

**My psychological reality  
about Huntington's Disease**

Practical guide



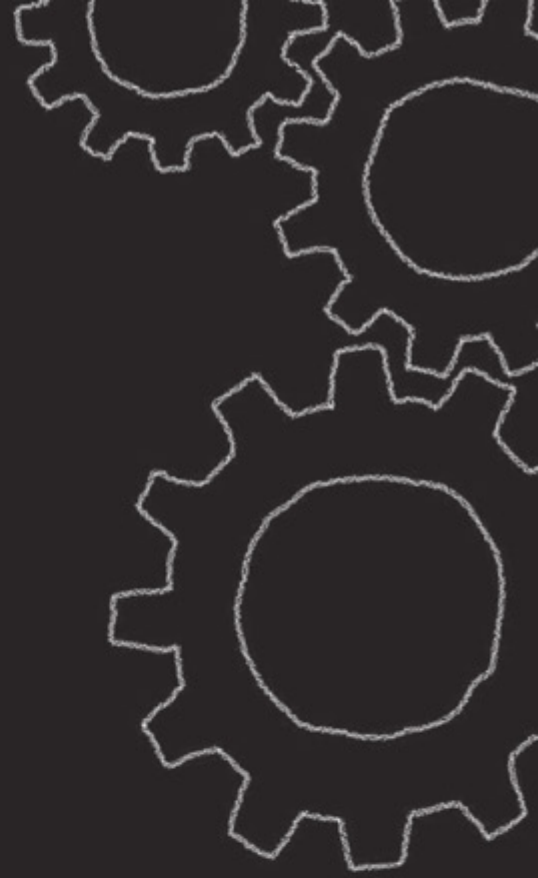
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*This writing is based on my own experience in relation to Huntington's disease (from now on I will refer to it as HD). Chance also crossed with us as a family. In 2015, my mother, pressured by my brother David as well as by me, began the link to Neurology for her diagnostic process. We had heard about HD as a "rare" disease that existed in my family. We needed answers to my mother's life situation. Among other things, we were surprised that she systematically lost her jobs. And the most surprising thing is that she couldn't explain what had happened to her, why they didn't renew her contract, why they fired her. She received her diagnosis with a positive result at the end of 2016. At the beginning of 2018 I received my diagnosis and it was negative.*

*This text has only been possible thanks to my personal experience and those of my relatives, integrating them with my professional experience as a psychologist.*

*Around the improvement of the text I have had the invaluable help of several people, including Dr. Sánchez, my brother David, Audrey De Paepe and Laura Borghi (to whom I also owe her dedication to the design of this guide).*

*Finally, thanks to Carmen Lucas for the translation of the original text. Without her patience and dedication, this would not have been possible.*



This text, according to the reader's interest, can be read linearly or by sections. There is a specific section dedicated to the person facing the diagnosis (**Diagnosis**), another in relation to the family (**Compass for relatives**) and another dedicated to professionals (**The care team**). I recommend reading the Introduction sections to give a basis to the other sections. The sections of **Modular genetics through what we do** and **Conclusions** are of general interest but not less important.

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# Introduction

Throughout this document I will try to answer the following questions:

- *How is the psychological reality of the person who faces with the possibility of being diagnosed with HD? How do the relatives cope with it?*
- *Is HD the beginning of the end for the person? What can relatives do about the problems they will encounter?*
- *Can professionals who attend to the problems arising from HD include some improvements in their intervention?*

HD when seen in its dimension as a genetically transmitted disease, its psychological part is usually ignored. It is something that I have been reflecting on these years, since 2015, and this text aims to be the description of that psychological reality, taking into account the person, the family and the health context. This text is not intended to be an “indisputable truth” about the psychological elements of HD. Rather, it obeys being a practical piece of material, of understanding and performance.

I will be very satisfied if it can be useful both to people who have to face the diagnosis and to family members or professionals who have to deal with the problems involved in this disease.

## Psychological concepts which guide us as a map in HD

Before I can get into the core of the psychological reality of HD, I need to explain some general concepts, which have been very useful to me, to get psychologically closer to the understanding of HD. These are: **cognition, theory of the mind, emotional processing, metacognition, mental representation and the metaphor of the person as a scientist.**

*Cognition* refers to the mental processes related to how we process the information of the environment and regulate ourselves based on it.

The great areas which have been studied within it are reasoning, memory, attention and visual perception. All of them interrelated. In HD, cognition in all its areas is impaired.

The *theory of the mind* can be defined as the ability to infer the inferences and beliefs of others and be able to act based on the states we perceive. The theory of the mind is severely deteriorated in people diagnosed with HD. I will give an illustrative example. When my mother was 46 years old, a year after her diagnosis she didn't have muscle symptoms yet. We were talking about her brother, my uncle Jesus. My uncle, since childhood, has had a terrible fear of hospitals, having symptoms such as sweating, palpitations and the subsequent running away from hospitals. I asked my mother why she thought he had that fear towards hospitals, if she remembered something meaningful that could explain it. She answered me laughing, it was to get attention. And she didn't add any more, concluding the issue. The important thing about this example is not to determine the cause of why my uncle avoided hospitals, whether my mother was "right or not," but the lack of elaboration of the answer. That is, my mother failed in her ability to explain in an elaborate way what could be going on with my uncle to flee the hospitals.

*Emotional processing* is the ability to perceive emotions and process the sensations associated with the emotional state. Within emotional processing, the recognition of facial expression is very relevant. People with HD make mistakes when identifying emotions in the faces of other people, which

gives you situations of confusion and misunderstandings. For example, they may believe that “you are angry” without you having that emotional state. Situations like this can happen very easily. Other times they may perceive that you are laughing at him/her for a gesture that is not properly decoded. This problematic identification of emotions also occurs in themselves, so it is more difficult to regulate one’s own emotions leading them to mental confusion and frustration.

**[ The theory of the mind and emotional processing are the most important components of social cognition. ]**

*Metacognition* is a set of psychological activities that involve the detection of simple thoughts and feelings as well as the integration of intentions, desires, feelings, and the connection between these elements. It is the cognition of cognition, a psychological function that orders cognition. When we talk to ourselves, when we regulate our thinking, to reach conclusions, or to continue developing a non- purely intellectual idea, metacognition is acting. Directed by the metacognition are the so-called internal dialogues that we have, the flow of our conscience. Without this mental daily speech, it would not be possible to plan future projects. Of course, metacognition does not occur in the emptiness, but in our social context, therefore, metacognition and social cognition are in continuous interaction and is what makes us “social animals”.

*Mental representation* is the image we build about abstract topics and material things. Mental representation is a product of the higher functions, which we have spoken of through cognition, social cognition and metacognition. In this guide, I will later develop this concept due to the importance it has in HD. We can think of these processes as the **gears** of the act of knowing and being in the world. Who supervises the gears is the figure of the person as a scientist.

*The man as a scientist* is taken from George Kelly. This psychologist wrote that the person builds reality based on his own experiences. That is, she/he does not deny an objective reality, he/she simply says that we cannot fully grasp it. Thus, reality is a personal psychological process. To build reality, we anticipate what the facts will be like, by creating hypotheses. The word hypothesis comes from the Greek ὑπόθεσις (hypothesis = affirmation, conjecture, purpose). Our hypotheses are made up of a set of mental representations. This personal elaboration on something we test through our experience and it is confirmed or invalidated. Then our hypothesis of work is reviewed or not, according to as how we see it convenient. Although there is a great difference between

scientists and the rest of the population. They are stricter in control of the experiment and in the conclusions that are derived from their experience. But the process is the same. We use personal hypotheses that, according to our experience, will be confirmed or rejected. We need to anticipate what will happen and what our surroundings will be like and the functioning of reality through hypotheses, by the sense of continuity. It is the psychological purpose for which we anticipate through personal hypotheses. That is, we need to feel that we are the same as in the past and that we will be the same in the future, even if we evolve as people and change our points of view and goals.

Based on our experiences, the links we have been having and the situations we have been experiencing, we create a construction of the world, a construction of our identity. This construction of identity can only be accomplished through the sense of continuity. It is validated or invalidated by our family, friends or acquaintances. Therefore, when we face a situation, we mentally imagine what is going to happen, in automatic terms based on past situations that may look like the new one.

Is it confirmed what I thought was going to happen? Isn't it confirmed? We are fully reviewing whether our personal reality is confirmed or rejected and if it is, we try to review how we could more accurately anticipate future situations. If we frequently fail to review our reality and anticipate future events, our sense of continuity is weakened, our identity is seriously affected. That's when clinical symptoms appear that generate significant discomfort.

Encouraging the increase of the scientific attitude improves our hypotheses and experiences. As I said, in general, our judgments about the experience are more hasty than in the case of scientists. For example, we can feel that a person we love doesn't love us, because he has forgotten our birthday and the impulse may be that she/he doesn't care about us. We may not stop to understand what exactly has happened so that he or she has forgotten an important.

