution for their wife’s intractable migraine pain. The author shares the despair they live as their wife is perceived as a drug seeker whose pain is in her mind because the experts have failed to pinpoint a tangible cause. The author invites you to join this family on their quest for relief and urge you to remember that for all of us faced with conditions medicine can’t fix the landmarks are painstakingly similar. They urge us to look and help without judging. The author contributed his cry from the heart in the hope that his view from the inside out could improve medical experiences for others and open the floodgates to compassion and serve as the motivation for the art of medicine.

Keywords: Botox, Compassion Fatigue, Decision Making, Family Career, Guilt and Sickness, Intractable Pain, Migraine, Physician Husband

Letter (dated: Jul 2012)

To XXXX Hospital Emergency Department staff and providers;

I am not sure where to start or how to best translate experience into words. The ultimate letter helps you to actually feel what we feel, to experience not sympathy but true empathy, without judgment or projection. Truly a feat.

My wife suffers chronic, severe and often intractable migraines. To you that means pain, vomiting, photophobia, and sound sensitivity. All of you are able to recite the symptoms, ask to have them rated and try to treat them. What many people forget is that there is a world of suffering that goes with it, though you took her pain away and I am exceptionally grateful for that, you can’t fix the birthday party she missed, the dance recital, the soccer game. You can’t take away the feeling of absolute isolation and being utterly alone that she has when she lays in her bed for two days because she is in so much pain and does not want to go to the Emergency Room once again (Farver, 2003). The pain in her heart when her three-year old asks, “you have a headache again mommy?” There is no way for you to know that her migraines put a strain on her family, her marriage, her household budget and resources........and because of this she feels a sense of profound guilt and sorrow that is hard to truly understand. Please know that though you have taken the pain away, for a short time, the suffering continues.

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Please know that we don’t want to come to the hospital emergency room, nothing about this trip is fun; in fact there is nothing that you can do or say to make this a pleasant experience. When we get there she has been in pain and vomiting for as long as 48 hours... 48 hours, think of it, when is the last time you were in pain so bad that it made you vomit for 48 hours? During that time I have taken care of four kids, meals, rides, bed times, baths, and probably worked one or two of my three jobs. When you see me sitting in the corner, I am tired. Just before we came I had to ask one of my family members, for the umpteeenth time to come to my house and watch my children. I try to do this after they have gone to bed so it is easier for the people watching them, and we try to come not during my work day as I have used most, if not all, of my sick time and am putting a strain on my colleagues.

My poor wife, her pain has to wait for me to organize our life so that it is convenient for other people. When we get to your Emergency Department she suffers quietly in moderate to severe anxiety, she fears the person caring for her is just going to see an addict or a “drug seeker” she silently prays for one of the three or four providers that have very clearly displayed to her true compassion, and/or one of the handful of nurses that have (Carlson, Greenberg, Rubin, & Mujica-parodi, 2010).

It is a strange phenomenon that I now understand, the more often we access the emergency room the less compassion we get, funny though, seems as though the longer we suffer the more compassion we need. I guess it is easy to be compassionate to people on occasion, and harder to do it every day. I know this for a fact; on one Emergency Room visit Dr. Russell Kay came into the room, got down on one knee beside my wife and said, “I have worked for 14 days straight and it has been terribly busy yet I know that your day has been 100 times more horrible than mine”... I cried, out of gratitude for the compassion and out of guilt for not showing my wife such compassion for weeks, maybe months. Compassion fatigue, I understand it, I’ve had it, and I am sure many of you suffer it. If there are those of you who are under the impression that my wife is a drug seeker I want to just give you some background. I understand that when the human mind only has part of a story, we tend to fill in the details on our own (Maskrey Underhill, Hutchinson, Shaughnessy, & Slawson, 2009).

Since being diagnosed with migraine headaches and since their significant deterioration she has; seen a chiropractor, had massages, seen the state’s premier headache specialist, and sees a pain management specialist, she has not missed a single appointment. She has tried Motrin, naprosyn, indomethacin, Tylenol, occipital nerve blocks, Ultram, nucynta, fentanyl patch, vicodin, percoct, zanaflex, benadryl, zofran, phenergan, imitrex, relpax, cafergot, DHEA IV, Depakote IV, she had botulim toxin injected into 20 + spots on her head and neck (which made her sob and wail in pain and have altered her facial features), and currently she voluntarily takes a medication every day that she is told likely will make her gain weight and lose hair. That is right, she has volunteered to be fat and bald so that she doesn’t have to have headaches any more (Biswas, Price, Chandra, Datta, & Biswas, 2012).

When she comes to the Emergency Department to get her “care plan cocktail” she often vomits on the way home, and for the next day or two feels “toxic.” That is how bad the pain is, she chooses to vomit and feel toxic rather than have the pain, and no one currently is offering another choice. She has looked up at me from our bed, drooping eyes and altered face and said, “I wish I had cancer.........then nobody would doubt how much pain I am in” The saddest thing I ever heard, she is not wishing for cancer, she is wishing for compassion, I believe on those days that I have failed her, many of you have failed her too. Have we come to a place that our judgments stand in the way of our compassion (Greenhal, 2011)? Please try to remember, she is not the migraine in six, the frequent flyer.
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