

HD as a sword of Damocles or as an Achilles' heel?

by: Francisco Iruela

In this article I will talk about the book *Chronicles of a Fortune Foretold*, by Luis Aguilar. It is a collection of short stories about the impact that [Huntington's disease](#) (HD) had on his father, as well as the repercussion it had on his family as a domino effect. But it also tells the impact it has on him now, in the probability of suffering from this pathology. 50% vs 50%. For those who do not know about this subcortical dementia, Luis explains it in an accessible way. Although, you can't expect it to be exclusively an informative book. You would miss too many things.



Text: Probabilities.

An act of sincerity, of meeting with himself, with his feelings of shame and guilt. Of fear and anguish. These are feelings that accompany him. In adolescence, shame, because of the comments of his soccer teammates and friends. Something is wrong with your father. Try to prevent him from coming to see you. Forbid it to him. As an adult, guilt looking in the rearview mirror. He wanted normality, to be one of the others, not for his father to be pointed out. Projecting himself on his father.

And always his firm gaze. Only seeing his son, only being there for his daughter. Deterioration could not silence love. There is something irreducible in ourselves.

Luis' struggle is the one faced by all of us immersed in this tangle of genetic risk of HD. The struggle against the prototypical mental representation of this dementia. Until recently, no one was interested in what people who are at risk or who will suffer in the future from this disease would think or feel. In neurology, they almost paraphrased Larra: "come back tomorrow, when you present symptoms". But those who are at risk have, as Luis said, the sword of Damocles hanging over their heads. One lives in a perpetual state of anxious-depressive symptoms. The disease is like shattering to pieces the sense of continuity. Yes, that sensation that, in peaceful conditions, we can feel. To have a future perspective, to aspire to the same dreams as anyone else. And what about us without this sense of continuity? Well, that drawer with anxious-depressive symptoms: insomnia, nightmares, panic attacks, palpitations, hopelessness, obsessions, compulsions, among other symptoms.

The pre-symptomatic or risk phase has many similarities with those who have experienced PTSD (Post Traumatic Stress Disorder). Why? Because when the sense of continuity is broken, there is a threat, a rupture with the sense of self, others and the world. This is what is conceptually understood by trauma.

I have been and continue to be fortunate to work with pre-symptomatic or at-risk individuals. We work, among other things, on the transformation of the prototypical HD mental representation. But of course, as Luis says, life is much more than the disease, and everyone carries his or her own story as a backpack. Does observing a parent's deterioration modify the basic trust you have in reference to others, yourself and the world? How can you understand that one of the people you love most in this world is deteriorating and will die earlier

than the norm? How can you understand that you will live or can also live a deterioration? You also run away because you cannot bear the pain.



Text: I stumble. I forget, I argue. Like yesterday, like the day before yesterday, like a few months ago. I am scared.

"I was already starting to have a disease with the name <<fear>> and the last name <<to miss out on something>>". It is what is now known as FOMO (fear of missing out). Additionally, Luis talks about Alexander the Great's concept of pothos. Pothos as insatiable desire. What interests me most about these constructs is how I imagine they are born in experience. Fomo and Pothos emerge with the purpose of maintaining a minimal sense of continuity, as a defense mechanism. Decorations that hide the background. That is, the fear of having the disease, the tear generated by the excess of huntingtin. FOMO and pothos are two sides of the same coin, as safeguards that momentarily derail the anguish. That is, to be avid for experiences, to live the intensity because of the fear of never being able to do so. However, there is a paragraph of a beauty that combines simplicity and depth: "now I am not afraid when the pothos

comes to scare me with his ambition, now I wait for him with the confidence of being in the place I want to be". He speaks of having chosen the life he wants. Then he talks about her: "Roxana, Parisatis and Statira, but also Hephaestion, Olympias of Epirus". She, internalized as a secure link, a platform that acts as an anchor. She sustains the uncertainty of the black birds.

In the end, we all have a death foretold. The question is when, the precision. We live as immortals. Death exists, but it happens to others. Therefore, being pre-symptomatic or being at risk, violates the basic laws of continuity as I have mentioned. And perhaps this is one of the greatest fears in Western societies. To have the certainty that your days are numbered or almost numbered. Apart from that, there are other types of certainties that are created through emotional impact, not through scientific proof. We can call them pseudo-certainties. One of them is the one that has conditioned Luis' life: his uncle's affirmation. In what seemed to be a family trap, he tells him the date when the disease will arrive. That is why thirty is the beginning of the end. Hence the motto "live beyond thirty" as a sentence. Words can also create realities. To paraphrase Goya, the dream of ignorance produces monsters.

It is not just a book about Huntington's disease, deterioration and death. It's about bonding, about the importance of seeking help when discomfort overwhelms us. And most importantly, it is about life. The humor Luis' is capable of transmitting is a balm for the journey. It transports you through the last decades of this Spain, leaving a taste of familiarity in the details. I did not live it, but I could have lived it. As he told me one day, he doesn't know how to write without giving his all.

In the last [Moving Forward](#) group session, I said to the patients: "well, you know what the antidote to the [obsessive, ruminating thoughts](#) around the onset of the disease is. And that is the satisfaction you can have in your life. Satisfaction through self-congruent goals and decision making." These principles are universal. This is why I would not call it Damocles' sword, but Achilles' heel. An Achilles heel that must be reinforced by means of a robust epigenetics that includes good nutrition, sports, meaningful bonds, and a lot of psychotherapeutic work. For facing these abysses from isolation is almost impossible. Asking for help makes you human, all too human. An arrow in the heel is remediable, getting your head cut off is not. That's why I say that HD can

be like Damocles' sword or Achilles' heel. Each person must elaborate to make it one or the other.



Text: How do you feel?

PD: The edition is in Spanish and English in the same book (curiosity: *chocolate con churros*, a typical Spanish snack, is untranslatable). The illustrations are by Paloma Agüera (some of them are the ones you have visualized).

This book has been possible thanks to the project of Moving Forward, excellent professionals and people. The benefits will go to give better support to families and affected people through the Spanish Association of Huntington's Disease (ACHE) and the European Huntington Association (EHA). The emotional prologue is written by Ruth Blanco, president of the ACHE (Spanish Huntington's Disease Association). Ruth has done, and continues to do, so much for the families. I also have to thank her again. She was the one who

counted on me when I did not imagine all that was to come. Her trust can never be thanked enough.

You can find the book at:

<https://www.agapea.com/libros/Cronica-de-una-suerte-anunciada-9788411818865-i.htm>