I experienced what it was like to lose the sense of continuity, not being able to project myself in the future, due to the possibility of having HD. My scientific self, I could not anticipate and build a future. I had no hypothesis to know what was going to happen in relation to my family and HD. My mental representation of what it meant to have the disease was so terrifying, that everything ceased to make sense. On a psychological level, it is preferable to be dead than to lose the sense of continuity.

**As we will see later, giving support before starting the diagnosis, to the sense of continuity, when projected into the future, is one of the main objectives to reduce discomfort.**

As we have already mentioned, there is a deterioration in mental functions in HD. Focusing on the aforementioned parts, some resist the passage of time better than others. The first thing that reduces its functioning are the most sophisticated pieces, such as the supervisor of the person as a scientist, metacognition and social cognition. Cognition, a nuclear piece, resists the passage of time better, although at an early stage, its deterioration begins to be noticed.

This construction of reality through this mechanism, is possible thanks in large part to the frontal lobe, which is the first focus of deterioration in HD. Likewise, the deterioration of the frontal lobe inhibits the person's will, their motivation and increases their isolation. The frontal lobe regulates the limbic system, "the center of emotions," so in people with HD, the amygdala, the nucleus of the limbic system, will be more activated. This implies an overactivation of emotions, especially anger and fear. This theoretical framework has the purpose that both the person diagnosed and the one who faces the possibility of diagnosis, as well as family members, can have a framework of understanding. This framework will positively influence the family and social dynamics. *We can't act without understanding.* By understanding and acting in coherence, we will be able to reduce discomfort and improve the quality of life in the face of a psychosocial situation as complex as HD.

## Mental representation

As I said, mental representation is the product of the gear, of the construction of the brain, through the different interconnected pieces (cognition, theory of the mind, emotional processing, metacognition) supervised by the metaphor of the human being as a scientist. Mental representations (from now on RM for both singular and plural) have a series of characteristics:

- *It is always associated with emotional and cognitive content. It is not synonymous with thought, there are associated memories, images with an affective tone.*
- *It is enriched due to the experience that we are accumulating in life and the review we do on MRI. Since the experience we have is personal, MRI will be unique and therefore has no direct correspondence with reality. They have a practical character, they guide our actions and attitudes towards the interpretation that we make of reality. Therefore, they are not exact copies*

*about the event or thing you are trying to capture. But an approach. Then we can not talk about what is true, but about what is the closest to what is true or useful.*

- *We tend to replace the content of our MR with the absolute truth. This helps us in the short term to give our mental system more stability and a sense of continuity, but it can induce us to make mistakes and not revise our hypotheses, harming us in the long term.*
- *It is never complete, it never ceases to be reviewed if the person and the environment require it.*
- *It is influenced not only by our direct experience, but by social opinion. For example, there will be many people who will not have any MR on it due to its low incidence at the demographic level. On the other hand, MR on cancer will be better at elaboration level since society carries out media campaigns due to higher incidence in the population.*

With what has been said, how can we know what is the MR we have about HD, in ourselves or our relatives? Just answer the questions. What do you think about HD? How do you imagine life after being diagnosed? The answers will take you to the MR. What kind of mental representation do we usually have of HD? The asymptomatic person usually a child and relatives the first thing they observe is the person who is already manifesting the symptoms (father or mother). They compare it how he/she behaves now and how he/she behaved before the onset of symptoms.

Sequentially, at the beginning of the disease, we can notice in the person in general, agitation, since he/she is being aware that cognitively he/she has deficits. It will be difficult for you to find the words you wanted to say, your thinking will be less orderly than it used to be. A breakup begins on “how I was” and “how I am now,” more focused on the personal awareness of the reduction of cognitive abilities. The sense of continuity is being reduced. This probably also generates anxiety and depressive symptoms, since the person with HD anticipates more deterioration and worse quality of life. Mood swings may be present in these phases due to depressive symptoms, but they can also occur later, due to the deterioration of the frontal lobe. In this phase, there is also a great impoverishment of language, more pronounced than before. Aggression also usually appears due to the deterioration of the frontal lobe. The muscular symptoms are the result of the deterioration of the areas related to movement, the basal ganglia, the parietal lobe and the primary motor cortex, located in the frontal lobe.

These symptoms can appear at any point in the disease, although they are more pronounced at the end of the disease, since there is more deterioration in the aforementioned areas.

We, as family members, observe the evolution of the disease. This experience becomes part of our MRI of the disease. The asymptomatic person will think: “This is what also awaits for me too.”

The mental representation of HD is usually associated with a very strong genetic component. As if destiny were deterioration and we were left with only resignation and passivity. This deterministic belief can be reduced, thanks to Epigenetics, a science that I will explain later. Although the significant transformation of MRI has to take place in a psychotherapy process, which I will talk about later.

Given the bewilderment of the symptoms, people usually look for an answer. Generally, something had already been talked or lived within the family. The family may have classified HD, as a “rare disease” or “the San Benito dance disease,” etc. The experience of other generations is also incorporated into the person’s MRI. For example, if the parents have taken care of a grandmother/grandfather who had HD, or uncles. Or even, the person in question, if he had a relationship with a grandfather or grandmother while he was alive, will also incorporate him/her into his own MRI. People in the need to find answers to their desperation, in addition to going to the family unit, will also look for information outside the most immediate environment. The most common thing, before going to any specialist, is to search the Internet. If you have not yet searched the Internet about HD, I invite you with caution to do so. You will be able to see how it is common that the most serious symptoms are talked about online, or even, on channels such as YouTube or in various forums, people explain their experiences and their mental representations with drama (in the best sense of the word). A special emphasis is made on anguish, transmitted by the rupture of the sense of continuity.

**( An MRI should never be left to be collapsed by anguish, as this prevents adaptation to the medium of such representation. )**

In this way on the Internet, the person who is reading, researching, who tries to seek comfort or minimize his anguish as much as possible, will encounter the opposite. The MRI of HD is then catastrophic, since it has been nourished by our experiences, family experiences, as well as social networks. That is, one identifies with the most serious symptoms of the disease.

Thus, this representation given its content poses a threat to the sense of continuity. There is a great difficulty in projecting yourself in the future and in continuing to build the desired life plan. Or even, the short-term future plan which was being built. The vision about HD makes us think: “if I will end up as my family member, does it make sense to continue living? Is it better to die?” These thoughts form a vicious circle in which anxiety and sadness feed each other. Everything is paralyzed, everything is in suspension.

In the short term, the objective in reference to MR of HD is to endure it with as little suffering as possible. In the long term, the objective, is to be able to transform it so that it is compatible with life and personal well-being.

# Diagnosis

At this point, with this fateful MRI, how do you consider carrying out the diagnosis? Facing the diagnosis is a decision-making, so it requires reflection and time. You have to ask yourself whether or not you want to know, and why. In the diagnosis, the person is positioned in three options (the first two are more likely than the third). The first and second options are not watertight and can be passed from one to another. The third is the one that involves a choice, which needs to have gone through the first and/or second option.

- ① **First option:** not wanting to know whether or not you have the disease out of fear. For this choice, the mental representation is synonymous with the reality of the disease. Therefore, to avoid mental collapse and crisis, it is preferable not to face it. Better not to think about the diagnosis and act as if nothing happened.
- ② **Second option:** face the diagnosis to clear the question of whether you have the disease or not. You hope to be negative in the genetic test, and to get rid of the anxiety you feel. You may even think that it may come out positive, but that possibility can be minimized. The most important thing in this position is to reduce the anxiety that is felt facing doubt. Anguish dominates the mental space, so the person prefers to eliminate the uncertainty of not knowing.
- ③ **Third option:** face the diagnosis assuming the possibility of chance. This third choice is the most difficult, and therefore, least likely to be generated spontaneously. It requires time and elaboration. To choose this option, an enrichment of the mental representation of HD is necessary.

If it is observed, only in the third option that the person has control: it is a personal decision, not dominated by the attempt to ignore fear (first option) or wanting to get rid of anxiety (second option). For the third option, several personal questions must be answered satisfactorily:

If I test positive in the diagnosis, what would my life be like from then on?

Will I have to adapt my expectations about life?



Does it mean the beginning of the end? Of the deterioration? Or not?

Am I condemned to reproduce the image I have of HD? Or not?

To answer these questions, it helps to imagine and anticipate what your life would be like after leaving the consultation room, having been diagnosed with HD. You could think about how this experience can change unsatisfactory aspects of your life and in relation to others. **These answers can not be possible without psychotherapeutic help. In the psychotherapeutic space of security and trust, one can generate these answers, which encourage doubt about the MRI of HD, so deeply rooted.**

If we modify the representation of HD, it will generate less discomfort and bring us closer to the possibility of assuming testing positive or negative in the diagnosis. MRI would then be more adaptive in the face of our daily functioning. In my psychotherapeutic process it took me some time to understand that the diagnosis was also an opportunity for personal growth.

