

Composing With Huntington's

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Why "Composing With Huntington's Disease"?

HD obliges those affected by it – as persons at risk, patients, carers, or next of kin – to perform an often-breathtaking series of metamorphoses. Such metamorphic transformations, however, do not have to be simply and passively undergone but turn out to be actively forged and molded by those involved in them. As it is, such fundamentally fragile performances require an incredible amount of creativity, tactfulness and rusing. Consequently the actors of Huntington's Disease are often in lack of time and words apt to tackle the immediate character of their experiential universes,

Composing With Huntington's aims at rendering the 'invisible knowledges' produced by those who live and evolve with HD accessible. It celebrates processes of ever ongoing ingenious invention, tries to account for the incredibly variable forms of cultivating sensitivities and nourishing faiths, of outwitting seemingly unsolvable difficulties through sophisticated stratagems, narrative savvy and loving connivance.

We are indefinitely thankful to our co-investigators who gave us their confidence and guided us into their respective universes thereby furthering our exploration into the enigmatic planet, we at Dingdingdong like to address as Huntingtonland.

The Method and Writing it Up!

The material that enabled us to do so was acquired via long qualitative interviews with 7 immediately concerned persons that were either at risk, confirmed carriers of the disease, or already symptomatic and 10 carers with varying degrees of experience with the disease. Two interviews were carried out with each of them, the second one taking up and prolonging those themes that – on the basis of the transcriptions of the first interview – had appeared as particularly intriguing, promising, irritating or simply requiring further precision. Proceeding in this manner, our interlocutors did not merely play the role of testimonies, they rather became actual co-producers of knowledge as it emerged gradually in these conversations.

The often unexpected ways of inventing and composing lives in negotiation with HD we discovered during this phase of intensive exchange, of trying to 'put it into words' together, have sometimes confirmed our preliminary intuitions, sometimes made us tremble, hesitate and reorient.

In a nutshell: They have made our thinking grow.

1. Making the Acquaintance

« The worst are those professional care-givers that are already trained... those who have certitudes, for example, with respect to degenerative diseases », says one of our interviewees who cares for HD patients in her family since three generations. Acquainting oneself with HD in ways that have empowering qualities turns out to be

quite an artful task requiring patience, a form of voluntary flexibility that allows for the gradual attunement with the rhythm of the disease, and a good portion of faith. The most central task in this process might be to free those involved with HD from those medical categories and definitions that prescribe the experience with the disease beforehand. In short : Making the acquaintance of HD is a process of experimenting, constructing, and composing with the disease, the ill person and the environment rather than the accumulation of ready-made knowledge. It is a complex practice of reception.

2. See Coming

“We are never ready. This is what will happen to you if you are a carrier: you become aware of the fact that finally it is impossible to foresee”, sais Charlotte, carrier and professional dancer. Most people at risk for HD have quite a clear picture of the disease, the forms it may take on through family-experience. Their ways of anticipating their own illness is strongly influenced by these experiences. However, it might be crucial for a fruitful activity of anticipation to de-construct these models. Anticipation then becomes a practice preparing oneself and one’s environment to being permanently surprised, perplexed and baffled. What is at stake, as it seems, is less the question of how to “fight the disease”, but rather of how to cultivate the art of oscillation between capturing and being captured.

3. Equipping

“And then, the ruse comes to mind: I tell him “come-on, get out” and into his ear, I whisper “I love you”, and hop, he got out of the car”, Michelle remembers one of the moments where she had to be inventive in order to resolve a difficult situation with her HD-sick husband. Tactful forms of rusing appear as fundamental for living and composing with HD. These loving strategies are not to be qualified as something negative, non-honest, as lying. They are, true or not, rather part and parcel of constructing, together with the disease and those persons involved in its development, a less violent process of felicitous collective metamorphosis. Producing the beginning of a collection of such tricks and gestures in all their inventiveness, is one of the tasks this report hopes to achieve.

4. Living *With*

« I am not sick, I am different ». At first sight these two statements might suggest that Suzanne is incoherent. But if we decide to confide in her expressions and in what she does with them, we start to understand the reasons for adopting this double stance. Those two versions can cohabit in her because each of them refers to another world. When she talks about the recognition of the *disease* she refers to the exterior social and medical world. Her second version, however, brings up her intimate experience with the *illness*. By never choosing to subscribe exclusively to one of these two version, she shows us how she manages to never get confined to any of them. She gives us faith in the possibility of escaping predefined versions of HD and instead of continuing to onscillate, that is to live ! To live *with*!

Continuation

Absolute Beginners

There is very little work on the often traumatizing early stages of HD. Paula, a young woman in a quite advanced stage of the disease once told us, « You will see, there is a dreadful moment. A moment, yes, where it is enough to commit suicide. But if you live through this moment and find yourself on the other side, there, things are rather well, they are even really better. »

Absolute Beginners is one of the projects dingdong started pursuing after *Composer avec Huntington*. We are still in the middle of this next exciting exploration with quite a number of early-stage HD users – a project that can partly build on the experiences and peer-to-peer transmission practices made with respect to other diseases such as hemophilia, diabetes, schizophrenia (voice-hearing) etc. Taking our co-investigators' interior, intimate experiences as so many starting points for a new collection of treasures, we together aim at producing a kind of multivocal guide for the absolute beginners to come.