

Illness Narratives – what can they teach us?

Oct 21, 2014 | 0 

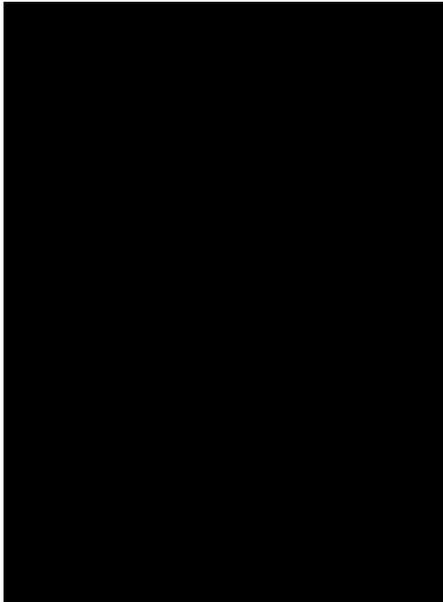
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The Diving Bell and the Butterfly (Jean Dominique Bauby) is likely one of the most popular illness narratives and has in fact been turned into an award winning movie. It's a story by a man who had a brainstem stroke leaving him with "locked-in" syndrome, possibly one of the cruelest diagnoses leaving the person with eye movement only (complete quadriplegia and loss of voice). The entire book was written with the author blinking his left eyelid to indicate a letter on a character chart and took ten months to complete. An average word took approximately two minutes. Bauby's book has become so popular partly due to his ability to rise above a condition which would seemingly break a person's will to live

"Want to play hangman? asks Theophile, and I ache to tell him that I have enough on my plate playing quadriplegic. But my communication system disqualifies repartee: the keenest rapier grows dull and falls flat when it takes several minutes to thrust it home. By the time you strike, even you no longer understand what had seemed so witty before you started to dictate it, letter by letter. So the rule is to avoid impulsive sallies. It deprives conversation of its sparkle, all those gems you bat back and forth like a ball- and I count this forced lack of humor one of the great drawbacks of my condition."

Illness narratives like these remind us of the fact that patients we treat have the vast complex moral, emotional and intellectual worlds that we inhabit ourselves; and that we need not reduce them to their diagnosis. On the busy ward round they are a stern reminder that each line on your list is a person that is under your care. The unfeeling doctor, the robotic doctor, the impersonal doctor are all variously parodied in many of these illness narratives. As a junior doctor you can play a key (and hopefully positive!) part in your patient's illness narrative.

Some of my other favourite illness narratives include

Susan Sontag, *Illness as Metaphor*

Temple Grandin, *Emergence: Labeled Autistic*

William Styron, *Darkness Visible*

John Diamond, *Cowards get cancer too*

Anatole Broyard, *Intoxicated by My Illness*

Susanna Kaysen, *Girl, Interrupted*

Bryce Courtenay, *April Fool's Day*

Feel free to add in any ones that you have been inspired by!

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