## **Mental representation of HD and personal history.**

Remember this image already described: Huntington's MRI as the beginning of the end, as the interruption of life, as early death. Now let's go to the stage of the economic stock market. Imagine that the shares systematically fall and investors throw their hands to their heads. Many have lost a large part of their savings and have to file for bankruptcy. The stock market in my analogy is the Huntington's MRI, where expectations, the sense of continuity is drastically reduced. There are two types of investors in this plot: **those who think about what they have**

**lost and look to the past and those who anticipate what they have lost for the future.** The sense of continuity not only has to do with the future but with the past, with the identity accumulated in previous experiences.

The investor who looks towards the future will regret seeing frustrated his aspirations, his quality of life, etc. The investor who looks back to the past will regret the efforts he made, he can see it as a waste of energy, the deprivations he had to go through to save and buy shares, etc. That is, whether you look back to the past or the future, there is regret, either for the effort and suffering of the past lived or for the loss, as well as the lack of projection towards the future, which is an anticipatory loss. If the stock market does not recover, investors will have the same mood or worse if possible. They will feed their despair with more despair, with more losses. Until the stock market does not increase profits. But what if it doesn't increase them? What if the mental representation of Huntington does not change and maintains all the negative content? Despair will continue to call for despair. Either by looking towards the future or by looking back to the past. Those of us who have lived or are living with such representation, have those two investors within us and they operate simultaneously. In other words, Huntington's MR paralyzes you into the future, but it also exalts the negative episodes you have experienced. A great feeling of injustice breaks into you. When you are in a depressive mood, negative things from the past automatically come to the mind. In other words, Huntington's MR and the paralysis focused on the present, activates not only a pessimism about the future, but an activation of the past, of the negative experiences you have lived. You begin to ask yourself why me, why my family, what is the point of life, what is the point of all past suffering, what kind of divine/athea justice exists. At the same time, images of the past come to you, which also evoke sadness and hopelessness. It is a massive questioning of both the past and the future. The system collapses. Everything ceases to make sense. This state is the gateway to a major depressive episode such as an anxiety disorder. In my experience, anxiety is what mobilizes you to look for answers to what happens to you. When you get exhausted after not being able to get any satisfactory answer, that's when depression appears. We can propose a formula in this regard:

$$\begin{array}{c}
 \text{+} \\
 \hline
 \begin{array}{c}
 \textit{Past negative experiences} \\
 \textit{Huntington mental representation} \\
 \textit{Experience of other family members}
 \end{array} \\
 \hline
 \textbf{High risk of anxiety and depression.}
 \end{array}$$

We all have a backpack of negative experiences, but we usually move on because of time, to personal goals and to the relationships we establish with others. Past negative experiences are not necessarily traumas. They are subjective experiences of discomfort. I am including the experience of other relatives, because they will usually have the same MR although expressed in a different way. There are those who immerse themselves in sadness, there are those who try to act as if “nothing is happening’s”, there are those who will be full of anger because of this RM which is lived as a destiny already genetically written... The observation of the negative states of the relatives will affect us and our states will affect them, creating **feedback**. This will affect us to a greater or lesser degree depending on the significant relationship you have with that family member.

## Evolution of the MR of HD

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As we have already mentioned, Huntington’s MR is not unchangeable , **that is, it can change**. Spontaneously, there is only one way for Huntington’s MR to eliminate its impact: if you test negative in the genetic test, if you don’t have the disease. It is not that the representation is transformed, but that such MR is no longer important to you. It no longer threatens the construction of your identity, your sense of continuity because you simply will not have HD.

However, excessive optimism is not a good advisor. We can not expect to “be lucky” or elaborate magical thoughts about our destiny. Chance does not understand any kind of personal justice. It is like’ throwing a coin in the air. Therefore, we also have to be prepared for the result to indicate the disease.

**How can you be prepared for something so horrible? Changing the mental construction of Huntington. How do you do that? One word: Psychotherapy.**

I am sorry to disappoint those who read this text. There is no magic recipe to face the diagnosis or solve the discomfort in relation to the illness of a family member. *In relation to the diagnosis, this text serves as a support, a restraint to the initial MR of Huntington.* The transformation of MR has to take place through a psychotherapeutic process, which will involve pain. Psychotherapists do not have any tricks to avoid pain to patients. Without pain there is no possible psychological change.

Although it is also important the aids which will help us to reduce the tension of the MR. Among these processes stands out: medication, medical visits, Epigenetics, associations, information texts, support groups for caregivers, Mindfulness groups, yoga, etc. Any resource within an ethical framework that helps you to reduce your tension must be welcomed.

If someone decides to perform a psychotherapeutic process to transform Huntington's MR, it may be beneficial for you to count on these types of advice. It should be around 45 minutes - 60 minutes a week or every 15 days. And the amount of time (months and years) can vary depending on the psychotherapeutic model used by the psychotherapist. In Spain and many other countries there is no professional regulation around Psychotherapy, so I recommend a series of **criteria to be able to choose a professional with a high probability of being effective:**

- *He/she must be a psychologist or psychiatrist.*
- *He/she must have completed specific training in Psychotherapy, either through university masters or psychotherapeutic schools. The minimum recommended training is that they have completed 3 years, with the relevant internship in different hospitals and healthcare resources.*
- *It is recommended that you be enrolled in the FEAP (Spanish Federation of Psychotherapists' associations) or in some other association that supports your professionalism. The FEAP website has a search engine for psychotherapists who meet a series of requirements for good practices.*
- *A distinction must be made between psychotherapists based on a scientific psychotherapeutic model and various "professionals" who perform pseudotherapies such as Bach flowers, alternative medicine and various interventions with religious content (for example, Buddhist), tarot, etc. These pseudotherapies can be beneficial for various people, such as a placebo. If they do not favor people as a placebo, they usually will have harmful effects on consultants, generating more discomfort and psychopathology. That is why it is so important to distinguish between a psychotherapist and someone without this training who calls himself a psychotherapist (or companion, consultant, healer, etc.). These pseudotherapies are not useful for generating lasting psychological changes. Even less they are to change the MR of Huntington.*

## Help to support HD of MR

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Although I make special emphasis on the transformation of HD of MR through Psychotherapy, we can also use other techniques or distractions to reduce discomfort, to withstand HD of MR. In this section, I will talk about the support that can be provoked by characters to whom we attribute values with which we identify ourselves as well as phrases that connect emotionally with us. The figures have a personal symbolism. It doesn't matter whether or not the meaning we attribute to it is debatable. The main thing is that the character gives us hope and strength. Let them be a reference model for us. They can be real people, novel characters, etc. These figures can help us mentally when we lack the strength to continue our day to day.

In my diagnostic process, I relied a lot on the philosopher Nietzsche, who represents for me vitality as well as strength, despite the circumstances that he had to live. The film "The loneliness of the long-distance runner" directed by Tony Richardson meant to me the desire for freedom of the protagonist, against the authority of the reformatory. In my case in relation to HD it meant transcending the mental representation of tragic HD, to be able **to look forward and face the future**. The image of the protagonist running was very important to me, deciding that his place was not in the reformatory. His desire for freedom. Music can also play a fundamental role. In my case, I especially took refuge in John Coltrane and Hiromi Uehara.

There are millions of possibilities, of icons, that can help us, that can represent the commitment to life and the values that represent us. The study of what is called "resilience" has fostered a more optimistic view of human life, after situations of serious disturbance such as wars, natural disasters, etc. See the story of the great psychotherapist Viktor Frankl, survivor of the Nazi concentration camps. Fortunately, there are and have been many people who have overcome the circumstances and inspire us a spirit of self-improvement. Likewise, many phrases can be just as inspiring.

In reference to phrases, the phrase "**get to know yourself**" inscribed at the entrance of the temple of Delphi, in ancient Greece, was very important to me. Before facing the diagnosis, I thought I knew myself very well. My mother's positive diagnosis was what generated a family crisis. The MR that we had in our family from the HD was disastrous. I experienced an undiagnosed depressive episode that mobilized me to seek psychotherapy. The psychotherapy process gave me the "Get to know yourself". Without the outbreak of Huntington's HD, the personal enrichment, the increase in control and responsibility of my own life, would not have occurred in me.

In relation to my psychotherapy, the phrase “**there is only one valid way of living life: dedicate yourself to fully living it**” by G. Kelly gained a lot of strength. No matter what happened, whether I had the disease or not, I had to commit myself to living it as the phrase stated, fully. The diagnosis could serve to prioritize my desires and immerse myself more in the experience and not be on “the side of regret.”

