

A Disappointed Woman

Synopsis

In 2012, I received a diagnosis of remitting-relapsing Multiple Sclerosis (MS), a turning point in my life. The unpredictability of the disease and the fear for an uncertain future submerged me into an unhealthy psychological state of disbelief and denial. The anxiety and frustration of confronting this new situation triggered the need to analyse and research MS, not only at a clinical level, but also the socio-cultural means of dealing with this chronic disease. This body of work represents an emotional exploration and the journey from uncontrollable angst and mental dissent to acceptance and understanding of living with MS.

The title of the work was inspired by the book *The Journal of a Disappointed Man* by W.N.P. Barbellion (a pseudonym of Bruce Frederick Cummings, 7 September 1889 – 22 October 1919) an ambitious naturalist who suffered from MS at an early age. In his diary, Cummings narrates the continuous health struggles and how this affected his career and relationships. Although his family knew about his "rare condition", they kept him in ignorance; at that time a diagnosis of MS was considered a death warrant. I believe that the social and medical approach to the origin of MS has influenced the general perception of the disease nowadays.

The Journal of a Disappointed Woman diary-booklet is a personal story chaptered in intimate thoughts, related literature and images that analyses and reflects on some of the issues I have encountered through the journey. The video piece *A Disappointed Woman* is shown in a loop and presents a visual allegory of the Remitting-Relapsing nature of MS; in clinical terms the demyelination of the central nervous system

disrupts the communication between the body and the mind, therefore impairing the ability to sense, to move, to speak etcetera. This disruption periodically goes into remission. The demyelinating lesions are internal and therefore they can only be seen in an MRI scan image. By submerging and emerging a body in water I intend to resemble the effect of relapsing and remitting MS lesions in the nervous system; a body underwater is also impaired in its ability to sense, move or talk. At the same time the performative image of the stare and the clinical environment sound intent to discomfort the viewer; an emotional response to the social stigma and otherness I am bound to suffer.

This work has been designed to be shown in gallery space; big screen projection in a black cubicle and a plinth for the booklet at the entry of the cubicle. I would like to mention that I consider this project the beginning of a bigger body of work that aims to produce a series of videos and booklets of other MS patients thus becoming in a collaborative project.

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