

Finalist, Non-Fiction

The Sea of Love, the Sea of Madness: A Reflection on Our First Year with Lou
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Sometimes I feel like I was born to tell only one story.

On June 20th, 2015, I married the man that I have been waiting to marry since I was a despondent teenager, rejected and awkward and misunderstood. The man that I'd waited through so much for.

But when you find that one person who you think will be your whole world, you are bound to be disappointed.

But in many cases, maybe disappointment isn't such a bad thing. You learn that no one can carry your whole universe for you on their back. I'm no Zeus, Sam no Atlas.

Early in to the diagnosis, I realized that we've been paired to something infinitely sad. We have a third companion. This ménage à trois of grief and love and sudden purpose: in the somewhat affectionate words of Dudley Clendinen, in his article "The Good Short Life," Lou (an uninvited companion, to say the least) may be here to stay. Us and ALS. We are suddenly a laughably, dysfunctional family.

Many times during the first year, we personified this unrelenting, cruel disease and imagined ways to kill him. Lou was going down. Lou was going to pay for our grief. Lou was going to explain why he showed up to the wedding uninvited.

We would fantasize completely absurd and unrelenting and vicious ways for Lou to suffer for how he has destroyed things that can never be rebuilt or repaired and taken what can never be given back.

Beating with a baseball bat, running over repeatedly with our car, pushed down the stairs, suffocation by pillow, punching again and again and again — we weren't going down without a fight. Albeit this was a totally misguided and futile way to begin approaching this disease, but this mental exercise was oddly comforting at the time.

Now, I know that this isn't my disease. It is my husband's. But I can't help taking it on. Often I speak for him. If you're reading this now, you know that I write for him. It isn't that he doesn't have a voice or an opinion about all of this; I just tend to take on everything he experiences for myself.

We visit the doctor, and my pronouns are always plural. His pain is my pain; his disease is my downfall and my salvation, as well. For better or for worse. In sickness and in health.

We just got a little more sickness and a little less health than most people.

One year later, I am a different person. The things that used to matter just don't. Sometimes I find myself basking in the minutiae of someone's day: She did what? I

can't believe that! That is such an inconvenience!

Maybe only someone who has had their life devoid of many normal events can understand what luxury that is. But I long for the gossip, the seemingly ridiculous complaints, the average achievements. They are balm to a stripped, raw life.

And it's better than listening to the uncomfortable attempt at drawing meaningful words from a disconnected heart.

I know that I am not the only caregiver to feel this way. Everyday life is now an anomaly. We go to support groups to get out of the house, to be around people who just may understand. We are all shadows of our former selves, haunting doorways and seeking companionship with opaque, happy people.

But to imply that life today is completely miserable would be misleading. We have our ups and downs. But this summer has been the best of both our lives, the best of our marriage. And in many ways, Sam is stronger than when he was first diagnosed. Our hopes are higher. Our peace is broader. Sam is doing better than 99% of patients do in the first year.

I guess I just want to shatter the romantic version of illness. I have found that this is often associated with cancer. In many cases, not all, a game plan is presented. You give all you have, and you may have a chance. The media presents terminal illness in such a way that it brings out the best in someone.

As a caregiver, I can tell you that this is not 100% the case. Terminal illness is not wonderful or acceptable, especially when you are 30 years old and your life has just begun. The process of acceptance with ALS is somewhat less graceful and more chaotic than what most people want to hear. It seems to move at a snail's pace. And no one knows what to say anyway. It's a disease that can leave everyone silent.

ALS forces you to slow down, to watch, to examine your priorities, and to wait. It's more like suddenly all doors have been shut synchronously by as many invisible hands as you had opportunities, and you couldn't even know that a door is closed until you try to open it. Even then, comprehension and acceptance are a long way off after attempting to turn the knob.

But, in the words of the Rolling Stones, you can't always get what you want, but sometimes you get what you need. Despite everything, I still consider this diagnosis a mercy, a severe mercy. I can't even explain fully this line of thinking yet. But I do know this: "For now we see in a mirror dimly, but then face to face. Now I know in part; then I shall know fully, even as I have been fully known." 1 Corinthians 13:12 ESV

In *West with the Night*, Beryl Markham's memoir about flying and growing up in Kenya, she said this about leaving a place behind you: "I have learned that if you must leave a place that you have lived in and loved and where all your yesteryears are buried deep, leave it any way except a slow way, leave it the fastest way you can. Never turn back and never believe that an hour you remember is a better hour because it is dead. Passed years seem safe ones, vanquished ones, while the future lives in a cloud,

formidable from a distance.”

Sam and I are leaving a place behind us. Yes, we just moved, but it’s more than that. We are leaving opportunities that were not meant for us. And what a waste of time it would be for us to sit and mourn missed opportunities. Doors have closed, but we have a whole ceiling that has been lifted. We see a bigger picture although we do not understand it all yet.

We have a quote hanging in our house by Albert Camus: “In the midst of winter, I found there was within me, an invincible summer.”

He goes on —

“And that makes me happy. For it says that no matter how hard the world pushes against me, within me, there’s something stronger – something better, pushing right back.”

Yes, something better, pushing right back.