## Responsibility regarding the diagnosis

As I have pointed out, when one can have a 50% chance of suffering the disease in the future, you must answer this question: do you want to know the result of the genetic analysis or not? That is, it is a choice, to weigh advantages and disadvantages. The choice involves reasoning about whether it is preferable to know it or not, which is incompatible with anxiety and fear. We need to mentally develop the consequences of knowing it or not knowing it. It implies a responsibility. That is, “I decide not to carry out the tests because...”

Or “I decide to take the tests because...” The reasons can be varied.

**The responsibility in the choice** must be with oneself and with others. In the diagnostic process through the three positions already mentioned, at some point it will be possible to think of phrases similar to the following:

- *I don't need to take the test, I'm optimistic and I know I won't have it.*
- *I have suffered so much, that I know that I will not be punished with this disease.*
- *I won't take the test since life can't do this to me, it wouldn't be fair.*
- *I prefer not to know, because if I have it, I know I won't be able to bear it.*
- *I prefer not to know, because if I have it, I will hurt my family very much.*

If you observe, the first sentence is an intuition: there is no solid basis for knowing that you will not have the disease. It's simply an excess of confidence. The second and third are also intuitions, beliefs, but this time based on personal justice. But the truth is that genetic chance is independent of any justice, whether divine or otherwise. That's why it's so difficult to comprehend, there

are no arguments that we can understand, it just happens. The last two thoughts of preferring not to know obey to fear and pain, in relation to yourself and/or your family. These apparent “decisions” are very activated by the mental representation of HD, as explained above. They are assumptions that we make by visioning the future, but there is no evidence that one cannot bear it, or the family cannot. The experience will modulate the mental representation as well as the professional help available.

Apart from fear, one raises questions about **motherhood / paternity**. This may be due to two reasons:

- *Because of the genetic characteristic of the disease: the genetic transmission of the disease makes us wonder whether or not to have children. Although there are currently methods for the annulment of HD in descendants, through in vitro fertilization, it is common for us to come to mind when coping with the diagnosis.*
- *For the anticipation with which we imagined HD, which would interrupt our life. Generally we all do what we call “life plans” and we imagine those plans seriously altered by the most serious symptoms of the illness. We can feel how the disease will invalidate our role as parents.*

It is common that the two reasons can be given together. In relation to point two, if you are not a parent, it is common for you to ask yourself: **If I have the disease, will I be able to be a parent? Will it be worth it?** This question is of very difficult personal answer and will favor doubts and anxiety without finding a clear answer, since the answer requires an elaboration and a time that is not possible before the diagnosis.

If you have already had children before making the diagnosis, you will feel a great guilt, fearing that they may also be affected. Guilt will require structural reforms, which must be treated in a psychotherapeutic field.

Responsibility becomes more present, when you wonder about paternity/ maternity, when you talk to your partner (if there is one) about having or not having children. I recommend taking the test, but in due time, without performing it due to fear. Any person needs to prepare for it. I only find positive consequences of taking the diagnosis, despite the pain it can generate. Even if the result is positive, it can be a turning point that will mobilize change, greater commitment to oneself and the environment, and greater self-care. But ultimate freedom lies in people, and as we have said, freedom involves choosing based on criteria not guided by anguish.

# Modulate genetics

## through what we do

When we think about genetics, determinism comes to mind, “everything is written.” One can lose hope, everything is left in the hands of “destiny”. Contrary to what we might intuitively think, it has been shown that genetics in the case of HD can only explain about 40% of the symptoms, while the environment could explain the rest. This is when **Epigenetics** comes into play. Epigenetics studies environmental factors, and how they modulate genetic manifestation. We know that there are four areas that influence the development of a disease, regardless of its causes: Food, Physical Activity, Social Relations and Stress Control. Next, I will briefly explain each area in relation to HD.

*Food:* Studies on food are promising although they have not yet shown satisfactory effectiveness. The nutrients studied such as Q10, Omega 3 and Creatine among others, help to slow neuronal deterioration and promote connectivity between cells. The Mediterranean diet is being studied because it is rich in unsaturated fatty acids and antioxidants.

*Physical activity:* Moderate physical activity reduces stress levels. Physical activity has been shown to slow down the progression of the disease, and reduces its severity in a significant way. Your health center or staff of a qualified gym, can help you create an individual plan to be carried out weekly, since physical activity must be adapted to the person and their needs.

*Social relations:* I think it's a factor that is not emphasized enough. Social relationships foster positive emotions and influence how we feel, as well as the evolution of HD disease. Significant social relationships, both family and outside the family, protect from isolation. Isolation predicts symptoms of discomfort such as sadness and anxiety, as well as cognitive deficits. We have already pointed out that one of the main symptoms of HD is the deterioration of interest in social relationships and the consequent isolation.

- *Stress control:* In the world in which we live, it is impossible not to have stress at some point. In fact, if stress is not prolonged and is not chronic, it is adaptive, because it helps us to finish the tasks we have at work more quickly, or to solve problems of our day to day. The stress we have to reduce is chronic, permanent. Chronic stress has been related to virtually all diagnosticable diseases. We know that stress worsens the course of any disease, as well as generates symptoms of anxiety and psychosomatic symptoms. There are several ways to promote your well-being and reduce stress:

**Relaxation techniques, Mindfulness exercises:** currently, they are carried out in Primary Care Centers and other resources through different courses that promote the reduction of discomfort through practical exercises such as the Jacobson technique or Mindfulness applied to our daily life.

**Support groups:** among them, mutual aid groups stand out. Through associations or entities related to the city council, a number of people meet to improve personal problems. There are usually one or two people who lead the group, who have some type of training in leading groups. It is not health professionals who lead the sessions, but attendance can be very useful, to generate hope and feel the support of others.

**Accompaniment and problem-solving groups:** different organizations within the health system promote various groups, such as Huntington's associations, Alzheimer's, Rare diseases. They are also very useful for family caregivers who can solve daily problems with the person with HD. It promotes the prevention of "burnout".

**Coach:** can help the activation in the day to day and achieve objectives not related to the meanings associated with Huntington. It is not a psychotherapeutic process but a process of instruction, of training to achieve goals. If you are consulted, you should be guided to improve healthy habits or solve complaints not related to Huntington's disease.

If the implications of Huntington's MR are treated, the professional who is coaching has a high probability of causing iatrogenesis, that is, "the remedy is worse than the disease." If you consult a coach who is also a psychotherapist and has extensive psychological training (which is not common in the world of coaching), you may be asked to perform a psychotherapeutic process.

## Is it Psychotherapy a type Epigenetics?

My answer is yes, but this statement is controversial today. At least it can be said that it has characteristics that it shares with this science.

**It is being demonstrated how, the psychotherapeutic process, once completed, reduces the probability of activation of genes related to psychopathology.**

In addition, at the brain level, effective Psychotherapy not only produces greater well-being in the person, but there is also less activation of the limbic system (the emotional center) and greater activation of the frontal lobe (center of cognitive integration and higher functions already described).

As I have said that Psychotherapy generates greater well-being and reduces stress and facilitates better management of it, it also includes some or all of the epigenetic aspects mentioned. That is, a change-oriented Psychotherapy not only **reduces stress** but also improves **healthy habits** (eating habits and/or physical activity), **increases the frequency and quality of social relationships**. The improvement is produced by the person's motivation to change in these areas. Through Psychotherapy, a greater awareness and responsibility is acquired in our life. The involvement to change epigenetic aspects comes from the implications that can be given in the future if these habits are not changed. For example, in a person with anxious symptoms that make her/him go to psychotherapy, who also has a family history of diabetes, she/he may realize that if she/he does not improve her/his diet she/he may have diabetes. Or a person who comes to Psychotherapy because she/he is feeling furious with others, may realize that anger separates her/him from others and that she/he would like to make friends, since life is very unsatisfactory in this way. The recommendable if we want an optimal adaptation to the disease or the possibility of having it, is to perform a Psychotherapy supported in the other areas of Epigenetics. Epigenetics by itself can relieve and help us endure Huntington's MR, as we have already mentioned. It is not a sufficient condition, although it is recommended. To come to this point as we have said this optimal adaptation, Psychotherapy must be translated into changes in behavior, an increase in self-care. Otherwise, it is not an effective Psychotherapy.

In my personal case, the two elements, psychotherapy and Epigenetics, went hand in hand. The diagnostic process laid on the table the question of what

would I do if I had the disease. I asked myself: “what can I do, within my limits, to be able to delay the onset of the symptoms of HD?” “What can I do?” I asked myself incessantly. Amid desperation, I became aware of my own body, of the responsibility I had over it. It’s the only thing we have for sure! Inhabiting our body. I thought about how I should take care of it, as if it were an oasis in the desert, a temple. I even proposed to myself that, if I didn’t have the disease, I would make drastic changes in my life. At the beginning of the diagnosis, the fear of symptoms, of deterioration, of the image I had of the disease, mobilized me to take more care of myself. “If the appearance of symptoms were prolonged, it would gain in quality of life and surely, the symptoms would also be less serious,” I thought. I mean, I would be better off. After all, that’s what Epigenetics is telling us. Then, it was no longer the fear, but the responsibility I exercised upon myself. I took it as an opportunity to gain in quality of life and vitality. I was able to make the change: from fear to opportunity.

