

Identity Dilemmas: The lives of two people irrevocably altered by neurological disease

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"If one doesn't have words, how does one think?" wonders Iris Murdoch, enchanting philosopher and writer in *Iris*, the 2001 film directed by Richard Eyre. Thanks to its talented cast including Academy Award winning actresses Kate Winslet and Judi Dench, noted actors Hugh Bonneville and Jim Broadbent, the movie does not disappoint. Based off John Bayley's (Iris' husband's) memoir *Elegy for Iris*, the film is a powerful narration of the life of passionate novelist Iris Murdoch, who was diagnosed with Alzheimer's disease, a prognosis which would irrevocably shape their story. Jean-Dominique Bauby too, is what one might call a 'free spirit', although his life before his stroke was less devoted to intellectual pursuits and more towards fulfilling material pleasures. *The Diving Bell and the Butterfly*, released in 2007, is a Julian Schnabel direction chronicling the story of Bauby, who, following an enormous stroke was left almost completely paralyzed. From his initial self-hatred to his successfully 'dictating' a book, we follow Bauby's remarkable emotional journey as he looks back on his life and comes to terms with 'locked-in syndrome'. Despite being unique in that they directly address neurological illnesses, the films speak more to the social issues related to these disorders than to the neuroscientific bases behind the diseases. Although they do this differently, both films force the viewers to engage with the diseases by giving them eyes in the lives of patients and their loved ones.

We all know of someone who has Alzheimer's disease. According to the Alzheimer's Association, more than five million Americans are living with Alzheimer's right now. But despite it being so common, the disease is still grossly under-represented by the media. Brilliant, beautiful, promiscuous, worshipped by male and female love interests alike and brimming with *joie de vivre*, Iris Murdoch is the perfect protagonist to explore. Her vibrant, unapologetic life before she begins showing Alzheimer's disease symptoms poignantly highlights the rapid change in her life and that of her husband as the disease increasingly takes control. The disease takes its course and we observe Murdoch being reduced to a shadow of her former pulsating self. By placing the disease in the context of a love story, the movie helps us understand not just the damage Alzheimer's causes to the brain, but also the damage Alzheimer's causes to relationships. The format of the movie was also cleverly chosen. Since we are being narrated the story from Bayley's perspective, we are able to see more clearly the symptoms of the disease appearing in Iris: from forgetting why she enters a room, to her almost unrecognizable self at the end. Flashbacks too, provide us with useful reference points to compare Murdoch to her past self. One of my favourite scenes in the movie was one which was repeated several times in flashback: where Iris and John are biking and Iris screams "Just keep a tight hold of me, it'll be alright!" This scene sums up their relationship, how she's always slipping away, and John "can't keep up". As we near the end of the movie, Iris starts 'slipping away' even more, her brain is cycling rapidly down the hill of decline, and John is forced to watch.

The Diving Bell and the Butterfly makes us aware of a neurological phenomenon that is even less portrayed in media than Alzheimer's. The National Organization for Rare Disorders defines locked-in syndrome, also known by scientists as cerebromedullospinal disconnection or pseudocoma, as "a rare neurological disorder in which there is complete paralysis of all voluntary muscles except for the ones that control the movements of the eyes". Schnabel cleverly uses pathos to his advantage in the film, making it more accessible to the audience, and hence more interesting. The film is shot predominantly through Bauby's eyes, and hence we connect with him: for the length of the movie, we are him. We hurt with him when the woman he is in love with refuses to visit him. We too are submerged in the wave of sadness he is in when he first realizes that he cannot hold his children anymore. We feel discovery softly warm our cheeks when Jean-Do discovers within himself a gift with stories. Oftentimes, we think of people living with locked-in syndrome or near-complete paralysis as being just the outer-body shell they are trapped in. We do not realize that they are

human beings who, apart from having thoughts, emotions and comprehension, have been brutally stripped of their agency. Things are done to them, more often times than not without consent. Bauby wasn't asked whether he wanted his eye stitched up, he was told. The doctors were fully aware that he could comprehend every word that they were saying. He was still mentally competent enough to be able to make such decisions on his own. He was screaming, but his mouth didn't move.

Hearing Bauby's voice and seeing the world through his perspective helps bring home the message we desperately need, that locked-in syndrome patients are awake and aware, even though it is not obvious to us. An especially touching scene in the film is when Bauby tells his doctor that he wants to die. The doctor, having grown close to Bauby, gets very upset that he feels this way. It is an emotionally charged scene that very realistically depicts disparities between the patient's feelings of despair and helplessness and what the patient's loved ones want them to feel: hopeful and positive. It is very hard for family members and other loved ones to truly comprehend the way patients feel in these situations. The fact that this movie depicts so effectively the feelings of 'locked-in syndrome' patients is one of the things that makes it brilliant; I am confident that I'm not the only one who was painfully ignorant of locked-in syndrome prior to watching the film.

Although both movies have very different styles, they both allow the viewer to engage with these phenomena of the brain. *Iris* does this by juxtaposing Murdoch in her prime to Murdoch during the last stages of Alzheimer's disease, while *The Diving Bell and the Butterfly* allows us to interact with the world the way Bauby has to, at the same time giving us intimate glimpses into his thoughts and past life. *Iris* is adventurous, dramatic and fast-paced, whereas *The Diving Bell and the Butterfly* is a typical 'artsy' film, with ample flashbacks, sad music and plenty of introspection by the protagonist. On their own, the movies would be geared to completely different audiences. However, it is my most earnest recommendation that any person even remotely interested in the workings of the mind (or brain, depending on whether you are a philosopher or a scientist) watch both these movies, if not for anything other than to understand the workings of our body. For neuroscience, biology and psychology students, both these movies are a must watch. But even for students with non-scientific or non-philosophical interests, these films, with their gripping storylines, vivid portrayal of characters and unique cinematography, are an enthralling escape into the minds and lives of those who function differently to us.

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Reference

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