I started running two to three times a week, doing brief and simple physical exercises, such as push-ups. During the time I’m running, I treasure the idea that I’m gaining in health, and in satisfaction. I drastically reduced alcohol consumption. I watched more closely what I ate, especially the percentage of saturated fats. All this, I did it and I do it without turning it into an obsession, transforming the changes into habits. Fear towards a disease can encourage obsession with these aforementioned changes. But from the commitment and responsibility with oneself, the obsession is annulled. The fear of the disease, of having it, has to be processed, digested. And it’s not an easy task. I could and I think anyone can, with the appropriate time. And that time is variable, it depends on each case.

Schopenhauer quoting Terencio translates: **“In human life it happens as in a roll of dice: if the dice does not come out with the number which is needed, the strategy must improve what luck granted.”**

This is what consists of responsabilizing on yourself. Biology can predispose the disease, in this case HD, but we must adopt that strategy that Terencio talks about, which consists of improving healthy habits and personal change.

# Compass for the family

*In this section I will speak about the “us”, as relatives of a person diagnosed with HD with whom we have to live with.*

## Position regarding the family member diagnosed with HD

→ **Gorgias: “And our struggle requires two virtues, audacity and wisdom. Boldness, to face the danger; wisdom, to know what is convenient.”**

I start with this phrase because it represents for me the recommended attitude for relatives who live the disease very closely. It expresses HD as a threat, a battle that requires courage and reflection. Courage and reflection are what allow us to take the necessary measures to reduce or solve the most serious symptoms of the disease. We have to have something very clear: we will feel powerless and overwhelmed by the seriousness of the conflicts. If we do not learn how to manage conflicts, it is very likely that we will feel overwhelmed and that we will also start to manifest anxious--depressive symptoms.

I like to think of HD as a battle that needs all our ingenuity and creativity. Even so, our effort does not guarantee the expected results. That definitive military victory. We have to be content with modest, partial victories. Audacity and wisdom is what they can give us. Otherwise, the defeat and the defeat is total.

The objective that this section dedicated to relatives is trying to fulfill is: when I have a conflict with my family member diagnosed with HD, what can I do? How can I cope with my family member's symptoms? To do this, I will explain a problem-solving model in a practical way. I must warn you that there will be conflicts that due to the cognitive impairment of our family member, we will not be able to avoid. So what good is what I am going to propose if there are situations that cannot be solved? This section is also dedicated to self-care, which we must nurture ourselves as relatives. It is true, there will be situations that we will not be able to avoid, but we can reduce their duration as well as reduce our discomfort, by being able to manage them with more efficiency and control.

As a relative, the question one has to ask is: *what position do I take between absolute passivity and overprotection?*



The popular saying teaches us that “**extremes are not good.**” The total passivity towards the care that the person with HD will need will make them worse clinically and to as relatives it will produce, as I have mentioned, first of all, psychological symptoms in addition to a complex situation. Secondly, this position will lead us to serious negligence towards our loved one in an advanced phase of the disease (medical complications due to feeding, excessive expenses of money, etc.), which would affect us very negatively.

The excess of overprotection promotes disappointment if the expectations that one has are not met, it makes us not take care of ourselves, also endangering our well-being. If we end up “burned out”, we can move on to the opposite side, to passivity. If we don’t know how to position ourselves, find the exact measure for us, we may be constantly oscillating blindly between total passivity and overprotection. So where should we position ourselves? The term of which Aristotle spoke about can be an answer which protects us from discomfort. Each situation and moment will require more passivity or less, more involvement or less. *Passivity-overprotection* go hand in hand with reason-emotion so we have to take them into account in order to be able to solve a problem. Good decisions require an integration between reason and emotion.



In reason-emotion we must return to the middle, to the balance. We can think about our experience, when we have been extremely rational or we have met people who have given us that feeling. If you remember that situation, you will see how difficult it is to get closer to such a rational world. It makes empathy difficult, wanting to understand the other. Deep down, much of the communication is interrupted. In the same way, when someone is in an intense emotional state, overwhelmed by emotion, he cannot hear, or get out of that discomfort. Anxiety and the intense emotional state also short-circuit communication.

The excess of reason will make us not empathise with our relative, trying to instruct him and pretending to show him “how right we are.” The excess of emotion will make us overflow easily and we will not be able to make decisions that help increase the well-being of both us and our family member with HD. We will feel anger and agitation, which will increase the anger and agitation of our family member. They are emotional mirrors, **we must give him emotions that counteract the ones which cause him discomfort**, especially sadness and anger.

Again, we have to oscillate between reason and emotion, having the right measure, depending on the situation. You have to ask yourself during and after the conflict: “Have I been too emotional? Have I been too rational? Have I been able to find the midpoint? What can I improve if a similar situation happens again?” These questions help the development of an internal dialogue that will help us in future situations. You can accompany the questions by remembering the situation and imagining the same situation but with a different, improved performance. This operation will allow you to elaborate an alternative outcome. This internal dialogue can later, in a similar situation, be tested.

The attitude of temperance can help us not to be extreme in reason or extreme in emotion. Temperance can be trained through the aforementioned questions, which seek to reduce excess reason and excess emotion for future situations. There are many ways to train “the right measure,” but they all require the analysis of the situation and analysis of emotions and thoughts, as well as alternative solutions. On the internet there are a multitude of tasks focused on this purpose, under the label of “self-registration”. The problem-solving process that I will explain later also helps us to encourage the attitude of temperance.

## Anticipate conflicts

We know that conflicts with our family member are highly likely due to neuronal deterioration. The ideal then is to be able to anticipate them. That is, prevent problems with the relative who has HD, or at least, those that can be avoided with the precautions indicated below.

As relatives, we must be observers and bring out our “scientific” part, which we talked about in the introduction. We can evaluate before acting the probability of generating in our family discomfort and based on this mental evaluation, act. To evaluate this probability, we can ask ourselves: if I say this, is it likely that you will not understand it and get frustrated and angry? This process also requires trial and mistakes.

Usually and depending on the phase of the disease, we can be alert to a series of recommendations to prevent conflicts:

- Avoid talking about that require complex reasoning. As we have seen, what we call social cognition is very affected and there are failures in the attribution of intentions. It is not uncommon that even memories of the past have been altered. If the person gives a very different version of what happened, it is preferable to accept it and not fight it. It is not about “giving

him the reason like a child” but about accepting it and a different version of your own can be given, but always under the label “I remember that...”, that does not delete and invalidate what was said by the relative.

- Avoid the *concept of “truth”* when opinions or facts contradict the person with HD. If we do without the “truth”, we will already have half a battle won. As a family member, we have to ask ourselves a question: “Is it useful for me to label what I say as the truth?” Among the “truths” that will generate a safe conflict, there are those that contain a critical element, of judgment or attribution of guilt/responsibility on matters of the past. These phrases usually begin with: “you did, it’s your fault...”. They are painful phrases for any person, so they are even more difficult for people with a diagnosis of HD.
- It is common that due to the lack of inhibition of impulsivity due to the deterioration of the frontal lobe, the person with HD makes *extreme statements* that offend or outrage us due to their content. I recommend not entering into questioning and showing some interest from the “scientific curiosity” for the explanation that can be given. Subsequently, it can be relativized through humor but not from the imposition of “that’s not like that.” A good example may be the affirmation of stereotypes and prejudices about countries.
- Also related to the deterioration of the frontal lobe, they are also the ratings that our relatives can attribute to us. In the anger they may have with us, it is common for us to be labeled as “selfish”, of “making their lives impossible” and various insults, depending on the intensity of the conflict. In these cases, like the previous ones, it is not a question of aggravating the duration of the conflict by demonstrating that its “truth” is wrong. It is more practical and advisable to take the statements and sentences of the family member as mental constructions, not as affirmations. On an emotional level, it is very different to think that “my mother thinks that I am selfish and I make her life impossible” to “my mother, from the deterioration caused by the disease, she believes that I am selfish and I make her life impossible.” It is not a question of eliminating the discomfort it may generate, but of reducing it significantly. Replacing “*truths*” with “*mental constructions of the person*”, makes us more tolerant and we suffer less.
- Avoid the “you have to” or “you should” in relation to the *tasks or desires* that we would like our relative with HD to perform. They can be changed to: “it would be nice if,” “what would you think if?” Through the imposition without dialogue, we have lost half a battle regarding improving the quality of life of our family member. For this reason, I’m talking about improving our “negotiator” side.

## Set out to to be negotiators

Being relatives of the person with Huntington, we have to think like negotiators. When cognitive impairment is noticeable, it is our duty to set aside “the logical”, “the obligation of him/her is.” These types of attributions give the message that the person has full responsibility over herself/himself. But the truth is that the deterioration of the frontal lobe prevents it. It is our obligation to maximize their autonomy, but inevitably they will no longer have the autonomy they had. When this is evident, it is common that they affirm or give excuses for things that they do not do despite our requests (management of procedures, cooking, self-care, going to the doctor, etc.). As relatives, we would like, by a stroke of grace, that they would react to our motives, to our reason.

**We must leave our desires and expectations aside and be realistic, taking into account the moment in which our relative is going through in the evolution of the disease.**

Well, the magical expectations (that my relative being as reasonable as I would like or as much as before) generate disappointment and discomfort to us. To avoid being private detectives and to be on the watch out of what they have done and what they have not done, and to scold them, you can use our negotiating part. Being a negotiator has a number of characteristics:

- *He/she doesn't speak from reason, he/she does not seek to correct anyone. He/she is not imposing from the beginning. He/she speaks from the attempt to balance emotion and reason, firmly.*
- *Understand, give encouragement and support, but maintain his/her position.*
- *In the dialogue, look for collaboration. He/she wants the other person to win something and make him/her a participant in the decision, so he/she must be skilled in his/her negotiation.*

As a metaphor and by bridging the distances, we can observe how a good police negotiator acts. They seek the complicity of the suspect. These go from absolute denial to collaboration with the interviewers. Look, they offer them a cigarette, they give them comfort, they empathize with them, they give encouragement to the suspect. Also, although strategically, they speak from emotion. They put themselves in their position. They negotiate agreements and these agreements are systematically carried out.

The good negotiator can not focus on the deterioration, “on how bad the relative does it.” If the person is praised, highlighting what he/she does well, or aspects of personality that he/she still retains or has had (such as being a good person, a fighter, etc.) it is easier for him/her to collaborate. **The praise**, the reinforcement of the positive things that our relative has, activates the limbic system, the most emotional part of the brain. In a process of dementia such as HD, the last thing that is lost is the emotional part and we must take advantage of it so that he/she can collaborate in what is necessary and not encourage anger and obligation before our requests. We will observe with the pass of time, that our relative will become a master of excuses and lies due to neuronal deterioration. **We should not see anything intentional in this matter, it will only harm us and alter the relationship by making it worse.** It is more profitable to see excuses and denials as limitations of the disease.

In order not to perform certain tasks which they are still able to perform, they can give various explanations and hold on to them. Setting my mother’s example, she gives the repetitive explanation that “now I want to be calm.” She clings to the fact that she has worked a lot in life, which is true, and that now is when she is living her life with greater tranquility. Therefore, for her, whatever thing means taking her out of that calmness . It is her explanation to being isolated at home almost without any stimulus, a characteristic symptom of the disease. If our goal as relatives is to reduce her isolation as much as possible, she will say that she wants to be calm. As a negotiator, we have to fit in our demand, with the representation that she makes of our demand.

That is, for example, asking her to do a medical check up when she refuses, she will live it as a way to interrupt her tranquility and can answer you that she/he is fine, that he/she does not need such a test. It is then necessary to sell it as a form of tranquility, which must be prevented in order to enjoy the tranquility you are having and lengthen it as much as possible. If possible, it is beneficial to offer to accompany her/him or make it easier so that she/he can perform the task.

Even with these tips and taking out the negotiator that each one has inside, we will not always be able to obtain the collaboration of our relative. And we have to be prepared for it, no matter how painful it may be. Let’s imagine one of the worst possible scenarios. Our relative is aggressive and we can’t reduce this aggressiveness , we are collapsed. **If the case requires it, call the emergency room.** We all have a limit and if we want to preserve our mental health, we must also think about taking care of it from highly stressful situations. When the crisis passes, the behavioral alteration, it can be useful to explain to our relative, that if a situation of serious discomfort occurs again, the same will be done. You can

explain the steps that will be taken, the sequence, explaining to them emotionally, that they want the best for him/her and that, we would not like to reach that point but if necessary, we will call the emergency room. When we explain this we don't mention the discomfort it generates us and the personal resentment, but the "concern for their well-being." The message will reach them in a more positive way and the chances of them feeling guilty will be reduced.

Being a *negotiator* will also help us reach an agreement with other family members to try to take better decisions. Although the problem-solving model described in the following section is applied, it may be that not all family members reach the same conclusion of the action plan. Or they are not willing to help. As negotiators, we have to ask ourselves: **Who is willing to help? Who could be willing to help if I ask for it?** The strategy is not only in relation to the person with HD, but with the whole environment. For this reason, the same negotiating attitude must work with everyone, adapting it to each person. It can be useful, with whom we want to work with, to explain why we consider their help and support to be important and to value their involvement. Everyone is more willing to take action when we understand the purpose of the action, why it is important, and when they value us as people. Someone practical as a good negotiator should be, must make sure that everyone understands what is going to be done, how and why, and will have the opinions and contributions that may be useful. That is, he/she will exercise the corresponding power, but without being blinded by his own ideas.

**Being a negotiator is combined with being flexible according to the situation and delegating when it is convenient.**

Our negotiating party should never give up, because even in the worst situations it can cushion our discomfort and that of our relatives.

## Set out to to be negotiators

Below I describe a problem-solving model, which has served me and serves me, not only in reference to HD but in any area of my life. This consists of defining the problem, situation where the problem appears, sequence of the problem, action plan, application and review.

**Definition of the problem:** In order to solve a problem, we need to define it as well as possible. The problem needs to be written as specifically as possible. A bad example could be: "my relative is lazy and I want to solve that." A more operational

way of stating the problem in that case could be: “my family member due to the illness, will no longer watch soccer on Sundays as he used to do with friends.” Success largely depends on the definition, since it is the foundation from which to apply a solution to the problem. The definition of the problem must be fed by the situation of the problem as well as the sequence of the problem, in order to be more specific.

**Situation where the problem appears:** It refers to the context, the physical place as well as the emotions and thoughts of the people involved. The conflict, “where does it appear? Who were there? What does everyone involved think and has done about it?” We may not know what others may think, it may be useful to ask them directly. In the event that you don’t know what your relative with HD thinks, one can ask oneself: “about the problem, what would he/she think about it, what would make him/her behave this way? ” The mental content of our relative will depend on cognitive impairment. Even in cases of greater deterioration, we can represent the mental state, such as despair or other emotions of discomfort, if it is compatible, with the situation of our relative. In this regard, I remember when my relatives told me that my maternal grandmother tried to suffocate herself with the bed sheets and they had to stop her. She was already in an advanced phase and barely spoke. There was no access to the reason, of “why she had tried to suffocate herself, what had led her to do it.” But it can be interpreted as an act of acute despair.

**Sequence of the problem:** I like to talk about this part with the following instruction: “imagine the problem, as you identify it, as it has happened, could you tell it as if it were a movie?” Telling it as a scene makes it easier to be aware of the process in which the conflict occurs.

**Action plan:** It requires two phases: elaboration of the plan and implementation of the plan.

**Elaboration:** It involves the integration of all the information collected. It could be condensed into the following question: “with all the information I have, can I have a total or partial solution to the problem?” It’s about finding an answer to the problem. The solution must answer the question: given the definition of the problem, “can it be solved, is this solution realistic, who will participate, how will it be applied?”. Its application should be clear and not give margin to improvisation.

**Application:** It is to put into concrete actions the solution used.

**Reviews:** The review of our response to the problem needs to respond whether the

solution has been effective enough. In the review it may be useful to think about improvement actions, if the problem still persists or if it can continue to improve. The review would be like “the manager” of the company who supervises the production method of a factory. If the problem is not solved or not significantly reduced, it should be analyzed to see where it has failed and what measures can be taken. In some cases it may be the lack of detail in the definition of the problem or that the action plan has not been executed as elaborated. The important thing is to be able to maintain the capacity for scientific observation throughout the process.

The method described on problem solving is based on the modern scientific method. That is, we observe a phenomenon (in our case *a problem*), we get an idea of the characteristics it has (situation where it appears), it is operationalized (defined), the development of the phenomenon is observed (sequence of the problem), the hypothesis of why it happens is created and how it can be solved (action plan: elaboration), the hypothesis is tested (action plan: application), the result is observed and it is checked if our hypotheses were correct (review). Often without being conscious, we use mental models of problem solving. We usually say then that “we use reason,” in a way that we can’t explain clearly. There are even complete psychotherapies that use more complex and extensive methods to solve problems.

The important thing about the various methods is that they are systematic and help us reduce our discomfort by responding to our demands.

## The sense of humor as an ally

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After my mother’s diagnosis, I thought about how I could make humor more present, in my interaction with her and with my siblings, as overwhelmed as we were. I knew that somehow that would help me reduce my concern and tension around HD. “How could I do it?” I thought. When one imagines how the disease will break out at the family environment, one usually imagines a catastrophic future where the symptoms will not leave room for any well-being. The terrible images that I imagined soon vanished. If one went to the movies and saw the film “Huntington’s disease” he/she would see that it is specially about the deterioration of the affected person. From the anticipatory anxiety of imagining the symptoms, you can move on to hopelessness, to the conviction that you can not do anything on your part. If we are shooting as directors at the pole of passivity, that is what we will end up seeing, feeling and thinking about the celluloid.

But you can direct the movie you want to shoot, even though there are economical pressures from the producers, which in our case are the HD symptoms. And in this movie we must include **humor** as one of the characters.

The first thing that will surprise us is the lack of will power, the so-called apathy. At first we will confuse it with depression from our relative. We will be saddened that they very rarely start conversations or have the initiative they had before. As it happens to my mother, the person can be smoking for hours, or even with the television turned off and without saying anything. Or she may be watching TV and not know what exactly she is watching. In those moments of isolation, muscle and language symptoms may increase (such as incomprehensible murmurs). Her mind is as if she were in a limbo where nothing happens. If you ask her at that moment, what she is thinking or remembering, she will answer that “nothing”, “my personal things” or some vague answer. In the presence of this disinterest, one can stay as a spectator or one can contribute to mobilizing the person. There is a margin for action, but we must also lower the expectations in reference to what we can achieve (because if we have high expectations, it is most likely that we will get frustrated and choose for the withdrawal, of giving up directing the film). Here you have to adjust expectations which is not the same as eliminating them.

The question to ask ourselves is: How can I encourage my relative to reduce their isolation and increase their well-being and live it as something positive? How can humor help me with it?

The first thing you will find before each suggestion or proposal for activity is a “no”. This can not be blunt or can be given through several justifications. Mental rigidity and deterioration of cognitive abilities will make you not to be able to convince her of anything about your suggestion (**let’s say that we suggest her/he to do some activity at a leisure center**).

The proposals must be adapted to the tastes of the family member, to the skills they already have. On many occasions, something as simple as taking a walk, they will avoid it so (hence my insistence on adjusting our expectations to the family member’s possibilities). Also here we try adopting as we said before the attitude of a scientist, of ascertainment and verification of the status of our relative with HD. Try not to impose or demand but to propose by adding some funny memory or comment, since it is easier for them to accept it. Phrases like: “How about if we go...? We had a great time there, do you remember...?” They are more useful than phrases such as: “We have to go...”

Conversations can also get them out of their isolation. Depending on the phase

of the disease, it requires more or less patience from our part. We will observe that, in accordance with the cognitive deterioration, the conversation around any topic, will be increasingly difficult to maintain. They may not finish the sentences, have very simple answers to any complex question, lack nouns, specification about what they want to express and use filler words in a very frequent way, “well, that’s the case, as I said...”. These language errors hinder the relationship and interaction in all areas of everyday life. This should not discourage us from giving up conversations with our family member. The complexity of what is talked about can be reduced to cut down the frustration of both parties.

We have to bring out the best scientist inside of us, our capacity for creativity with our family member. And our best scientist necessarily has to have a sense of humor. The scientific attitude, which does not seek the truth or the objective, which only focuses on curiosity about the other, how he/she thinks or feels, awakens the person with HD from his/her apathy. When I talk to my mother, I foment her curiosity, I exaggerate experiences of my day to day to encourage surprise in her. I ask her about what she thinks about what I am telling her and I do not try to “correct or instruct her”, I help her if necessary to complete the sentences. All this is possible through active listening. If we want to promote the well-being of our relative, we can not afford not to have active listening.

**Humor has no effect if the person with HD does not feel heard, valued and is not involved in the conversation.**

An illustrative example can help us visualize how humor can help us with our relative: My mother did not want to go to her appointment with the Neurologist. After talking to her, I accompanied her even though she was “half forced by me.” It seemed as if she was about to “blow up”. I was trying to reduce the tension but she wasn’t in the mood. Then, already in the waiting room, taking advantage of the fact that there were more people and they were talking to each other, I said smiling at my mother: “Well, mom, people here seem to be having a good time.” She looked around and laughed.

→ **Situations where there is tension are favorable to introduce humor.** Humor can be the antidote to fatigue, the so-called “burn-out” of living with a person with HD. Well, it is easy for widespread disinterest to “infect” us and fall into pessimism. And despite our effort, as I said, in spite of following all the indications I have written, it is very likely that we can not avoid arguments or unpleasant situations with our relative. In those moments we also need humor even if it is for our sake, to be able to dissociate ourselves from the pain generated by the

situation. An example that can be useful is an argument I had with my mother. I was going to take a train and my mother put a large amount of food in a bag, not necessary for the duration of the trip. I thanked her for the gesture and told her that there were things that I would not take with me, because the bag weighed a lot. She kept insisting that I take everything. I explained to her again in other words, following with a neutral tone of voice. Then she got angry for not wanting to take the food.

She accused me of not eating and started yelling at me. I tried to play the matter down but she stuck to her guns. My attempt to introduce humor and reduce tension was not effective. But I did get discouraged. It helped me to think that what my mother was really telling me in an incorrect way is that she was worried about my diet. I mentally visualized how that same scene could have been by changing the message from “you do not eat much” to “son I’m worried that you eat well, that’s why I am screaming at you.” It helped me to reduce the discomfort and in the process, to be able to laugh at the situation.

# The Healthcare Team

*This section is dedicated to professionals who work with patients diagnosed with HD and family members.*

From my experience with HD, I have been thinking about how the diagnostic process could be improved so that the person who faces HD, lives it with as little discomfort as possible. The same is the case with his/her subsequent treatment plan, if the diagnosis is positive.

As we have said before, HD is within the framework of genetic disease, within the biological field. This biologicism means that the mental representation about the disease does not take into account the psychological part. Therefore, it is not only about epistemological issues but also implies how the treatment applied should be. It is likely that we do not pay attention to the life experience of the patient in relation to his diagnosis and the implications if in the end he/she is positive in the genetic analysis. As well as the subsequent moments after the diagnosis, very critical because of the fragility they foster. The first indispensable requirement, although on many occasions it is not met, is that the patient has a reference professional. That is, in the greatest number of occasions, except when the professional is on vacation or some exception, the assigned neurologist can visit the person. There can be no therapeutic link if in each visit there is a different professional. In my experience, I have seen how a reference doctor is assigned but then that function is not fulfilled.

**The referring doctor in addition to the individualized pharmacological treatment for the patient, has the purpose of mediating in the resolution of problems in the family as well as instilling hope in the family.**

His/her help and advice will be very useful when there is a refusal on the part of the person diagnosed to follow the recommended guidelines (for example, health habits or adherence to pharmacological treatment). The doctor will use his ability and commitment as much as possible to reduce discomfort in the family.

In the process of diagnosing and subsequent coping with the disease, the function that the Neurology team can fulfill at a psychological level is to contain the mental representation that the person has. We can not contain it, if our vision is strictly biological, if we do not know what exactly the mental representation of the patient is. To restrain, first you have to ask about the mental representation. When we interview the person, to find out what the mental representation about HD is like, the ideal is to show a credulous attitude to what the patient says. The best example of a gullible attitude, I have found it in George Kelly's phrase: "if you don't know what is happening to your patient, ask him, maybe he/she will tell you."

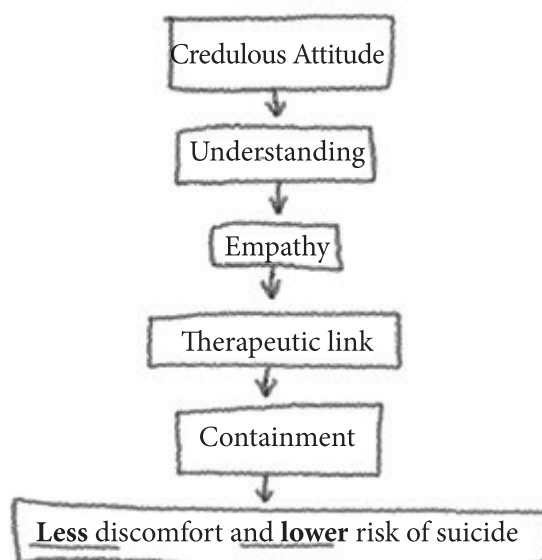
The credulous attitude has a number of **characteristics**:

- *Take for granted everything that the patient says. When I say real, I mean that it is real, for him/her. It doesn't matter if in our opinion it is not.*
- *Active listening in the interview with the patient is essential. This active listening will focus on the person's worries and concerns. Active listening requires not only questions and interest in the speech, but also an interaction between verbal communication and non-verbal communication (such as eye contact, gestures, etc.).*
- *It is indispensable a genuine interest in wanting to understand the patient, his world and the mental representation which means or supposes for him/her, to feel how the disease is altering his/her plans and his/her life.*
- *It does not require a direct confrontation of the mental representation of the patient. It is not advisable to tell him/her, "that will not be the case" and disagree against the person's speech. If this procedure is followed, in the best case, the patient will remain silent and will not dare to express what he/she feels and thinks and will self-censor.*
- *Equally inadvisable is paternalism with the person. They are very untherapeutic phrases such as "Do not worry, you will see how in the end it will turn out well," "everything has a solution," etc.*

Both confrontation and paternalism stop and/or hinder the analysis of mental representation. From my experience I can say, that some people around me have surely already given these types of paternalistic and confrontational messages, why will a professional with the same phrases generate a different result? The **credulous attitude** apart from the analysis of mental representation,

encourages hope in the person. When you feel that there is 50% that your world will come to an end, or having already received the diagnosis he/she feels how 100% of his life is threatened, that there is someone who can understand him/her without judging, can make you feel less alone.

In addition to the anxiety symptoms and depressives, we can not forget the risk of suicide in the diagnosis of HD. We can describe a simple sequence of the psychological process described here:



There will be cases in which the risk of suicide is not reduced spontaneously, but it is more likely that they will communicate it so the professional will have a margin of action. Analyzing the mental representation of the patient requires some training. Mental representation is usually implicit in concerns and motives that the person brings. Let's look at an example:

**Doctor:** Hello Mr. Pérez, it's been a while since we've seen each other. How are you doing?

**Patient:** Well, more or less doctor, I'm a little worried and I can't sleep at night.

**Doctor:** Wow, and what is it that worries you that will not let you sleep?

**Patient:** Well, doctor, the disease, if I have it...

**Doctor:** If you have it, what will happen?

**Patient:** Surely my life will come to an end.

**Doctor:** And exactly, what things will end?

**Patient:** Well, everything, I will have to quit my job which I have put so much effort, as well as the project of having children.

**Doctor:** So if I have understood you well, you feel that the disease will take away everything you know.

**Patient:** That's right, doctor, that's what comes to my mind when I try to sleep at night.

**Doctor:** And with these thoughts that come to your mind, what could you do to sleep a little more?

**Patient:** I don't know doctor, this is what paralyzes me, I guess try to distract myself.

**Doctor:** Is there a day that you don't get assaulted by these thoughts when you sleep?

**Patient:** When I'm busy or I have spent a day away from home. I arrive so exhausted that I can not even think and I fall asleep right away.

**Doctor:** Is there anything you can do to feel so exhausted that can distract you before falling asleep? Something that has worked for you or can work for you?

**Patient:** Well, when I was studying, I watched humorous monologues on my cell phone or some series on TV that distracted me.

**Doctor:** So if I have understood you correctly, the thoughts at night, when the day is over are activated and do not let you sleep and perhaps something that will help you reduce these thoughts is to watch a humor video or a series that does not require much attention. Is this so?

**Patient:** Yes, I think I could watch a video so I do not think so much.

As observed in this interaction between a professional and the patient, it is not a matter of "correcting" the patient in his mental representation of the disease as an annulment of life, but of **understanding** his/her mood, his/her insomnia and how it makes it difficult for her/him the next day and suggest some simple

strategies which reduce insomnia. As we can see, the professional supports the patient and helps him make his/her day to day more bearable. He/she does not propose an immediate pharmacological solution. In fact, a lot of medicalization is needed to “appease” a mental representation as disabling as the prototypical of HD. The great disadvantage of the drugs, although necessary in cases of serious psychopathological symptoms, is that they do not offer any enrichment for the mental representation of the disease.

## About the limitations of the public system:

The professional who is reading these lines may think that this reconsideration of the diagnostic process as well as the subsequent visits is unfeasible, given the nature of the public system, which is in charge of these processes. If I had to imagine a critic of the proposal, I could say something like this: “you have not taken into account the time limitations we have to treat patients. We can not also deal with the mental representation which it has about HD. That is what psychologists or psychiatrists are for, and in addition, it is not our competence. In case we think it is convenient, we derive.” And in the face of this criticism, I would agree with the time constraints that exist in the public system to take care of the patients.. And not only that, but those limitations are variable depending on each autonomous community. But what I propose is the **incorporation of basic therapeutic skills into the medical methodology that is already practiced**. Basic therapeutic skills are the psychological element that is scarce in the units of Neurology and other sciences labeled under genetics and/or biology. Note that I am talking about containing the mental representation so that it is bearable and the diagnosis can be faced with the least possible anguish. I’m not talking about transforming the mental representation of HD, which requires more time and a psychotherapeutic process, hardly viable in the public system.

There are multiple trainings about basic psychotherapeutic skills. An awareness is being generated that these skills do not only correspond to the work more typical of the contexts of mental health units, but that these skills can be generalized to other contexts, such as companies, organizations and as may be our case, to Neurology units.

## Need for psychosocial treatment

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Finally, I would like to emphasize the need to plan treatment with patients diagnosed with Huntington in a psychosocial way. In my opinion, treating them only from the Neurology unit is a sign of a need for improvement. Let's remember the reduction of functionality in daily life as well as the null awareness of the disease lead to multiple problems, which will need from various professionals from other units. Some fields are already integrated into Neurology, such as Nursing and Social Work. Coordinations are carried out with other teams that are not accomplished systematically in general. I make reference to *fields of health sciences* that it would be advisable to have regular meetings or systematic coordination with the Neurology team in relation to patients with HD:

**Social work:** the inability to keep a job will affect their economic income and they will need a pension. My mother called the pension "the best medicine," because not being able to sustain a job, anxiety about payments and debts contributed to emotional instability and worsening of the clinical course of the disease.

**Nursing:** nurses can advise on the appropriate nutrition for our family member. They will know how to advise us on health habits that will influence the epigenetic level.

**Psychiatry/Psychology:** Psychiatric symptoms are very common in HD, so their stabilization through the appropriate psychotropic drugs will be necessary at some point. In the same way, the Psychology unit can help the family members to solve the new difficulties that will appear in the course of the disease. We can make a distinction between individual and family psychotherapy. Depending on the needs of the moment. Individual psychotherapy seeks, as we have said, to transform mental representation, so that the person's life can be more adaptive and reduce symptoms. Family psychotherapy is compatible with personal objectives, but also actively involves the nuclear family. Let's not forget that the diagnosis is not only a personal crisis, but also a family imbalance, and it is common for the couple and children, if any, siblings, etc., to have a mental collapse. If the situation requires it, the family intervention, can increase the feeling of control, on the part of the family.

**Primary care center:** the family doctor, usually sees the patient and/or the family more frequently, for small consultations. He is the one who has a closer relationship with all of them, so in general, he has more confidence to be able to advise and refer, if the situation requires it.

**Other devices:** At some point, it may be necessary to refer to the pain unit, rheumatology or other units, due to the variety of symptoms, or comorbidity with other diseases, so it would be advisable the coordination as well as meetings among different medical units.

To sum up, when I talk about psychosocial treatment I want to emphasize the importance of collaborating with the family as well as with other specialized professionals. **That HD be classified as a neurological disease and be treated strictly from Neurology, is not enough, given the severity of the clinical picture.**

# Conclusions

When I started this text I thought of calling it “Enclosing Huntington’s disease.” I wanted to use enclose as a synonym to besiege, but the verb to besiege had a component of war and annihilation which did not convince me. What I wanted to transmit with the title was that we can take the necessary precautions to limit the meaning, to put a security wall, which helps us separate HD, from what we imagine and affirm about it, that is, from its mental representation. Although this enclose, is not synonymous of a final solution. But it takes the necessary step for the transformation of the meaning of HD. When you can distinguish the anticipation you make of HD, from the progress of the disease, you can draw the boundaries between both spheres and you can transform the mental representation of HD. In the face of this disease, believing that “the map is the territory” is the first mistake we fall into, whether as a person who faces the diagnosis, family member or professional.

Enclose also involves **taking control**. That is why there is an emphasis on decision-making and problem solving. The experience of the disease or its possibility increases the feeling being victims, placing ourselves in passivity, feeding back the lack of control. When families observe the deterioration and suffer the conflicts, it is very likely to position themselves in resignation, another form of passivity.

In this text I couldn’t leave the family out. We are the ones who live it very closely, with everything that it entails. The disorientation about how to act and pessimism are feelings that can appear frequently. Do not let yourself be overcome by fear and silence. Silence nourishes isolation. You will be surprised how, using the scientific spirit and communication as a team, collaborating with everyone, as a unit, unexpected results can be achieved! Not only the negative calls the negative, but the positive calls the positive. This text, as I said in the introduction, had the objective of instilling hope, of giving a framework of psychological understanding and action regarding HD. Understanding we can act without being guided by anxiety and precipitation. Now it is up to you who will have to judge if the aforementioned objectives have been met.



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